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Coláiste na Tríonóide, Baile Átha Cliath

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The role of specialist palliative care services in cancer survivorship

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Clinical Medicine

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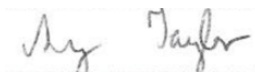
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“I shall be telling this with a sigh
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I took the one less travelled by,
And that has made all the difference.”
- Robert Frost, *The Road Not Taken*

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List of abbreviations

Abbreviation	Term
ADPM	Academic Department of Palliative Medicine
AIHPC	All Ireland Institute of Hospice and Palliative Care
APCU	Acute Palliative Care Unit
AYA	Adolescent and Young Adult
ASCO	American Society of Clinical Oncology
CanCon	Joint Action on Cancer Control
CRC	Colorectal cancer
CREDES	Guidance on Conducting and REporting DElphi Studies
CRF	Case Report Form
CROSS	Checklist for Reporting Of Survey Studies
CS	Cancer Survivors
dx	Diagnosis
EAPC	European Association for Palliative Care
e-Delphi	Electronic Delphi
ECCF	European Cancer Community Foundation
ECO	European Cancer Organisation
ECOG	Eastern Cooperative Oncology Group
ECPC	European Cancer Patient Coalition
EONS	European Oncology Nursing Society
ESMO	European Society for Medical Oncology
GI	Gastrointestinal
GDPR	General Data Protection Regulations (GDPR)
GP	General Practitioner
GYN	Gynaecological
IAHPC	International Association for Hospice & Palliative Care
IE	Ireland
IOM	Institute of Medicine
ISCED	International Standard Classification of Education
MASCC	Multinational Association for Supportive Care in Cancer
MDT	Multidisciplinary team
MeSH	Medical Subject Headings
N/A	Not applicable

NCCS	National Coalition for Cancer Survivorship
NCHPC	National Coalition for Hospice and Palliative Care
NCI	National Cancer Institute
NCRI	National Cancer Registry Ireland
NHS	National Health Service (UK)
NR	Not reported
OED	Oxford English Dictionary
OLH&CS	Our Lady's Hospice & Care Services
ONC	Oncology
OSG	Online Support Group
PCC	Population, Concept, Context
PICOS	Population, Intervention, Comparison, Outcome, Study design
PIL	Participant Information Leaflet
POST	<u>P</u> alliative care and <u>O</u> ncology <u>S</u> urvey on <u>T</u> erminology
PPI	Patient and Public Involvement
PRiSM	Specialist <u>P</u> alliative Care's <u>R</u> ole in Cancer <u>S</u> urvivorship <u>M</u> odel
PRISMA-ScR	Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews
PS	Performance Status
RCT	Randomised Controlled Trial
REC	Research Ethics Committee
tx	Treatment / therapy
SCP	Survivorship Care Plan
SPC	Specialist Palliative Care
SPCS	Specialist Palliative Care Services
SPCT	Specialist Palliative Care Team
SCP	Survivorship Care Plan
SPSS	Statistical Package for the Social Sciences
UK	United Kingdom
Urol	Urological
USA	United States of America
WHO	World Health Organization
WHOCC-ICO	World Health Organization Collaborating Centre for Public Health Palliative Care Programmes

Scientific abstract

Given the advancements in cancer treatments and outcomes, more people are living longer with, through and beyond cancer. All these individuals may be referred to as cancer survivors. Many also live with adverse consequences of cancer and its treatment, even though they may have no evidence of disease. Specialist palliative care services (SPCS) provide holistic care (physical, psychological, social and spiritual) for individuals with health-related suffering and those close to them. Historically, SPCS have cared for people with advanced cancer and towards the end of life. Most people on anticancer treatment or with no evidence of disease do not have access to SPCS, despite having an array of unmet needs. There is much contention about the role of SPCS for these groups, and surrounding the terminology used to describe them. This thesis aims to establish the potential role of SPCS for the different cohorts of people who have or had cancer, to determine the views of people with cancer about the terms used to describe them, and to use these findings to develop a new model of care.

A narrative literature review on the role of SPCS for people living beyond cancer demonstrated many synergies between the core activities of SPCS, the essential components of survivorship care, and the unmet needs of this group, but limited data on the actual involvement of SPCS, and potential barriers. A scoping review on the meaning and acceptance of the term cancer survivor identified diverse results, and showed that the views of all groups of people who have or had cancer have not been identified. In a European electronic Delphi study, 86 specialist palliative care experts, and 54 oncology experts (including professionals and patient advocates), reached consensus that cancer survivor terminology should be applied to people post-treatment with no evidence of disease, and about the roles of SPCS in supporting people with stable disease, and people living beyond cancer. A multi-site cross-sectional survey-based study assessing the perspectives of a heterogeneous group of 1328 people with cancer in Ireland and the United Kingdom (UK) on the terms used to describe them revealed mixed perceptions regarding cancer survivor, but a trend towards disliking being described by the term, although most found it acceptable for people with no evidence of disease. Results suggest that application of cancer survivors to people with active cancer should be reconsidered. Considering all outcomes, a model of

SPCS for people who have or had cancer has been proposed, requiring further research to identify if it can improve the care of people who have or had cancer.

Lay abstract

Due to advances in cancer treatments and outcomes, more people are living longer with cancer, and more people are being “cured”. However, many of these people also live with challenging consequences of cancer and its treatment. Specialist palliative care services (SPCS) provide physical, emotional, social and spiritual care for people suffering because of a health condition and those close to them, and so SPCS may have a potential role in helping individuals with these problems.

Supporting unmet needs is considered part of cancer survivorship care, although application of the cancer survivor term is a divisive area. Despite being widely applied to individuals from the time of diagnosis and throughout their lives, the views of some groups included in this description have rarely been assessed, including those with cancer on anticancer treatment and those already known to SPCS. The way these individuals view cancer survivor terminology could have important implications for research, education and clinical practice.

This body of work aims to establish the role of SPCS in supporting groups of people who have or had cancer, and who would not traditionally access these services. A literature review showed that there is limited evidence to guide this action. A group of European experts agreed that SPCS should have a role in supporting the physical, psychological, spiritual and some social needs of people with stable cancer, and in supporting the pain management of people with no evidence of disease.

This research also sought to determine the perceptions of different groups of people with cancer regarding the terms used to describe them, particularly “cancer survivor”. A literature review showed that people hold a variety of views about the term, but previous studies have generally not included people with active cancer. People with cancer in Ireland and the United Kingdom undertook a once-off questionnaire which showed they have mixed views about cancer survivor

terminology, but more of them disliked the term, especially if they were known to SPCS. Both the study participants and European experts believed the term cancer survivor would be more appropriate for people with no evidence of disease. The findings of these studies have been used to suggest a new model of care for the role of SPCS for people with cancer or a history of cancer, hoping to better support the needs of this diverse group.

Aims and hypotheses

Aim

The overall aim of this thesis is to determine the potential role of SPCS in the different cohorts of people with cancer or a history of cancer to inform a model of care. (Specific aims for each study are provided in the individual chapters.)

The objectives are:

- To explore the evidence for the current / potential role of SPCS in supporting individuals living beyond cancer i.e. people with a history of cancer and no evidence of disease.
- To explore the evidence for the meaning and acceptance of cancer survivorship terminology.
- To determine the views of professional and non-professional specialist palliative care (SPC) and oncology experts on the role of SPCS within cancer survivorship.
- To determine the perceptions of individuals with cancer known to SPC and oncology services regarding the terms used to describe them, in particular cancer survivor.
- To develop an overarching European model of care for SPCS for people with cancer or a history of cancer.

Hypotheses

- SPCS have a potential extended role in supporting the different cohorts of people who have or had cancer.
- Individuals with cancer known to SPCS and individuals with cancer on anticancer treatment will dislike being described as cancer survivors.
- Consensus expert opinion will be able to identify core functions of SPC, who should be described as cancer survivors, subgroups / categories of individuals with cancer or a history of cancer, and the appropriate role of SPC for these categories.
- The perspectives of people who have or had cancer and professional experts can be used to develop a model of care for the role of SPCS for people with cancer or a history of cancer.

Value of research

This research has the potential to impact people who have or had cancer, healthcare practitioners, clinical services, academia and policy.

People who have or had cancer

This is the first study seeking to generate expert consensus opinion about the role of SPCS for people with a history of cancer and no evidence of disease, and it will also lead to fresh insights into the perceptions of people with cancer towards the healthcare terms used to describe them. This research ultimately seeks to use these findings to positively influence outcomes in the heterogeneous population of people who have or had cancer in optimal and achievable ways.

Clinicians

The importance and originality of this research is that it explores two contentious issues: the clinical responsibilities of SPCS for people with a history of cancer who would not have traditionally accessed services, especially those with no evidence of disease; and the application of the term cancer survivors in clinical settings.

Services

It is anticipated that findings from the project will help to direct service provision by clarifying nomenclature and formalising groups of people with cancer or a history of cancer. Achieving consensus on the role of SPC for these groups and developing a new model of care could also inform the use of SPC resources.

Research

The findings should make an important contribution towards developing a new model of care for the role of SPCS for people with cancer or a history of cancer, to be evaluated through subsequent studies. Additionally, the research should provide important insights into the perspectives of people with cancer on the terms used to describe them, which should be considered when conducting research that includes or refers to these groups.

Education

This body of work will also provide opportunity to advance understanding about areas for development in SPC curricula, and educational needs regarding the preferences of people with cancer about the terms used to describe them.

Policy

It is anticipated that this research will highlight the expanding relevance of SPCS. Any recommended increase in SPC service provision will need increased resources and dedicated funding. Changes in healthcare policy would be required to drive this.

List of outputs / achievements to date

Publications

Journal articles

- Taylor A, Davies A. The role of specialist palliative care in individuals "living beyond cancer": a narrative review of the literature. *Support Care Cancer*. 2024;32(7):414. <https://doi.org/10.1007/s00520-024-08598-w>
- Taylor A, Davies A. Palliative care or supportive care? *Clin Med (Lond)*. 2025;25(4):100487. <https://doi.org/10.1016/j.clinme.2025.100487>
- Taylor A, Davies A; PRiSM e-Delphi Group. PRiSM project: e-Delphi study on the role of specialist palliative care services in the care of people living beyond cancer. *Palliat Med*. 2025:2692163251376957. <https://doi.org/10.1177/02692163251376957>
- Taylor A, Davies A; PRiSM e-Delphi Group. e-Delphi study on European expert views about "cancer survivor" and related terminologies. *J Cancer Surviv [Internet]*. 2026 Jan 31 [cited 2026 Jan 31]. Available from: <https://doi.org/10.1007/s11764-026-01972-z>

Presentations

Oral: international

- Taylor A, Davies A. European e-Delphi consensus recommendations on the role of specialist palliative care services for people with stable locally advanced or metastatic cancer. Presented at 19th World Congress of the European Association for Palliative Care, Helsinki, Finland, 29 - 31 May 2025.
- Taylor A, Davies A. European e-Delphi consensus recommendations on the role of specialist palliative care services for long-term "cancer survivors" (people "living beyond cancer"). Presented at 19th World Congress of the European Association for Palliative Care, Helsinki, Finland, 29 - 31 May 2025.

Oral: national

- Taylor A. The role of specialist palliative care in cancer survivorship (lectures x 3). Presented at Guildford Advanced Pain and Symptom Management Courses, UK & Ireland (Manchester, London, Dublin), September & December 2024.
- Taylor A. POST: Palliative Care and Oncology Survey on Terminology. Presented at UKASCC Supportive Oncology Conference 2024, Manchester, England, 9 - 11 October 2024.

Poster: international

- Taylor A, Davies A. PRiSM: Specialist Palliative Care's Role in Cancer Survivorship Model. Developing European consensus recommendations on the role of specialist palliative care in cancer survivorship to inform a model of care. Presented at the European Cancer Summit, Brussels, Belgium, 20-21 November 2024.
Abstract publication: J Cancer Policy. 2025;43:100541.
<https://doi.org/10.1016/j.jcpo.2024.100541>
- *Accepted:* Taylor A, Gouldthorpe C, Davie A. "I'm never going to be free of cancer, so I won't ever be a survivor." Content analysis of free text responses in the Palliative care and Oncology Survey on Terminology (POST). Accepted for the 20th World Congress of the European Association for Palliative Care, Prague, Czech Republic, 14 - 16 May 2026.

Poster: national

- Taylor A, Davies A. European e-Delphi consensus recommendations on the role of specialist palliative care services in cancer survivorship. Presented at the Palliative Care Congress, Belfast, Northern Ireland, 20-21 March 2025.
Abstract publication: BMJ Support Palliat Care. 2025;15(Suppl 2):A66-A67.
<https://doi.org/10.1136/spcare-2025-PCC.173>

Poster: local

- Taylor A, Davies A. The role of palliative care in cancer survivorship. Trinity St James's Cancer Institute Christmas Research Blitz, Dublin, Ireland, 8 December 2023.

Award

- Grant recipient: European Cancer Community Foundation Rising Star Grant, November 2023.

Chapter 1: Introduction

1.1 Background

Hospice care has existed since the late 1800s, although the origins of modern palliative care are generally attributed to the community-based hospice movement of the 1960s, which developed from the recognition that people with terminal illnesses, especially cancer, were dying with high levels of suffering (1). The term palliative care was first applied to a dedicated hospital inpatient unit and its interdisciplinary service in the 1970s, which also provided inpatient consultations and community visits (2). These foundations led to palliative care being associated with end of life care, and also with cancer, which was often considered incurable. Indeed, the Oxford English Dictionary (OED) defines palliative care as “care for the terminally ill and their families” (3). The principles of palliative care have also been intertwined with the concept of total pain (4); the idea that there are physical, psychological, social and spiritual dimensions to an individual’s experience of suffering, which all necessitate consideration in symptom assessment and management. As well as end of life care, symptom support is a central role of specialist palliative care services (SPCS), and indeed the OED defines the word palliative as that which “relieves the symptoms of a disease or condition without dealing with the underlying cause” (3).

Cancer is a large group of diseases where normal cells in any part of the body transform into malignant tumour cells. There are numerous potential causes, including genetic factors and exposure to physical, chemical or biological carcinogens (cancer-causing substances) (5). Advanced cancer refers to a solid organ or haematological malignancy which is unlikely to be controlled or cured with treatment, and metastatic cancer refers to cancer that has spread beyond its primary origin to distant tissues (6). A significant global burden, cancer is the second leading cause of death worldwide (5), and has serious consequences for individuals’ physical, psychological and social lives, as well as for communities and healthcare systems (5). Importantly, in recent years cancer services and outcomes have changed dramatically (in higher income countries). Greater numbers of people are living longer with cancer and after cancer (7, 8) due to earlier diagnoses, novel anticancer treatments, and supportive care services (later defined) (5). (Anticancer treatments refer to treatments that seek to eradicate cancer or prevent recurrence, for example, chemotherapy, immunotherapy, radiotherapy, surgery (9).) All these individuals who have or had cancer may be

classed as cancer survivors, and there is a growing body of literature that recognises the problems they face and the corresponding increasing need for support. The care of these individuals has emerged as an important healthcare and research priority.

The relevance and role of SPCS have expanded to align with the changing needs of individuals with a history of cancer. Historically, SPCS have cared for people with advanced cancer, but SPCS now also provide “early palliative care” (10, p.7) for certain people on anticancer treatment. However, most individuals on anticancer treatment, especially maintenance treatments, and most deemed in remission or with no evidence of disease do not have access to SPCS. Many of these individuals still have significant unmet needs across several domains, including poor symptom control. In recent years, there has been increased interest in the potential role of SPCS in supporting such individuals, but the idea is controversial, dividing opinion amongst professionals, people with a history of cancer, and their advocates. However, there has been no attempt to generate agreement and there is a lack of evidence to inform the discussion. Additionally, there are potential barriers to this suggestion, and current specialist palliative care (SPC) models of care would not necessarily be applicable to the relevant people with a history of cancer.

A model of care outlines the way that healthcare services are delivered for a person / group as they progress through a condition (11), and a models of care approach refers to the design, delivery and integration of services across settings and professions, according to patient needs and best available evidence (12). A conceptual model demonstrates the interconnections between the many parts of an issue (13), and conceptual models of integrated care propose how teams should interact, especially regarding referrals and roles / responsibilities (14). Clinical models then outline the strategies, feasibility and outcomes of applying a conceptual model to specific settings (14). Given the increasing number and complexity of people who have or had cancer, historical SPC models may no longer be efficient or effective.

The terminology surrounding these individuals poses another issue. The words used to describe people who use healthcare services have important implications for public and professional understanding and expectations, and there are debates surrounding the terminologies of both palliative care and cancer survivorship,

notably who should be defined as a cancer survivor (15, 16). The National Cancer Institute (NCI) Office of Cancer Survivorship United States of America (USA) (17) provides one of the most widely used definitions, stating that, “an individual is considered a cancer survivor from the time of diagnosis through the balance of life. There are many types of survivors, including those living with cancer and those free of cancer.” Thus, anyone with cancer, or a history of cancer, may be described as a cancer survivor. Despite this, many statements and organisations use cancer survivorship terminology to describe the specific phase and issues arising following primary treatment (18). Moreover, interpretations of cancer survivors and cancer survivorship continue to evolve, particularly as oncology treatments and outcomes advance and the very nature of being a survivor changes. Such ambiguity has led to variable application in clinical and academic settings.

This thesis presents a body of work that discusses and develops evidence for the role of SPCS for the different groups of people who have or had cancer, who may be described as cancer survivors, informing a new model of care. This introduction discusses the key terminologies, definitions, and care models associated with both palliative care and cancer survivorship, and highlights the need for greater evidence to inform the debate about their alignment. An overview of the proposed research and the aims and objectives are then provided.

1.2 Palliative care: terminologies and models

1.2.1 Definition and characteristics of palliative care

The definition of palliative care has changed over time. The original World Health Organization (WHO) definition specified the relevance of palliative care for individuals not responsive to curative treatment, especially the last stages of illness (19). This was updated in 2002 to describe palliative care as, “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial or spiritual” (20). This definition has become widely used (21) and implies threat to the lives of individuals utilising palliative care. The International Association for Hospice & Palliative Care (IAHPC) noted ongoing differences in perceptions about palliative

care between those who believed palliative care was relevant to everyone with suffering, and those who believed it was only for those with limited prognoses. A new consensus definition described palliative care as “the active holistic care of individuals across all ages with serious health-related suffering due to severe illness and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers” (22, p.755). The definition also included certain characteristics, outlined in Box 1.

Box 1: Components of palliative care according to the IAHPC definition (22, p.761).

- “Includes, prevention, early identification, comprehensive assessment, and management of physical issues, including pain and other distressing symptoms, psychological distress, spiritual distress, and social needs. Whenever possible, these interventions must be evidence based
- Provides support to help patients live as fully as possible until death by facilitating effective communication, helping them, and their families determine goals of care
- Is applicable throughout the course of an illness, according to the patient’s needs
- Is provided in conjunction with disease-modifying therapies whenever needed
- May positively influence the course of illness
- Intends neither to hasten nor to postpone death, affirms life, and recognises dying as a natural process
- Provides support to the family and caregivers during the patient’s illness, and in their own bereavement
- Is delivered recognising and respecting the cultural values and beliefs of the patient and family
- Is applicable throughout all health care settings (place of residence and institutions) and in all levels (primary to tertiary)
- Can be provided by professionals with basic palliative care training

- Requires specialist palliative care with a multiprofessional team for referral of complex cases

To achieve palliative care integration, governments should:

- Adopt adequate policies and norms that include palliative care in health laws, national health programmes, and national health budgets
- Ensure that insurance plans integrate palliative care as a component of programmes
- Ensure access to essential medicines and technologies for pain relief and palliative care, including paediatric formulations
- Ensure that palliative care is part of all health services (from community health-based programmes to hospitals), that everyone is assessed, and that all staff can provide basic palliative care with specialist teams available for referral and consultation
- Ensure access to adequate palliative care for vulnerable groups, including children and older persons
- Engage with universities, academia, and teaching hospitals to include palliative care research and palliative care training as an integral component of ongoing education, including basic, intermediate, specialist, and continuing education.”

1.2.2 Terms associated with palliative care

There are various terms associated with palliative care. Palliative care is often used interchangeably with palliative medicine, whereas hospice care is considered to be one part of palliative care (specifically a multidisciplinary community service caring for individuals with terminal disease and their families) (21). Specialist palliative care refers to a highly specialised team focusing on palliative care provision (23). Reinforcing the relevance of palliative care before the end of life (22), early palliative care refers to its application from the diagnosis of a life-threatening disease alongside active treatment, such as individuals with advanced cancer receiving chemotherapy (10). The concept is endorsed by national and international oncology organisations (24, 25), given the evidence that this

improves symptom control and quality of life for people with advanced disease (10, 26, 27) and promotes patient-centred care (28).

Such service expansion has led to discussions about rebranding palliative care (29). There are some negative public and professional perceptions surrounding palliative care from its historical affiliation with end of life care, so the term supportive care has been advocated instead (30). Some organisations do not explicitly differentiate between palliative care and supportive care (31), and indeed it has even been suggested that the phrase supportive oncology should be used instead of supportive care, given the increasing interpretation that the latter refers to palliative care (32). Other organisations specify differences (33, 34), and indeed the Multinational Association of Supportive Care in Cancer (MASCC) and the NCI identify supportive care as physical, psychological, social, and spiritual support for patients and their families with the problems from cancer and its treatment, and cite palliative care as one facet of supportive care (9, 35). Lastly, the term best supportive care is sometimes used interchangeably with supportive care, but there is no agreed definition and this phrase was historically used to describe the control arm in many oncological clinical trials relating to advanced cancer (for which consensus guidelines have now been developed) (36).

These considerations demonstrate the challenges of using the term palliative care in service provision throughout the journey of an individual with cancer. Given its definition, the uncertainty of its applicability to individuals with early stage or curative-intent disease, and to individuals with no evidence of disease, appears justified. Indeed, a recent evolutionary concept analysis showed that palliative care remains misunderstood by healthcare professionals, resulting in variable integration within oncology and affecting the timing of referrals (37). Ultimately, as the potential relevance of palliative care expands, its definition needs to be updated and disseminated so that public and professional understanding align.

1.2.3 Specialist palliative care models

There are three levels of healthcare integration: linkage (where one practitioner refers to another specialty); coordination (defined processes / pathways of interaction); and full integration (shared resources) (14, 38). Different levels are applicable to different systems, resource availabilities and populations (14). There

is a large body of evidence underpinning the integration of palliative care and oncology, widely supported by national and international organisations (24, 25, 39), with meta-analyses demonstrating improved symptom control (10, 40) and quality of life (10, 40, 41). Integration may be time-based (along the disease continuum), provider-based (generalist or specialist), issue-based (where issues are dealt with by the primary oncologist, through referral to multiple specialties, or through integrated services), or system-based (where clinical events trigger automatic streamlined referrals) (14). The traditional SPC model was time-based, and SPCS entered towards the end of life to support symptoms, quality of life, and end of life care, whereas the current model integrates SPCS from the point of diagnosis alongside active treatment, particularly in advanced cancer, with its role increasing as time becomes shorter for the individual (24, 39). This section explores the different SPC clinical models and their applicability to people with cancer or a history of cancer.

SPC models have been widely analysed. Hui and Bruera's comprehensive review identified five clinical models of SPC for people with cancer, each predominantly serving different cohorts and enabling specialist provision from diagnosis to end of life, with the models evolving as SPC relevance has widened (42). These include outpatient clinics (allowing timely access and promoting care coordination earlier in the disease trajectory), inpatient consultation (for hospital inpatients with acute issues), acute palliative care units (APCUs) (people with complex needs requiring urgent admission), community-based teams (people with low to moderate symptoms), and hospice care (people with poor functional status) (42).

1.2.4.1 Outpatient models

Outpatient clinics are widely used and have proven to be effective, efficient and resourceful, leading to numerous positive outcomes for patients and carers (43, 44). They promote timely access to early palliative care (previously defined) (42) and provide a range of services, including symptom management, caregiver support, care coordination, and advance care planning (45-47). In response to diverse referral thresholds (48), an international expert consensus study agreed referral criteria as severe physical, emotional or spiritual issues, request for hastened death, request for referral, assistance with care planning, and specific

medical issues including delirium, spinal cord compression, and brain / leptomeningeal metastases (49). Importantly, these criteria would not be generalisable to people with a history of cancer and no evidence of disease.

Furthermore, outpatient models lack standardisation (14). The ideal model of stand-alone multidisciplinary outpatient clinics depends on funding and resources (44). Other outpatient models vary from embedded clinics (delivered alongside oncology), to telehealth (digital services provided in isolation or to augment in-person consultations), to enhanced primary palliative care (provided by community non-specialists) (42). Indeed, the level of integration between oncology and palliative care is impacted by the extent of primary palliative care (14). Embedded clinics may better integrate practice and utilise oncologists' time more efficiently (50), as well as reduce hospital visits (51) and potentially minimise stigma towards attending SPC (52), but patients may find double appointments tiring (51), and the model is less efficient for SPC practitioners (44). Additionally, there is a lack of evidence to support embedded clinics and, indeed, primary palliative care (42). The appropriateness of such models and essential characteristics requires further research to become embedded within a new model of SPCS for people who have or had cancer.

1.2.4.2 Hospital inpatient models

Inpatient SPC consultations can improve the quality of life of individuals with cancer during acute hospital admissions (53, 54) and reduce care costs (55, 56). Notably, El-Jawahri et al.'s (54) randomised controlled trial (RCT) included individuals undergoing curative intent treatment for haematological cancers, demonstrating the relevance not just for people known to haematology (where there was less historical engagement) but also those people hoping to be cured. A similarly high-quality methodology would be helpful to determine the role of SPCS for individuals post-curative intent treatment. Additionally, some centres have dedicated inpatient hospital beds for intense SPC (APCUs), where specialist palliative care teams (SPCTs) assume primary responsibility for the occupants. These have been less robustly evaluated (42), and so the place for people with no evidence of disease within this model is even less clear.

1.2.4.3 Hospice and community models

Community and hospice models of palliative care are utilised more towards the end of life (42), and would probably be less applicable to individuals post-treatment. Home-based SPC supports patient satisfaction (57) and the wish to stay at home for end of life (57, 58), especially if introduced early (59). However, the impact on symptom control, caregiver wellbeing, staff and cost is unclear (57, 58).

1.2.4.4 SPC models: discussion

A universally appropriate and acceptable model of care is hard to achieve. Key aspects of care models include clinical structure and processes, as well as education, research and administrative factors (14), but overarching models must account for the variations in resources and needs between regions and groups, so most are not prescriptive or standardised regarding personnel or programme. Timing of SPC referrals is also contentious. A meta-analysis demonstrated that early referral in the disease course is optimal (41), but this may not be practical or appropriate (60), especially given the diversity within prognosis, treatment trajectory, and performance status (49). Different strategies have been proposed to account for these variations, such as pragmatic personalised needs-based referral that triages patients to available targeted services (described as precision palliative care) (61). Indeed, El-Jawahri et al. (54) identified that palliative care for people with haematologic malignancies was feasible, acceptable and effective at improving recipients' quality of life, but highlighted that population-specific interventions and models were required, given the diverse needs within limited resources (62). An SPC model for people who have or had cancer should therefore be based on transferable and generalisable best-practice characteristics and standards, within which population and regional-specific interventions can be applied, enabling SPCS to be provided in the right setting, at the right time, for the right person (44).

Another important consideration is the rising pressure on SPCS due to increasing workforce challenges alongside expanding demand (63, 64). There is corresponding need to also enhance the relevant skills of other specialties, but this has its own challenges. Oncology / haematology training programmes typically

have inadequate palliative care education / experience (65), despite international recommendations for palliative care competencies (66). Oncologists' confidence in providing general palliative care is variable (65), and usually equated with end of life care (67). Furthermore, oncologists also require broadening knowledge and skills regarding anticancer treatment, which will be prioritised.

Given these conditions, service delivery has to adapt, so other forms like nurse-led models and digital medicine are gaining interest (42). Although nurse-led SPC models are pragmatic in resource-limited areas, interdisciplinary teams are more effective (44). Distinct team members are also likely relevant at different times (44), with further exploration of the post-treatment period required. Digital health, telehealth, and eHealth are interchangeable terms for "the provision of healthcare services supported by telecommunications or digital technology to improve or support healthcare services" (68, p.4590). Such an approach is applicable within the increased demand and limited SPC workforce, particularly with its potential to minimise patient burden and maximise time at home (69), so it may be relevant within a model for SPCS for people who have or had cancer. Telehealth in palliative care has also been found to be feasible and acceptable (70, 71) and can improve healthcare access and feelings of security (70). A recent RCT comparing telehealth to in-person early palliative care consultations for people with advanced lung cancer demonstrated equivalence of outcomes in quality of life, coping, mood and care satisfaction (amongst patients and carers) (72). Interest in virtual wards has also been increasing, which may provide safe and effective alternatives to inpatient admission (73). However, more research is needed to clarify uncertainty about the ability and appropriateness of telehealth to improve symptoms and quality of life for other groups (70, 71, 74), and indeed barriers include familiarity / comfort with technology and the inflexibility of reporting systems (69).

Ultimately, the population of people who have or had cancer is becoming larger and more complex, and the issues they face are receiving critical attention. Despite the impact this has on healthcare services, there remains a paucity of evidence on how models of care should adapt accordingly. Within this, there is an increasing need to clarify the role of SPCS so the needs of people who have or had cancer can be supported appropriately and effectively across diverse groups, settings and systems.

1.3 Cancer survivorship: terminologies and models

1.3.1 Definitions of cancer survivors and cancer survivorship

Cancer survivorship terminology is a contentious and nebulous area. Leading cancer organisations and advocacy groups endorse different definitions, so a precise and universal description has proved elusive. As previously highlighted, the NCI's definition is widely used: "an individual is considered a cancer survivor from the time of diagnosis through the balance of life. There are many types of survivors, including those living with cancer and those free of cancer" (17). This idea that cancer survivors include anyone living with, through or beyond a cancer diagnosis was first proposed by Cancer Nation (formerly the National Coalition for Cancer Survivorship (NCCS)), a cancer advocacy organisation (75). The term was adopted as one of empowerment and advocacy for all individuals affected by cancer, in contrast to cancer victims which was previously applied (75).

Although the European Society for Medical Oncology (ESMO) and American Society of Clinical Oncology (ASCO) endorse this all-encompassing definition, these organisations use functional definitions for research / reports, with ESMO including "patients with a diagnosis of cancer who are managed with curative intent, from completion of active therapy (despite eventually on or off maintenance therapy) to long-term follow-up" (76, p.1121) and ASCO similarly including "individuals who have successfully completed curative treatment or those who have transitioned to maintenance or prophylactic therapy" (77, p.642). Indeed, given such lack of consensus, the European Cancer Organisation (ECO) "decided not to adopt a specific definition, but to acknowledge the different definitions, which relate to some degree overlapping populations" (78, p.6). Clarity and agreement about the definition and application of cancer survivors are therefore lacking.

Cancer survivorship is conceptually different from cancer survivors (although often used interchangeably (79)), and refers to the unique physical, psychological, social and economic issues affecting an individual with a history of cancer (80). The essential components of survivorship care include prevention (of late effects and second / recurrent cancers), surveillance (for late effects and cancer), intervention (for sequelae of cancer and its treatment) and coordination (between primary care and specialists) (18). However, the time period attributed to cancer survivorship also varies between organisations. The Institute of Medicine (IOM) and National

Research Council of the National Academies report, “From Cancer Patient to Cancer Survivor: Lost in Transition” focuses on “the period following first diagnosis and treatment and prior to the development of a recurrence of cancer or death” (18, p.23). This does not align with the NCI’s cancer survivor definition, and moreover, identifying the end of treatment has become increasingly challenging (81, 82). Indeed, ESMO and the European Cancer Patient Coalition (ECPC) have specified that survivorship refers to “people having no disease after finishing treatment, people who continue to receive treatment to reduce the risk of the cancer coming back and people with well controlled disease and few symptoms, who receive treatment to manage cancer as a chronic disease” (80, p.3). Applications have therefore become more nuanced and less straightforward.

Alternatively, MASCC use cancer survivorship to refer to the period between diagnosis and the end of life (83). This aligns with the increased recognition of the relevance of cancer survivorship principles (particularly assessment and management of unmet needs) to the greater number of people living longer with incurable cancer (84, 85). Indeed, the term *metavivor* has even been proposed for the latter group (86, 87), differentiating them from *curvivors*, used to describe people who have completed curative intent treatment (87).

Cancer survivorship terminology has variable endorsement from people with a history of cancer (88, 89). Many observational studies have sought the perspectives of these individuals about the term, identifying a variety of interpretations and opinions (90). Some individuals embrace the term positively, found to be associated with better wellbeing and quality of life (90). Others perceive the term negatively, criticising the confusion it stirs around prognostic outcomes and the potential psychological impact of forcing individuals to appear stronger than they feel (91). However, studies have not necessarily represented the breadth of all groups of people who have or had cancer, especially those on anticancer treatment or with advanced / progressive disease. Identity changes throughout the cancer continuum (92), so previous findings cannot be generalised to these groups. Furthermore, an increasing number of healthcare professionals dislike the term, opting for more pragmatic / factual descriptions (84).

Such disagreement on semantics is generally accepted (93), and it is recognised that applying unclear labels could impact treatment aims, decisions and wellbeing (94). Consequently, many advocate that cancer survivors should not be used as a

label (17), and that its meaning should be determined by individuals themselves (84). The current application of cancer survivorship terminology within research, education and services may therefore need revision.

Given these disparities, the use of cancer survivorship terminology in this thesis will be accompanied by a definition / application for the relevant section. This body of research will include exploration of the meaning of these terms for different groups, so consistent definitions will not be adopted from the outset.

1.3.2 Groups of cancer survivors and phases of cancer survivorship

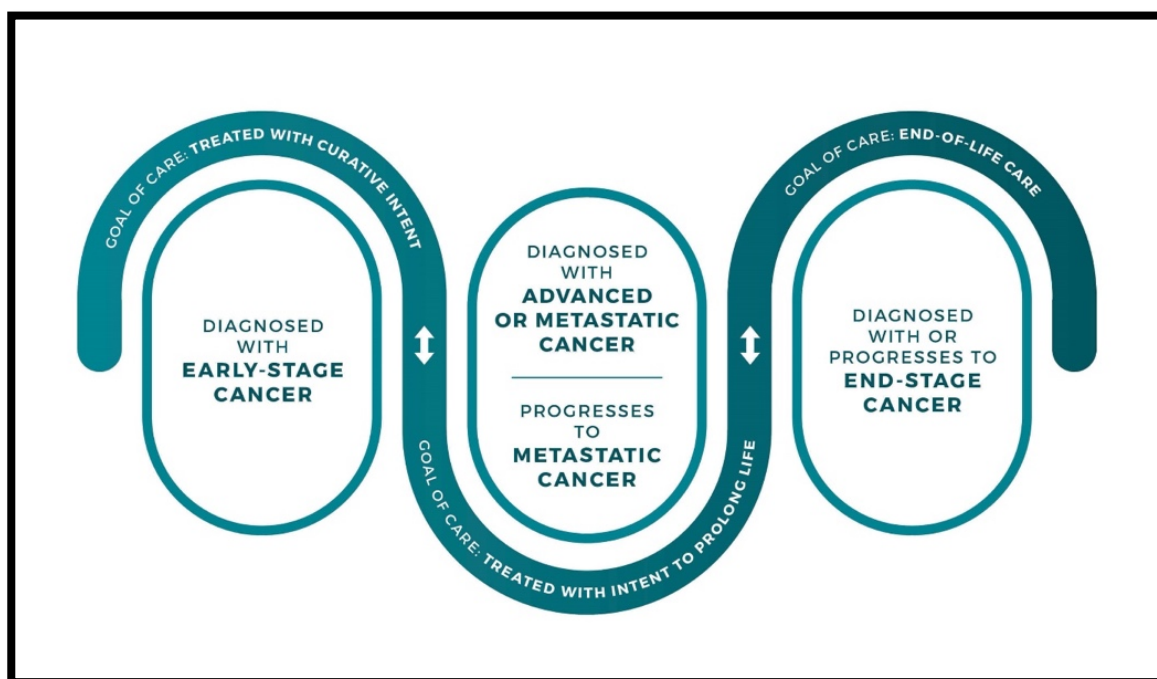
Given the scope of individuals encompassed by cancer survivor terminology, some authors have proposed categories of individuals with a history of cancer, phases of cancer survivorship, and trajectories of cancer survivorship.

Regarding groups of cancer survivors, many include individuals from diagnosis to chronic care or cure, such as Surbone and Tralongo (95): acute (first diagnosis or relapse); chronic (slowly progressive cancer or alternating remission / relapse); long-term (long-term remission at risk of relapse / second cancer or treatment-related sequelae); cured (disease-free individuals where cancer has not impacted life expectancy) (95). Similarly, Park et al. proposed, “patients newly diagnosed receiving active therapy with curative intent, patients who have completed active therapy with curative intent (on or off maintenance therapy), patients living with cancer” (91, p.1164). Other groupings, however, focus on individuals post-primary treatment (80).

Cancer survivorship has also been described as consisting of various phases. In 1985, Mullan proposed three seasons of survivorship: “acute”, (the period of diagnosis and treatment), “extended”, (post-treatment completion / remission), and “permanent survival” (cure) (96, pp. 271-272). These phrases have stood the test of time, but have little clinical relevance, and updates have been offered as the complexity of cancer survivorship has grown (97-99). Alternatively, the NCI divides cancer survivorship into three phases; individuals with early-stage cancer where the goal is curative intent, individuals with advanced or metastatic cancer where the goal is to prolong life, and individuals with end-stage cancer where the goal is end of life care (Figure 1). These are presented as a continuum, as individuals may be diagnosed within any phase, move between phases, or leave the

continuum with no evidence of disease (17). Indeed, such expanded trajectories of cancer survivorship have also been proposed (Box 2).

Figure 1: NCI phases of cancer survivorship (17).



Box 2: Trajectories of cancer survivorship.

Welch-McCaffrey et al., 1989 (100, p.518)

"Living cancer-free for many years.

Living for a long time cancer-free, but dying rapidly of late recurrence.

Living cancer-free (first cancer), but developing a second primary cancer.

Living with intermittent periods of active disease.

Living with persistent disease.

Living after expected death."

American Cancer Society, 2012 (101, p.1)

"Living cancer-free for the remainder of life.

Living cancer-free for many years but experiencing one or more serious, late complications of treatment.

Living cancer-free for many years, but dying after a late recurrence.

Living cancer-free after the first cancer is treated, but developing a second cancer.

Living with intermittent periods of active disease requiring treatment.

Living with cancer continuously without a disease-free period.”

Some centres avoid survivorship nomenclature and use person-centred terms to describe similar stages. The University of Texas / MD Anderson Cancer Center coined the phrase, “living with, through and beyond cancer” (102, p.1), dividing the time after cancer diagnosis between “living with cancer”, where the focus is on treatment to eradicate / control disease, “living through cancer,” the period of post-treatment rehabilitation where there is risk of recurrence, and “living beyond cancer,” which describes post-treatment long-term survivorship (102, p.4). These phrases and interpretations may be more acceptable (93), particularly in patient-facing material, given the potential confusion and alienation of cancer survivor terminology (90).

Alternatively, the phases following a cancer diagnosis have been described as time periods in relation to diagnosis, prognosis, or treatment (including complications) (103). Indeed, cancer prevalence studies use three clinical phases to report outcomes: initial (first 12 months post-diagnosis); end of life (last 12 months before death); and continuing (time in between) (104-106). Although this attempts to better define groups and their associated supportive care needs (91), individuals within these phases remain extremely heterogeneous and require disparate management strategies (107). Moreover, individuals in distinct categories tend to have care coordinated by different healthcare professionals (91).

Classifications for specific cancer types (108), age groups (109) and subgroups (109, 110) have also been proposed. An example is pancreatic cancer, a poor prognosis cancer, for which only two phases are recommended (an initial phase focused on surviving, followed by living on with cancer, its consequences and the

fear of recurrence / progression (108)). This highlights that the generic all-encompassing application of cancer survivorship terminology can be unsuitable. Furthermore, there will always be atypical responses according to the clinical context and disease subtype, warranting their own approaches (111).

There is clearly a variety of categorisations of cancer survivors / cancer survivorship, with original attempts now outdated, and limitations in subsequent suggestions. An evidence-based approach to describe the groups relevant to a research study or clinical service would enable comparability and improve usability, and would be useful in clarifying the role of SPCS for people who have or had cancer.

1.3.3 Unmet needs of people who have or had cancer

1.3.3.1 People living beyond cancer

The issue of unmet needs of people living beyond cancer has received considerable attention. Although many people experience low symptom burden post-treatment (112, 113), others have a range of unmet needs across physical, psychosocial, financial and informational domains (114-116). There are also significant differences in needs between the first five years post-treatment and later time intervals (117). Notably, within physical needs, 40% of individuals post-treatment experience chronic pain (118), 28% of which is moderate or severe (119). It has been argued that an interdisciplinary approach (including SPC) is required (119, 120), involving opioid and addiction education, and management of expectations surrounding outcomes (120). Psychological and informational unmet needs are frequently identified as the most burdensome throughout the cancer continuum (114, 121, 122), including emotional distress, lack of information, and uncertainty (113, 121). Reviews of unmet needs of individuals with a history of cancer consistently report fear of cancer spread / recurrence as the most prevalent need across all cancers (123, 124). The holistic service provided by SPC may again be considered relevant.

Understanding the complexity of unmet needs is vitally important. Indeed, achieving quality care for all people who have or had cancer is part of ECO's strategy, with priorities including management of pain, other symptoms and cancer distress, support for occupational and financial issues, education, and information

provision (78). However, the purpose of needs assessment is not always clear (125). Supportive care services are variable and fragmented (126), so acting on identified needs lacks standardisation (125). It has even been suggested that continued emphasis on the illness by identifying unmet needs may prevent return to normalcy (127). Cooperation between care systems, clear referral pathways and service availability are therefore required to adequately meet the diverse needs of people post-treatment (125), so the need for evidence-based coordinated care models is apparent.

Despite the importance of unmet needs, there is a lack of tools to predict them (128), and a paucity of evidence to guide the process. Novel anticancer treatments have contributed to greater numbers of people living with, through and beyond cancer, but such advancements have established unclear long term / late effects, symptom clusters and prognostic impact (129, 130). Cancer is common, yet understanding of the future burden of unmet needs of people living beyond cancer is limited. Strategies to reduce the risk of adverse effects of anticancer therapies include symptom monitoring, patient communication and advocacy, educational tools, and improved care access (especially to supportive care services) (131, 132), but ultimately further research is required to identify ways to stratify risk and create / update evidence-based guidelines for follow-up (131, 132), as well as increase resources / capacity within the cancer framework to provide this care (126). The role of SPCS within this is unclear, and the need for clarity rising.

1.3.3.2 People with advanced or metastatic cancer

Survivorship care is deemed to be relevant for people with advanced / metastatic disease given the physical and psychosocial impact of cancer, the challenges of prolonged treatment adherence, and the benefit of health behaviour change (81, 85, 133). Palliative care principles are similarly applicable, especially considering the uniqueness of their uncertainty about the future and protracted caregiver burden (85, 86). This group therefore has a continuum of chronic needs between palliative and survivorship care (81, 134). Indeed, some studies propose blending palliative and survivorship care interventions to address the population-specific supportive care needs of people with advanced cancers on treatment (including coping with uncertainty, prognostic awareness and health promotion) (133). The strategies required to support people living for a prolonged time with cancer differ

from those with a limited prognosis (135), so there is uncertainty about the particular role of SPCS in supporting the unique problems of this group.

1.3.4 Cancer survivorship care provision

A major issue in cancer survivorship care is ownership of care provision. All services are already overstretched, and there has been little agreement about who should lead and provide care (136). Following the landmark IOM report (18), recommendations to improve the quality and coordination of post-treatment care included assessment of different care models, survivorship care plans (SCPs), and the support of resources, funding and research (137). There has been much recent progress in cancer survivorship advocacy (138), and national and international guidelines have endorsed the principles of survivorship care, recommending systematic, multidisciplinary and coordinated approaches and risk stratified pathways to enable timely access to appropriate services (76, 88, 139). Specific requirements vary between individuals based on their cancer, anticancer treatment, comorbidities and circumstances (140), and so a personalised approach is required (138, 141). However, such progress has not necessarily been reflected in clinical care (141), and the most effective and efficient ways of providing survivorship care remain unclear. This section will explore the various models of care and dimensions of delivery, SCPs, and the barriers to cancer survivorship care provision.

1.3.4.1 Cancer survivorship care models

There are different types of cancer survivorship models (128, 142), including specialist-led (medical), primary care-led, nurse-led, shared care and self-management (143). Specialist-led models involve conventional follow-up from oncology / haematology / surgery (144), with some clinics incorporating multiple specialists (145). Patients prefer multidisciplinary primary care models for health promotion, cancer prevention and management of comorbidities (146, 147). Primary care models may help to normalise post-treatment life (136), and are considered feasible within advanced healthcare systems if there is educational support (148), with the primary care provider facilitating communication with oncology when required (136). In shared care models, primary care and

specialties collaborate (149), which may help to build capacity for primary care to deliver post-treatment survivorship care (150). Models led by specialist nurses (supported by multidisciplinary team meetings) have been successfully implemented across hospital and community settings (151), and nurse-led screening programmes for symptom distress are feasible and acceptable (112). Finally, self-management describes an individual's ability to monitor and manage their disease and its physical and psychosocial impact (152).

Despite all of these options, research to date has not determined the most effective or preferable model. An overview of systematic reviews did not detect statistically significant differences between nurse-led, primary care-led care and specialist-led models regarding cancer prevention, surveillance, management of most physical and psychological effects, quality of life and survival (143), although data is lacking about some important outcomes, including fear of cancer recurrence, occupational / financial issues, and communication / decision making indicators (143), as well as model sustainability (153). However, shared care models are superior at promoting communication and coordination between services (18, 145) and generally viewed more positively (150). Shared care and nurse-led models may be more cost-effective (143), and along with primary care-led models have higher patient satisfaction than specialist-led (143). Indeed, specialist-led models likely over-burden the acute cancer care system (144), and focus more on cancer treatment and recurrence instead of supportive care (144, 154). Patients nevertheless prefer specialised supportive care services for certain issues including psychological problems, rehabilitation, sleep and sexual health (146). Self-support and web-based interventions may enable more effective use of cost and resources (128), but more research in self-management strategies is needed, including access and measuring systems (152).

1.3.4.2 Service organisation

Similarly, the ideal service organisation within these care models is unclear. Some centres provide survivorship care team consultations upon request, whereas others provide longitudinal care (140), and there is little difference in outcomes (155). Indeed, service quality (comprehensive with personalised plans) is valued amongst people with a history of cancer more than continuity (156). Alternatively, service organisation can be disease-based, treatment-based or as a

comprehensive stand-alone model (such as Adolescent and Young Adult (AYA) oncology) (157). Oncology practitioners generally prefer disease-specific models, particularly for long term / late onset effects from specific anticancer treatments, but accept centralised models for generic issues, such as nutrition or fertility (158). Some centres practice a tiered-based model where individuals are classed as low, intermediate or high-risk based on their particular cancer, treatment and comorbidities, then followed up by either primary care or oncology, supported by disease-specific algorithms for risk reduction, symptom management and psychosocial support, late effects management and recurrence risk (157, 159). Indeed, care transition also occurs at different times within different models, ranging from the completion of active treatment, to when risk of relapse is considered minimal (157).

1.3.4.3 Personnel in care provision

Although survivorship care is generally multidisciplinary (128), there is disagreement amongst professionals, patients and their advocates about the distinct roles of oncologists, general practitioners (GPs) and other specialty providers (136). It has been argued that oncological leadership is initially appropriate given the higher relapse risk (136), and indeed patients are generally reassured by consultant care (146, 156). Care is predominantly provided by GPs in primary care models (149), but many people who have or had cancer lack confidence in GPs' understanding of symptoms related to anticancer treatment (160), and indeed clinicians themselves agree they lack relevant knowledge (161). Non-medical practitioners (such as nurse practitioners, specialist nurses, physician associates) have important roles in survivorship care (128, 140); nurses are superior at patient education (136) and information provision (146), but less confident in survivorship care compared to doctors (158). The most appropriate personnel to provide survivorship care across specialties is not yet clear, and moreover there is a need to improve the ability and confidence of various professionals providing it.

1.3.4.4 Location of care

The optimal location of care also remains undefined, and a variety of settings have been employed (128). Flexibility impacts patient engagement post-treatment (143, 146), and patient preferences fluctuate according to need (146), so multiple options are likely desirable (156, 162). Although the multiple specialties required are usually located in specialist cancer centres (157), these tend to be least accessible (147). In-person primary care consultations are viewed positively (147), but care coordination / referral processes are needed for specialty access when necessary (157). Telehealth models can potentially support interprofessional coordination (157) and care delivery (143, 157) as they are accessible, flexible and least burdensome (146). They may be particularly suitable for those living rurally and those with self-perceived low need (146).

1.3.4.5 Survivorship care plans

There has been much debate surrounding survivorship care plans (SCPs), which are summaries of the cancer, its treatment and plan of care. SCPs are generally standardised within certain organisations, consultation-based, or self-support orientated (128), and are recommended as a communication tool between practitioners and between professionals and patients (18). Although SCPs are acceptable and may improve patient adherence and practitioner survivorship knowledge, a meta-analysis showed no significant difference at six months following implementation regarding patient knowledge, satisfaction, functioning or self-efficacy (although the reasons for the lack of impact are unknown) (163).

1.3.4.6 Barriers

There are numerous barriers to effective survivorship initiatives, including resource and time constraints, lack of engagement from both clinicians and patients, lack of role clarity, and inadequate communication, coordination, information provision, and care transition procedures (128, 136, 143, 164). Effective interdisciplinary communication and education are needed, particularly as care moves away from specialist-led models, but this also requires time and engagement, which are already lacking (128, 143), and it is challenging to coordinate the multiple specialties required for complex survivorship care (including SPCS) (157).

Crucially, there is a paucity of evidence about survivorship care, leading to lack of care standards (145) and inconsistent evaluation measures (146, 165).

1.3.4.7 Summary

Ultimately, there is a lack of high-quality evidence about the most effective cancer survivorship care model. Studies are based on small sample sizes, report data inconsistently and lack generalisability across populations, healthcare systems / settings, and cancer types and stages (143). There is also limited guidance on best practice follow-up for some cancer types (166), inadequate information resources (167), and deficient healthcare professional education regarding cancer survivorship (167). Many different models are possible, and a universal model likely inappropriate due to the variety of people with a history of cancer and their needs (143) and the differences between healthcare systems / settings (157). Services are essentially dependent on existing capacity and funding (168), so variation remains striking (166), and indeed cancer survivorship models are still not widely implemented (143).

1.4 Alignment of specialist palliative care and cancer survivorship care

The evidence to guide the role of SPC within cancer survivorship care is unclear. As demonstrated, both palliative care and survivorship care are similar regarding comprehensive assessment, holistic symptom management, promotion of quality of life, collaboration, and prioritising flexible, coordinated patient-centred approaches (154, 169-173). However, most palliative care cancer research focuses on people with advanced / metastatic cancer or towards the end of life, and most survivorship research focuses on individuals with no evidence of disease, so there is limited data to inform any overlap. In addition, guidelines are limited, and the absence of SPC from formative survivorship reports is notable (18). The literature to guide the role of SPCS, and the appropriate associated nomenclature within cancer survivorship, requires review, enabling gaps to be identified and understanding to be advanced, promoting effective knowledge transfer to inform a new model of care.

Developing a new care model is a complex task. The Agency for Clinical Innovation describes a practical process, encompassing the phases: project

initiation, diagnostic, solution design, implementation and sustainability (11). More evidence is required to develop a generalisable care model for the role of SPCS for this heterogeneous group of people who have or had cancer. Additionally, the ideal model will still be limited by external influences, since quality of life in cancer survivorship is ultimately influenced by a combination of individual (cancer-related, psychosocial and financial), organisational (care and support access) and political (policy and system setup) factors (174), all requiring consideration in model implementation and evaluation.

1.5 Conclusion

The population of people who have or had cancer is becoming larger and more complex. In recent years, one of the most important discussions surrounding palliative care has become the role of SPCS in cancer survivorship (or for all groups of people who have or had cancer), but the evidence to guide the debate remains lacking. Many models of SPC and cancer survivorship care have been proposed, but as these services continue to evolve the most effective models are unclear, and an evidence-based model is yet to be described. The most suitable role and model for SPCS within cancer survivorship must be clarified to enable the optimal use of limited resources to support the needs of people who have or had cancer.

1.6 Aims and objectives

Aim

The overall aim of this thesis is to determine the potential role of SPCS in the different cohorts of people with cancer or a history of cancer to inform a model of care.

The objectives are:

- To explore the evidence for the current / potential role of SPCS in supporting individuals living beyond cancer i.e. people with a history of cancer and no evidence of disease.
- To explore the evidence for the meaning and acceptance of cancer survivorship terminology.
- To determine the views of professional and non-professional SPC and oncology experts on the role of SPCS within cancer survivorship.
- To determine the perceptions of individuals with cancer known to SPC and oncology services regarding the terms used to describe them, in particular cancer survivor.
- To develop an overarching European model of care for SPCS for people with cancer or a history of cancer.

Chapter 2: The role of specialist palliative care in long-term cancer survivors (individuals living beyond cancer): a narrative review of the literature

2.1 Abstract

Introduction

Many long-term cancer survivors (individuals living beyond cancer) experience significant unmet needs across physical, psychological, social and informational domains, although few of these individuals are currently reviewed by specialist palliative care teams (SPCTs). The aim of this narrative review was to explore the current and potential role of SPCTs in the management of this cohort of people.

Methods

A search strategy was developed for Medline (Ovid), and adapted for Embase, CINAHL, and PsycInfo. All types of articles were considered. Additionally, websites of leading oncology, cancer survivorship, and specialist palliative care organisations were examined. The focus of the search was on individuals living beyond cancer rather than other groups of people with cancer or a history of cancer. Two independent authors completed title and abstract screening, full text reviews, data extraction, and data checking. Disagreements were resolved by consensus.

Results

5267 articles were screened. 111 articles were retrieved from the search for full text review, and 101 other sources of information were identified after hand searching the reference lists of the full text articles, and the aforesaid websites. Ten articles focused on palliative care and cancer survivorship, and eight articles considered the role of SPCTs in chronic pain management for cancer survivors. Six of the remaining references were generic cancer survivorship articles (that mentioned palliative care), and four were generic palliative care articles (that mentioned cancer survivors / cancer survivorship). The themes of the review encompass the definition of palliative care / specialist palliative care, current models of specialist palliative care, core activities of SPCTs, relevant expertise of

SPCTs, and potential barriers to change in relation to extending their support and expertise to individuals living beyond cancer. The review identified a paucity of evidence to support the role of SPCTs in the management of this cohort of people.

Conclusion

Individuals living beyond cancer have many unmet needs, and specific services are required to manage these problems. There are many synergies between the core activities of SPCTs, the essential components of cancer survivorship care, and the unmet needs of individuals living beyond cancer. Currently, there is limited evidence to support the role of SPCTs in the management of this cohort of people, and several potential barriers to greater involvement, including limited resources, and lack of relevant expertise.

2.2 Introduction

Cancer survivor is a ubiquitous term, which has various connotations amongst healthcare professionals, people with cancer, family carers, and the general population (15). The National Cancer Institute (NCI) in the USA states that “an individual is considered a cancer survivor from the time of diagnosis through the balance of life. There are many types of survivors, including those living with cancer and those free of cancer” (17). The NCI definition is widely quoted, and has been adopted to a greater or lesser extent by many other national and international organisations. However, the colloquial (general population) meaning of a survivor is “one remaining alive after some disaster in which others perish” (3), that is, a cancer survivor is an individual that has been cured of cancer. This disparity in meaning is highlighted by studies investigating the acceptability of the term cancer survivor amongst different cohorts of people with cancer (90).

The NCI acknowledges this disparity, and notes that “years ago, some suggested that the definition should only include people who were cancer-free for a minimum amount of time after their diagnosis”, and goes on to say that “this term (*cancer survivor*) is meant to capture a population of those with a history of cancer rather than to provide a label that may or may not resonate with individuals” (17). The NCI definition of cancer survivor is supported by a three-phase model of cancer survivorship (Figure 1, Chapter 1), which specifically includes people with “end stage cancer”, but surprisingly not individuals that no longer have evidence of disease (17). In response to concerns about nomenclature, the terms “living with, through and beyond a cancer diagnosis” (102, p.1) (either alone or together, e.g. living with cancer, living beyond cancer) have been introduced: living beyond cancer “refers to post-treatment and long-term survivorship” (102, p.4), i.e. individuals that have been potentially cured of cancer.

Many cancer survivors experience significant unmet needs, which encompass the continuum of physical, psychological, spiritual, and / or social domains (Table 1) (175, 176), and which relate to the cancer (directly or indirectly), the cancer treatment, and / or the presence of a chronic (potentially life-limiting) disease (177). Indeed, these unmet needs are the primary driver for the ongoing discussions around greater involvement of SPCTs in the management of individuals living beyond cancer, and similarly underserved groups of people who have or had cancer, e.g. people with stable cancer on maintenance anticancer

treatment. Importantly, there is significant heterogeneity amongst individuals in the same phase, and especially between individuals in different phases, in terms of the problems experienced, and the most suitable options for management (173). Hence, healthcare services for cancer survivors need to be tailored to the different phases / subgroups of people (and then personalised to the individual).

Table 1: Unmet needs of cancer survivors (adapted from Burg et al. (176)).

Unmet domain	Description	% individuals reporting
Physical	Needs and issues experienced in or affecting the body, including pain, symptoms, sexual dysfunction, and care of the body (such as diet, exercise, and rest).	38.2%
Financial	Needs related to money, insurance, and the affordability of required services and products.	20.3%
Education / information	Needs related to unanswered questions and the lack of knowledge regarding what to expect in the future, follow-up care, self-care, cancer and health research, and cancer risks, causes, and prevention	19.5%
Personal control	Needs related to an individual's ability to maintain autonomy in terms of the physical self (sexual function, evacuation, and ambulation) and the social self (disclosure about cancer and ability to make plans and socialise). Also includes wishes to return to "normal" and finding a "new normal".	16.4%
System of care	Needs related to the health care system, including constraints and flaws that affect early detection, diagnosis, treatment, follow-up care, continuity of care, and	15.5%

	inadequate responses from health care providers.	
Resources	Needs related to availability and access to supplies, equipment, therapies and medications (including alternative and complementary), and transportation services.	13.8%
Emotions / mental health	Needs related to psychological issues, including fear (recurrence, new cancers, death, and dying), depression, anxiety, and negative feelings (mistrust toward body, anger, and guilt).	13.7%
Social support	Needs related to psychosocial and interpersonal issues, including intimacy, access to support groups, opportunities to use one's own experiences to help others, and participation in social situations.	12.7%
Societal	Needs revealed from respondents' commentary about conditions and issues related to society's response to cancer, including social norms, discrimination, misinformation, policies, and resource allocation (including insurance coverage).	10.0%
Communication	Needs related to discourse (talking) and information exchange (explaining) about cancer and cancer experience with others (including survivor and doctor, and survivor and family/friends/employers) and among medical providers.	8.5%
Provider relationship	Needs related to trust in health care providers, including decision-making, follow-through, follow-up, and support.	8.5%

Cure	Needs related to a wish for a cure for cancer and hopes of effective treatments for self and others.	3.5%
Body image	Needs related to negative perception of body, including feeling unattractive and/or ashamed and loss of trust in body.	3.5%
Survivor identity	Pertains to the respondent either explicitly identifying or not identifying as a cancer survivor because the respondent does not like the term or feels that a specific milestone needs to be reached to warrant the term (e.g. treatment completion or living a specific number of years since diagnosis).	3.1%
Employment	Needs pertaining to maintaining or obtaining a source of income that is appropriate given the cancer experience.	2.3%
Existential	Needs pertaining to attaining peace in life and spirituality and making sense or meaning of the cancer experience.	0.6%

2.3 Aims and objectives

The aim of this narrative review article is to explore the potential for greater involvement of SPCTs in supporting individuals living beyond cancer as already defined (102), rather than other cohorts of people who have or had cancer: the objectives are to define palliative care (and SPC), to outline current models of SPC, to outline the core activities of SPCTs, to determine the relevant expertise of SPCTs, and to highlight the potential barriers to change.

2.4 Methodology

2.4.1 Narrative review methodology

Narrative overviews are a type of knowledge synthesis where authors comprehensively evaluate a range of previously published literature on a broad

topic (178, 179). Although different approaches can be taken, narrative reviews typically apply qualitative methods, which utilise linguistic data for meaning-based analysis (180). Narrative reviews therefore seek to summarise the literature content, research methods if applicable, and outcomes (178), as well as analyse the information within a critical discussion (181). The information may be organised in different ways, such as by theme, chronology or complexity (181).

Although there are no specific guidelines for undertaking narrative reviews (179, 181-183), a number of prominent, frequently cited papers suggest approaches to maximise utility and credibility (178, 181-183), with the overall aim to objectively describe and synthesise the literature on a topic and draw appropriate conclusions (178). This review adheres to these recommendations, as well as more recent considerations (179), described in further detail below. Additionally, it is recommended that authors themselves have some content expertise to enable appropriate and respected interpretation (178).

The flexibility of the non-systematic nature of narrative reviews makes it a useful method for reviewing debated issues and new interventions (182), particularly where the information largely extends from routine clinical practice instead of high-quality evidence (181). It is therefore appropriate to explore the potential role of SPCTs in supporting individuals living beyond cancer, allowing this question to be considered in the context of previous literature, where the knowledge base is limited (178, 179, 182) but the scope is potentially wide (182). It aims to summarise and discuss previous studies and develop a rationale for future research within this thesis (i.e. it does not aim to inform clinical practice or decisions) (178, 182, 184). Furthermore, this is an ideal method for such a potentially controversial topic, as when executed effectively and objectively, it can present a balanced perspective and stimulate discussion (178).

2.4.2 Review-specific methods

A preliminary literature search to refine the topic was undertaken, specific terms relevant in the review were defined, a robust search strategy was developed and followed (described below), and a qualitative descriptive and interpretive analysis was applied (178, 181). The relevance of findings to the general fields of cancer survivorship and SPC are also discussed, including issues of contention,

particularly important for narrative reviews so that clinical significance can be determined (178, 181). The process and findings are presented in a recognisable style for a literature review, given the lack of specification for narrative reviews (179). There is no formal critique of included studies since this is not required for narrative reviews, although some critical appraisal is applied in interpretation (178, 184).

2.4.2.1 Search strategy

A rigorous search strategy increases the utility of a narrative review (182). A literature search was initially undertaken in May 2023, and subsequently updated in January 2024. The search included four electronic databases (Medline (Ovid), Embase, CINAHL, PsycInfo), the internet (i.e. websites of leading oncology, cancer survivorship, and SPC organisations), and hand searching of SPC textbooks. These databases and sources were chosen according to relevance to the topic, and to increase the scope of the information identified (178). A broad search strategy was developed for Medline (Ovid) (Appendix 1) using Medical Subject Headings (MeSH) terms and key words (185), and adapted as needed for the other electronic databases: the electronic databases were searched from their inception to the present. Basically, articles were sought relating to the role / potential role of SPCTs in the management of cancer survivors (and specifically individuals living beyond cancer).

2.4.2.2 Eligibility

All types of articles were considered if they addressed SPC for individuals living beyond cancer, including editorials / commentaries, review articles, and particularly original research (including conference abstracts) (178, 184, 185). Although the preferable article type to include in narrative reviews is primary research (182), other types were also reviewed since only a small number of studies have been undertaken. Conference abstracts were included as they could provide useful preliminary information not available elsewhere. Articles relating to children were not included since this review focuses on adult SPC. Non-English articles were not reviewed, unless there was an English abstract (which was assessed).

2.4.2.3 Screening, data extraction and data synthesis

EndNote 20™ bibliographic software (Clarivate Analytics LLP, USA) was used to store the retrieved articles, whilst Covidence systematic review software (Veritas Health Innovation, Australia) was used to screen these retrieved articles. Two researchers (AT and AD) independently screened the titles and abstracts for full text articles to review. Disagreements were resolved by consensus. They also independently reviewed the full text articles, and extracted the relevant information using a review-specific template: this information was predetermined, and was collated using a PICOS framework (i.e. Population, Intervention, Comparison, Outcome, Study Design) (Table 2) (186). The reference lists of all retrieved full text articles were reviewed for further potential articles or sources of information (187).

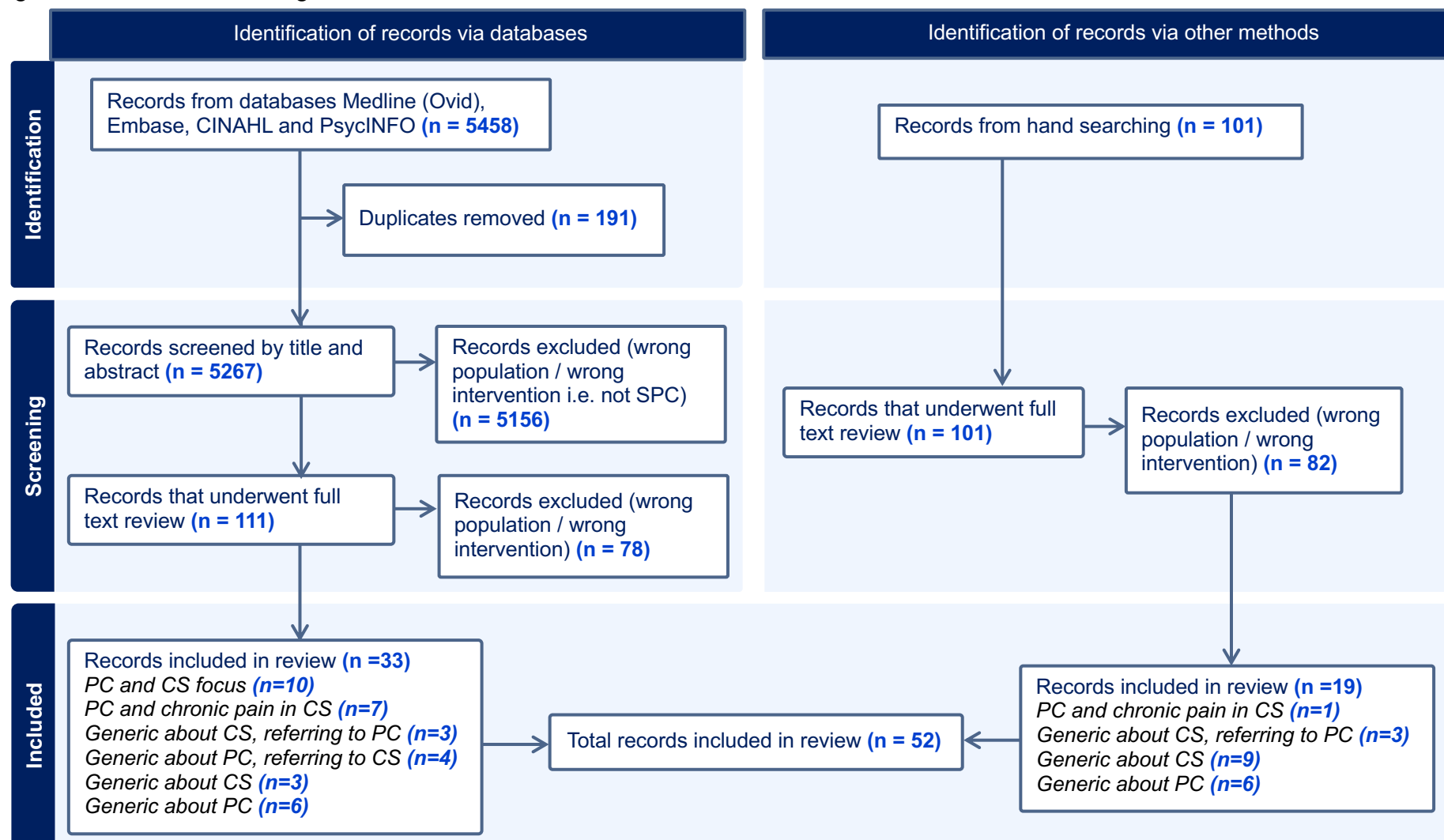
Table 2: Eligibility criteria using PICOS framework (186).

PICOS framework	Inclusion criteria	Exclusion criteria
Population	Cancer survivors, specifically individuals living beyond cancer	Articles relating to children / adolescents
Interventions	Specialist palliative care services	Non-specialist palliative care interventions
Comparators	Not applicable (N/A)	N/A
Outcomes	Experiences, perceptions	N/A
Study design	All article types, especially original research (quantitative or qualitative)	N/A

2.5 Results

The searches of the literature identified 5458 articles, which included 191 duplicate articles that were removed, and 5156 irrelevant articles that were excluded (on the basis of their titles and abstracts). Thus, 111 articles from the search underwent full text evaluation. Another 101 articles / sources of information were identified (and underwent full text evaluation) following searching the internet, hand searching of SPC textbooks, and hand searching of the reference lists of the included full text articles. Figure 2 gives an overview of the search of the literature.

Figure 2: Flowchart showing literature search for narrative review.



Key: PC = palliative care; SPC = specialist palliative care; CS = cancer survivorship.

Ten articles had a specific focus on palliative care and cancer survivorship (89, 169-171, 173, 188-192): five were commentaries (89, 169, 171, 173, 188), two were literature reviews (170, 192), one was an editorial (190), one was a letter to the editor (189), and one involved original research (i.e. postal survey) (191). Of note, six of these articles were published in oncology journals (three in oncology nursing journals) (89, 169, 170, 188, 190, 192), two in generic journals (171, 173), and only two in palliative care journals (189, 191).

A further eight articles concerned chronic pain in cancer survivors, and the actual / potential role of SPCTs in managing this cohort (193-200). Six of the remaining references were either generic cancer survivorship articles (that mentioned palliative care) (18, 88, 201-204), and four were generic palliative care articles (that mentioned cancer survivors / survivorship) (39, 205-207). Again, few of these articles were published in mainstream palliative care journals.

2.6 Literature review

2.6.1 Definition of “palliative care”

A number of definitions have been proposed for palliative care (21), although the most widely quoted ones are the older WHO definitions (19, 20), and the newer IAHPHC definition (which evolved from the later WHO definition) (22). The IAHPHC define palliative care as “the active holistic care of individuals across all ages with serious health-related suffering due to severe illness and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers” (22, p.754). The definition is supported by a series of additional characteristics, which include “is applicable throughout the course of an illness, according to the patient’s needs”, and “is provided in conjunction with disease-modifying therapies whenever needed” (22). Chapter 1 provides further detail.

2.6.2 Definition of “specialist palliative care”

The European Association of Palliative Care (EAPC) define three levels of palliative care: a) palliative care approach – “applies to those with limited experience and knowledge in dealing with palliative care but can apply the basic principles of good palliative care”; b) generalist palliative care – “applies to those who are frequently involved with palliative care and have some specialist palliative

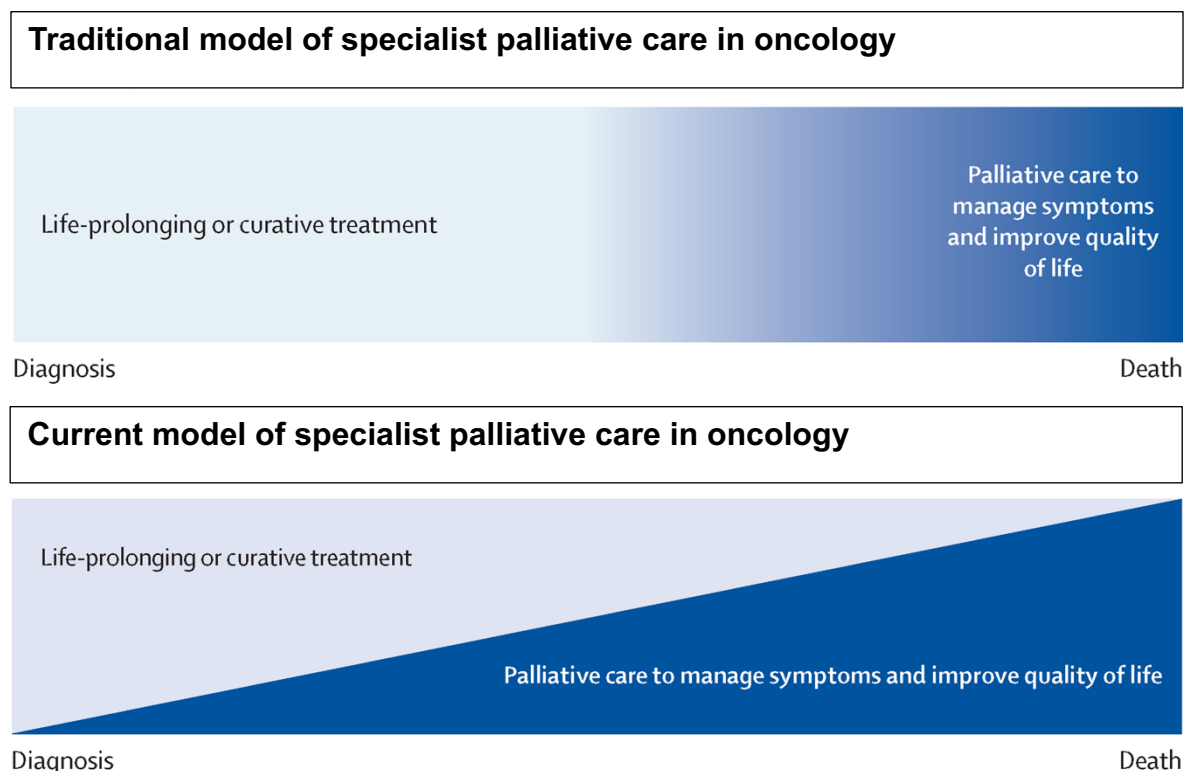
care knowledge”; and c) specialist palliative care – “team members must be highly qualified and should have their main focus of work in palliative care” (23, p.686).

It is important to note that most palliative care is currently provided by generalists (e.g. general practitioners, oncology clinicians), rather than palliative care specialists due to resource constraints, and that this scenario is unlikely to change due to ongoing and increasing workforce challenges (i.e. recruitment, retention / natural turnover) (63), changes in population demographics (i.e. higher population, more aged population) (64), and improvements in oncology treatments and outcomes (resulting in more people living with, through and beyond cancer).

2.6.3 Current models of specialist palliative care

The traditional model of SPC focused on people with advanced cancer, and involved both symptom control and end of life care (Figure 3) (39). The current model of SPC reiterates the relevance of end of life care, but also highlights the importance of symptom control in other groups of people with cancer from the point of diagnosis (39). Indeed, ASCO recommend that “patients with advanced cancer, whether inpatient or outpatient, should receive dedicated palliative care services early in the disease course, concurrent with active treatment” (24, p.97). The latter is often referred to as “early palliative care” (24, p.97), and is endorsed by other national and international oncology organisations (25).

Figure 3: Traditional and current models of SPC in oncology (adapted from Kaasa et al. (39)).



Importantly, according to the NCI definition (17), all of these individuals are cancer survivors, including those with advanced / progressive disease, and even those in the final (terminal) stage of their illness. Indeed, MASCC and ASCO jointly proposed international principles of quality survivorship care for people affected by advanced or metastatic cancer (6). Thus, SPCTs already manage a significant number of people who may be described as cancer survivors, although as previously indicated there is usually a clear demarcation between those subgroups that are routinely reviewed by these services, and those subgroups that are rarely (if ever) reviewed by these services (Table 3).

Table 3: Subgroups of people who have or had cancer and typical engagement with SPCTs.

LIVING WITH CANCER (person has active disease)	
Pre-oncology treatment (primary)	Hospital-based SPCTs may be involved in cancer symptom control.
On oncology treatment (primary or other) - curative pathway	Hospital-based SPCTs often involved in cancer symptom control.
On oncology treatment (primary or other) - palliative pathway	Hospital-based SPCTs often involved in cancer symptom control (and other core functions of SPC – see Box 3). People with advanced disease may also be referred to community based SPCTs.
Not on oncology treatment - watch and wait pathway	Hospital-based SPCTs may be involved in cancer symptom control.
Not on oncology treatment - no further treatment planned (advanced disease)	People usually supported by community-based SPCTs.
LIVING THROUGH / BEYOND CANCER (person has inactive disease)	
On active oncology follow up (some risk of recurrence)	Generally not reviewed by SPCTs.
Not on active oncology follow up (low risk of recurrence – potentially cured)	Generally not reviewed by SPCTs.

Currently, SPCTs are seldom involved in the management of individuals living beyond cancer, although it should be noted that SPCTs are extremely heterogeneous in their availability to different subgroups (and the services provided to different subgroups) (206). The European Cancer Organisation (ECO) therefore established a Survivorship and Quality of Life Focused Topic Network, which aims to enhance cancer survivors' quality of life by improving access to supportive and palliative care (78). The Joint Action on Cancer Control (CanCon), a collaborative venture between 17 European Union Member States, also developed policy recommendations for quality improvement in cancer survivorship and rehabilitation (202), which included integrating palliative care into the entire cancer pathway, including survivorship, and posed that SPCTs should be part of / associated with the teams providing long-term cancer follow-up (202).

The current model of SPC (Figure 3) does not address the issue of individuals living beyond cancer. The Lancet Oncology Commission on Integration of Oncology and Palliative Care (39), which designed the model, suggests that cancer survivorship (meaning living beyond cancer) falls under the remit of supportive care rather than palliative care. The latter is backed up by MASCC, who define supportive care as “the prevention and management of the adverse effects of cancer and its treatment. This includes management of physical and psychological symptoms and side effects across the continuum of the cancer journey from diagnosis through treatment to post-treatment care. Supportive care aims to improve the quality of rehabilitation, secondary cancer prevention, survivorship, and end-of-life care” (35).

As presented in the introduction, supportive care has been used by some as a synonym for palliative care, with a major driver for this change being the widely held opinion that palliative care is synonymous with end of life care (30). Indeed, ESMO's Patient Guide on Survivorship (80) uses palliative care and supportive care interchangeably to negate this association, emphasising the relevance of a holistic approach to symptom control from the time of diagnosis onwards, including follow-up care (survivorship). However, although palliative care is an integral component of supportive care (as previously defined), supportive care is much more than palliative care, and requires input from a range of specialist teams and services (205). Importantly, most SPCTs often have limited knowledge / experience of managing the active toxicities of anticancer treatments, and

especially the newer immunotherapies and targeted treatments (206). Furthermore, most SPCTs have even more limited knowledge / experience of managing the chronic toxicities of anticancer treatments, which has major implications for their involvement in the care of individuals living beyond cancer.

Interestingly, a recent scoping review on models integrating palliative care and survivorship care predominantly identified abstracts of low-quality evidence that described localised initiatives (192). Most of these services targeted individuals throughout the entire cancer trajectory (including into survivorship) (208, 209), some involved “survivorship” for individuals living with advanced / metastatic cancer (210-212), and a minority involved people post-treatment with no evidence of disease (208, 213). Additionally, one simply incorporated education on palliative care principles (214).

2.6.4 Core activities of specialist palliative care teams

SPCTs are extremely heterogeneous in terms of their membership, services provided, and populations served (206). Nevertheless, most SPCTs provide the core functions outlined in Box 3, although this range of services is usually restricted to people with advanced cancer. As discussed, some SPCTs also provide early palliative care, some provide supportive care, and a smaller number also provide services for individuals living beyond cancer (generally symptom control).

Box 3: Core activities of SPCTs.

Management of physical symptoms

- cancer-related
- cancer treatment-related

Psychological support

- patient
- family / carers (and children)

Spiritual support

- patient
- family / carers

Social assistance

Advance care planning

Bereavement support (family / carers)

2.6.5 Relevant expertise of specialist palliative care teams

The influential IOM report outlined four “essential components of survivorship care” (18, p.3): 1) prevention of recurrent and new cancers, and of other late effects; 2) surveillance for cancer spread, recurrence, or second cancers; assessment of medical and psychosocial late effects; 3) intervention for consequences of cancer and its treatment, for example: medical problems such as lymphoedema and sexual dysfunction; symptoms, including pain and fatigue; psychological distress experienced by cancer survivors and their caregivers; and concerns related to employment, insurance, and disability; and 4) coordination between specialists and primary care providers to ensure that all of the survivor’s health needs are met.

At first glance, there seem to be many synergies between the core activities of SPCTs, the essential components of survivorship care (18), and the well described unmet physical and psychosocial needs of individuals living beyond cancer (Table 1) (116, 175, 176). Unsurprisingly, there is some (limited) data to suggest support for the involvement of SPCTs in “long term cancer survivors” (201, p.351) from oncologists, general practitioners, and people who have or had cancer themselves (201). Moreover, a number of oncology-related organisations have recommended involvement of SPCTs in the management of these cancer survivors (and

specifically the treatment of pain and related problems) (88, 202, 203). However, there is less obvious support from palliative care-related organisations (215). The reasons for the apparent reticence are discussed in the following section.

Many of the focused (palliative care and cancer survivorship) articles supported a palliative care approach to the management of individuals living beyond cancer, which is unsurprising since a palliative care approach is essentially a holistic approach (and is the basis for satisfactory healthcare irrespective of the cohort of patients) (171, 173, 192). However, some of the focused articles supported actual involvement of SPCTs, and this ranged from targeted interventions in specific cohorts (especially symptom control) (170, 173), to provision of wide-ranging activities in those with unmet needs (e.g. advance care planning, coordination of care) (169, 188).

In terms of pain, SPCTs are adept in the treatment of acute / chronic cancer-related pain, and to a lesser extent acute cancer treatment-related pain. It has been suggested that SPCTs have a role in challenging post-treatment pain, such as refractory chemotherapy-induced peripheral neuropathy (213) and the assessment of psychosocial factors impacting the pain experience (200). Indeed, chronic cancer treatment-related pain is a major problem in individuals living beyond cancer, but SPCTs are generally inexperienced in its management (216-218). Moreover, the treatment of chronic cancer treatment-related pain is fundamentally different to the treatment of acute / chronic cancer-related pain (204), and especially that used for individuals with limited prognoses (217). Thus, the neurophysiology is different, the efficacy of analgesics is often different (usually decreased), the risk / benefit of analgesics is often different (usually increased), and the focus of care is on improving individual function (rather than reducing pain intensity) (193, 219). Furthermore, non-pharmacological interventions (e.g. physical exercise, psychological interventions) have a major role in the management of chronic pain, but the skills required to manage psychosocial factors in chronic pain may be lacking amongst palliative care practitioners (199, 200), and interventions are invariably provided by multidisciplinary chronic pain teams rather than SPCTs. Evaluation and management of analgesic drug dependency / abuse is also relevant in post-treatment chronic pain management, (196, 220), but SPCTs are not universally competent in such areas (197).

Importantly, the same is true for the treatment of other physical symptoms, and to a lesser extent psychological symptoms. For instance, many of the chronic gastrointestinal problems caused by anticancer treatments require specialist investigations, and / or specialist interventions (which are outside the scope of practice of SPCTs) (221): an example would be rectal bleeding from radiation-induced telangiectasia following pelvic radiotherapy. Similarly, SPCTs are not trained to deal with fear of cancer progression (173), which is a common problem amongst individuals living beyond cancer. Importantly, SPCTs do not tend to have experience in other “essential components of survivorship care” (p.3) such as cancer surveillance, and cancer prevention (18), or the certain other unmet needs in this cohort of individuals (e.g. financial toxicity, issues relating to employment) (Table 1) (176).

Ultimately, there is currently a paucity of evidence to support the role of SPCTs in the management of individuals living beyond cancer (192).

2.6.6 Potential barriers to change

There are a number of barriers to increasing SPC involvement with individuals living beyond cancer (and similarly underserved groups of people who have or had cancer):

2.6.6.1 Limited resources

The National Coalition for Hospice and Palliative Care (NCHPC) in the USA contend that SPCTs do not have the capacity to see individuals living beyond cancer as well as their usual cohorts of patients (215). Moreover, this situation is likely to worsen due to changes in expected population demographics (resulting in greater numbers of patients, and smaller numbers of healthcare workers) (63). However, the NCHPC suggest that SPCTs may be able to support dedicated cancer survivorship services in terms of education about the principles of palliative care, development of treatment algorithms, and potentially sharing relevant resources (215).

Importantly, any increase in service provision from SPCTs will require dedicated funding (169), and this will necessitate either provision of additional funding, or

reallocation of current funding (which may have negative impacts on existing services). Moreover, this funding would need to be ongoing, and so necessarily supported by changes to healthcare policy / priorities at regional and national levels (192).

2.6.6.2 Lack of relevant expertise

As discussed, many of the problems encountered by individuals living beyond cancer are fundamentally different from those encountered in people with advanced cancer (Table 1), and so SPCTs will need additional education / training if they are to provide the most suitable options for individuals living beyond cancer (200, 207). Indeed, extrapolating practice from people with advanced cancer to individuals living beyond cancer is likely to lead to utilisation of ineffective interventions, and potentially to development of significant complications.

2.6.6.3 Nomenclature - palliative care

The view that palliative care is synonymous with end of life care is commonplace amongst healthcare professionals, patients (including individuals living beyond cancer) (191), family carers, and the general population (169). Indeed, such views have resulted in a reluctance from some oncology professionals (and other healthcare professionals) to refer people with non-advanced cancer to SPCTs (30). Thus, consideration will need to be given to improving understanding about palliative care, and / or rebranding of relevant services (e.g. supportive and palliative care team).

2.6.6.4 Lack of professional willingness

Many SPCTs have opted for a variety of reasons to solely manage people with advanced cancer (and other life-limiting diseases), and have not engaged in developments such as early palliative care, and / or supportive care for people with cancer (206). It is likely that the same would be true about providing services for individuals living beyond cancer.

2.7 Strengths and limitations

The weakness of this review relates to the current paucity of evidence regarding the involvement of SPCTs in the management of individuals living beyond cancer, i.e. small number of studies, limited quality of studies. Indeed, this lack of evidence lends itself to performing a narrative review, rather than other types of review (e.g. scoping, systematic). Although the search strategy employed was systematic, it is possible that relevant information sources were not identified, and the exclusion of publications not in the English language as well as lay literature may also be limiting. Author subjectivity is also particularly relevant (222) as selection and evaluation biases cannot be known (179, 182): narrative reviews are particularly prone to bias, which limits their credibility (222). Thus, since the authors (AT and AD) are European palliative medicine practitioners, their clinical and academic experience and circumstances will likely impact their perspectives and evaluation. Furthermore, most of the literature was from the USA, limiting generalisability.

Despite these potential limitations, this review is unique in terms of its focus, and its strength relates to the methodical approach which adds clarity to the findings (178). The systematic process used to select information sources is a particular strength, including the comprehensive search strategy (182), supported by the variety of databases and journal types searched (182), clear inclusion criteria (178), and the transparency of methods (179). The independent approach to data selection and extraction, resolving disagreement by consensus when required, attempted to minimise biases, and promote objectivity in article selection and assessment (178). For example, the review prioritises the objective results of primary research studies, and the inclusion of editorial / opinion pieces are presented critically (178).

2.8 Conclusion

Individuals living beyond cancer have many unmet needs, and specific services are required to manage these problems. Moreover, a whole system, multidisciplinary, and inter-specialty approach is needed, given the magnitude of these problems. SPCTs could have a role to play, but this would require targeted education / training, and especially research to ensure that this input is effective and well tolerated (and does not disadvantage the usual cohort of people known to SPCTs).

Chapter 3: A scoping review on the evidence for the meaning and acceptance of cancer survivor terminology

3.1 Abstract

Introduction

The definitions of cancer survivors and cancer survivorship have evolved with time, and applications of these terms vary in academic and clinical settings, causing confusion and even alienation. The current meaning of cancer survivors for those who use it, and for those it describes, should be explored and understood. The aim of this scoping review is to explore the evidence for the meaning and acceptance of cancer survivor terminology by identifying evidence-based definitions, evidence-based classifications, and the perceptions of individuals who are described as cancer survivors towards these terms.

Methods

This scoping review was conducted using Arksey and O'Malley's framework and updated methodological guidance, and reported using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews. Medline (Ovid), CINAHL, APA PsycInfo and Embase databases were searched for articles from their inception until December 2023, supported by hand-searching relevant sources, and updated in September 2025. EndNote 20™ bibliographic software was used to store the articles retrieved from the database searches and the Covidence systematic review software was used for the screening process. Eligible studies were original articles published in English that focused on the definition or categorisation of cancer survivors / cancer survivorship, or explored the perceptions of adults with a history of cancer about the terms. The final selection included original research articles and formal evidence syntheses.

Results

8494 articles underwent title and abstract screening, from which 52 studies were selected for data extraction. Twelve further articles were identified through hand-

searching. Sixty-four articles were included in the final review. The studies included nine articles on defining cancer survivor / cancer survivorship, 54 articles exploring participant endorsement and / or interpretation of cancer survivors and one on classifying cancer survivors. Academics and clinicians often describe cancer survivors as individuals from the time of diagnosis onwards, or individuals post-treatment. Individuals with a history of cancer commonly describe cancer survivors as people who are alive, who no longer have cancer or who have fought a battle, and describe cancer survivorship as either a process or an outcome. Studies researching acceptance of the term demonstrated diverse results, identified a variety of associated factors, and most commonly recruited white participants from the USA who had completed primary treatment for early-stage breast cancer.

Conclusion

There are a variety of interpretations and perceptions regarding cancer survivor terminology. However, previous studies on the perception of cancer survivors towards the terms do not reflect the views of all groups of individuals with a history of cancer. Future studies should incorporate individuals on anticancer treatment and with advanced / progressive cancer across cancer types and geographical areas so that research and clinical practice can integrate their perspectives. Consensus studies should determine which definitions and categorisations to apply, if not universally at least contextually, and incorporate these into service model development.

3.2 Introduction

There were 18 million new cancer diagnoses worldwide in 2020, and by 2040 it is estimated there will be 28 million new cases every year (223). In Europe, there are over 12 million people with cancer or a history of cancer, described as cancer survivors by the European Commission, set to increase by 24% by 2035 (7). Similarly, in the USA there were over 18 million people with cancer or a history of cancer in 2022 (8), projected to increase to 22.1 million by 2030 (224). Although growing and ageing populations contribute to this rising incidence (224, 225), people are also living longer with and beyond cancer due to earlier diagnoses, novel anticancer treatments, and supportive care services. The care of cancer survivors has therefore become an essential healthcare and research priority.

The definitions of cancer survivors and cancer survivorship have evolved with time. The term cancer survivors first described family members who survived the loss of a loved one in the 1960s, when cancer was considered incurable (226). As survival improved, cancer survivors referred to individuals still alive 5 years after diagnosis, aligning with survival statistics (227). However, many organisations now subscribe to ideas proposed by Cancer Nation (75), an advocacy organisation which adopted cancer survivors as a term of empowerment to describe any individual with cancer or a history of cancer, replacing previous application of cancer victims to this group (228). The National Cancer Institute (NCI) endorses this concept, defining cancer survivors as individuals, “from the time of diagnosis through the balance of life. There are many types of survivors, including those living with cancer and those free of cancer” (17). This description previously included family members, friends, and caregivers, recognising the additional impact on them (145, 229). Although many organisations endorse the NCI’s definition, only a select few incorporate it into guidelines (88) and a number of alternate functional definitions have been adopted in clinical practice, typically incorporating individuals post-treatment with no evidence of disease (18, 76, 77).

The concept of people living with and beyond cancer in cancer survivorship was first described by Mullan in 1985 (96). Rejecting the binary concept of people being “cured or not cured”, three seasons of survivorship were proposed: “acute”, (the period of diagnosis and treatment), “extended”, (post-treatment completion / remission), and “permanent survival” (cure) (96, pp. 271-272). Suggestions to update these phases have included a transitional phase (moving from active

treatment to observation) (97), chronic phase (cancer as a chronic disease, including metastatic disease) (98) and end of life phase (99). Alternative descriptions of cancer survivorship phases (17, 103) and cancer survivor groups (91, 95) have been developed. Notably, the NCI presents phases of cancer survivorship as individuals with early-stage cancer where the goal is curative intent, individuals with advanced / metastatic cancer where the goal is to prolong life, and individuals with end-stage cancer where the goal is end-of-life care (17). Ultimately, groupings remain varied and somewhat subjective.

Although the term cancer survivors was not designed to be a label (17), it is widely used by healthcare professionals and people who have or had cancer. As medical advancements enable more people to live longer with, through and beyond cancer, and the very nature of being a cancer survivor changes, the term necessitates reconsideration. The current evidence for the term's application should be explored.

3.3 Aims and objectives

The aim of this scoping review is to explore the evidence relating to the meaning of cancer survivors and cancer survivorship. The objectives are:

- To explore the evidence for the development of definitions of cancer survivors / cancer survivorship.
- To explore the evidence for the development of classifications of cancer survivors / cancer survivorship.
- To describe the perception (meaning and acceptance) of individuals with a history of cancer about the terms cancer survivors and cancer survivorship.
- To describe the individuals included in studies assessing the perception of individuals towards cancer survivors / cancer survivorship.

3.4 Methodology

3.4.1 Rationale for scoping review methodology

Scoping reviews are a type of evidence synthesis aiming to systematically collect, extract and describe the breadth of evidence available on a particular topic in

order to clarify key concepts, describe related factors, and identify gaps in knowledge (230-232). Such an approach is ideal to explore the broad study objectives. Scoping reviews can also integrate the background / contextual information, ascertaining how previous research has been undertaken, and help to update research priorities (231, 232). Unlike systematic reviews, they do not seek to determine effectiveness or make analytical comparisons (232, 233). Traditionally including primary studies and reviews (230), scoping review methods continue to be refined (234) and can include any type of literature with limits dependent on the aim (231, 235).

A scoping review was chosen to establish if the evidence-based meanings and categorisations reflect the scope of individuals encompassed by the NCI definition (17), and if studies assessing the perception of individuals with a history of cancer towards the terms also reflect this broad group. In particular, this approach sought to clarify if individuals on anticancer treatment and with advanced / metastatic cancer are viewed as cancer survivors alongside individuals post-treatment with no evidence of disease, and how all of these individuals perceive cancer survivorship terminology. This could determine the risk of alienation posed by these terms and have important implications for service development, as well as identify areas for future research.

3.4.2 Review-specific methods

This scoping review was conducted using Arksey and O'Malley's framework (230) with updated methodological guidance (234, 235), and is reported using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) (236).

3.4.2.1 Search strategy

Medline (Ovid), CINAHL, APA PsycInfo and Embase databases were searched for articles from their inception until December 2023. The search was updated in September 2025. Appendix 2 shows the search strategy adapted for each electronic database.

3.4.2.2 Study eligibility criteria

Eligible studies were original articles published in English that focused on the definition or categorisation of cancer survivors or cancer survivorship, or explored the views of adults with a history of cancer towards the terms (Table 4 shows the eligibility criteria). The final selection included original research articles and formal evidence syntheses. This review does not include non-empirical evidence as it seeks to explore if such suggestions are supported by higher levels of evidence, so abstracts, editorials, and articles without original information were excluded. Studies on childhood cancer survivors were excluded as identity development would be impacted in different ways through childhood and adolescence, and studies defining long-term survivors were excluded since this differs between cancer types.

Table 4: Eligibility criteria using Population, Concept, Context (PCC) framework (235).

PCC framework	Inclusion criteria
Population	• Healthcare professionals or studies without a population (regarding definition and categories) • Adults with cancer or a history of cancer (regarding definition and acceptance)
Concept	Definition, classification or acceptance / endorsement of cancer survivors or cancer survivorship
Context	Academic or clinical settings in any geographical location.

There is no formal guidance about including evidence syntheses in scoping reviews (232), so reviews were included if aims differed from this review and / or time had lapsed since completion (237), ensuring the available evidence was comprehensively mapped (233). If primary sources were incorporated into an evidence synthesis, relevant data was reviewed and reported if not included in the evidence synthesis, with overlapping information described (237). Concept analyses relating to cancer survivorship were included since these can

demonstrate how concepts have changed over time, through creating specific measurable definitions and / or identifying knowledge gaps (238).

3.4.2.3 Data management and synthesis

EndNote 20™ bibliographic software (Clarivate Analytics LLP, USA) was used to store results from database searches. Title and abstract screening was carried out by two independent researchers (AT and LD) using the Covidence systematic review software (Veritas Health Innovation, Australia). Disagreements were resolved by consensus, supported by a third reviewer (AD). Articles selected for full text review were assessed independently by the same researchers. Reference lists of these articles, relevant sections from oncology / cancer survivorship guidelines and chapters from applicable textbooks were hand searched. Data extraction was carried out by AT using review-specific templates, and data checked by another two researchers (AD and EJ).

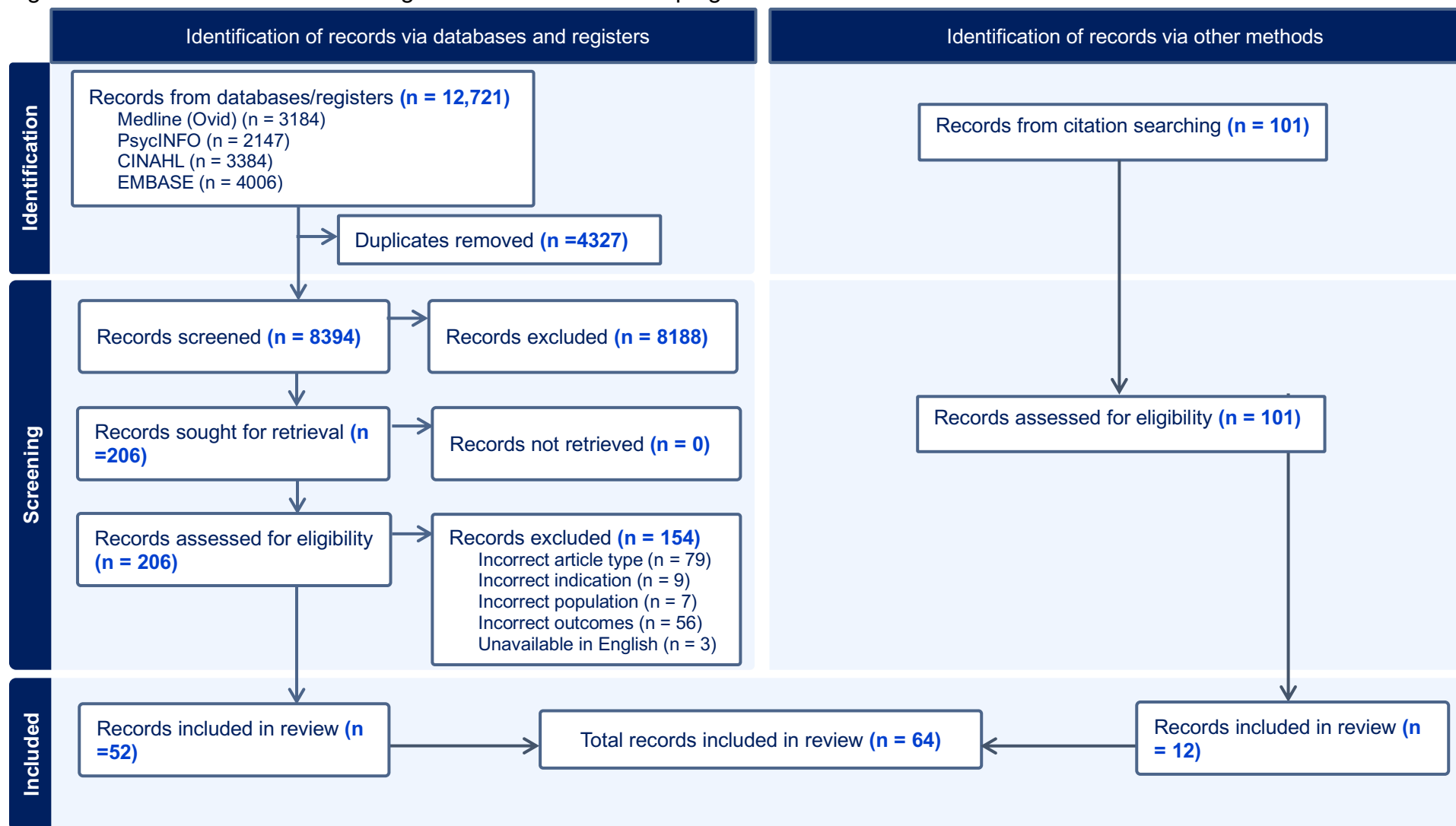
Basic analytical methods are standard practice for reporting in scoping reviews (237). A narrative descriptive approach was applied in this review as the evidence was expected to be limited. Data from concept analyses was extracted into a pre-defined table, including the definition, attributes, antecedents (factors preceding the concept), consequences (factors resulting from it), and surrogate and related terms, according to Rodgers (239) and Walker & Avant (240) methods. For the evidence syntheses, overlaps with relevant sources of primary evidence were described (237). For the primary studies, data from quantitative articles was extracted into tabular format, including the study type, sample size, participant and cancer-related characteristics, method of evaluating cancer survivor perception, endorsement and associated factors. The intention was not to synthesise results (237), but to present the context of the research studies (230). Qualitative studies underwent basic descriptive analysis to present sample demographics (person and cancer-related) and key findings. Frequency counts of data extraction items were employed overall (230, 237). Lastly, data on the meaning of cancer survivorship terminology underwent basic coding and was categorised using a qualitative descriptive approach (230), recommended for mapping the meaning of a concept in a scoping review (237). (Further discussion on qualitative descriptive analysis can be found in Chapter 6.)

3.5 Results

3.5.1 Search results

Results from the search strategy are presented in Figure 4. After duplicate removal, 8394 articles underwent title and abstract screening, from which 206 articles underwent full-text review. Fifty-two studies were selected for data extraction (15, 90, 113, 158, 241-288). Twelve further articles were identified for inclusion through hand-searching reference lists (92, 289-299). Thus, 64 articles were included in the final review. The studies included nine articles on defining cancer survivor / cancer survivorship (15, 158, 241-246, 289), 54 articles exploring patient perception / interpretation of cancer survivors (90, 92, 247-288, 290-299), and one on classifying groups of cancer survivors (113).

Figure 4: PRISMA-ScR chart showing literature search for scoping review.



3.5.2 Overview of articles

The articles on defining cancer survivors included one Delphi study (241), one observational study (158), one systematic review (15), and six concept analyses (242-246, 289). One observational study classified groups of cancer survivors (113).

The articles exploring the perception of people who have or had cancer towards the terminology were heterogeneous in type, aims and methodology. Results included three reviews (90, 247, 248), quantitative results from 16 articles (249-259, 277, 290-293) (incorporating 17 studies, six of which used mixed methods (249, 252-254, 256, 258), and 35 qualitative articles (92, 260-276, 278-288, 294-299) (consisting of 34 studies). Thirty-two were conducted in North America (25 in the USA (92, 252-254, 256-260, 268, 270-273, 275-277, 279, 284, 287, 290, 293, 295, 297, 298), five in Canada (249, 261, 285, 292, 294), one between USA and Canada (251), one in Mexico (267)), 11 in Oceania (253, 255, 265, 266, 278, 280, 281, 283, 288, 296, 299), four in Europe (250, 262, 269, 274), two in Africa (282, 286), one in South America (263), and one in Asia (264).

3.5.3 Results on the definitions of cancer survivors and cancer survivorship

Marzorati et al. (15) undertook a systematic review of published definitions of cancer survivor and cancer survivorship in 2015. A search of five databases identified 15 sources providing definitions for cancer survivor (two national reports, three organisational endorsements, one policy paper, seven editorial / opinion pieces, one website, and one qualitative study), and 10 providing definitions of cancer survivorship (two organisations, three opinion / special issue pieces, one concept analysis, one clinical update, and three qualitative articles). No primary research outcomes were included. The most widely used definition of cancer survivorship identified was a process that begins at diagnosis and continues through the balance of life (15).

Table 5 summarises the concept analyses. Five explored the concept of cancer survivorship (242-244, 246, 289), one cancer survivors (244), one the transition to cancer survivorship (245), and two focused on specific groups (African-American women with breast cancer (242), and adults with colorectal cancer (289)). Four studies defined cancer survivorship as a process beginning at diagnosis (242, 243,

246, 289), but two identified survivorship as the period following completion of primary cancer treatment (244, 245). Survivor was described as the individual experience of a person living with a history of cancer (244).

Matsuoka et al.'s (241) Delphi study developed oncology expert consensus components for cancer survivorship guidelines in Japan. 95.5% defined cancer survivorship as, "the entire experience of a patient after receiving a diagnosis of cancer, regardless of cancer status," and that, "a patient becomes a cancer survivor upon receiving a diagnosis of cancer and remains a cancer survivor throughout their lifetime. Cancer survivors also include family members, friends, and caregivers of cancer patients, because they are strongly affected by the survivorship of the patients themselves" (p. 279).

Gage et al. (158) surveyed 377 USA cancer healthcare professionals who provided mixed definitions of cancer survivorship; 38.7% endorsed "from initial cancer diagnosis", 34.5% "completion of active therapy and in remission", and 8.5% "five years from date of initial diagnosis" (p.221).

Table 5: Concept analyses that define cancer survivor or cancer survivorship.

Author, year	Term	Method	No. data sources (source date range)	Concept	Antecedents	Attributes	Consequences	Surrogate and related terms
Farmer & Smith, 2002 (242)	Cancer survivorship (for African American women with a history of breast cancer)	Rodgers	50 (NR)	The process of living through the cancer experience beyond a breast cancer diagnosis	• Cancer diagnosis	• Complex • Individualised • Process • Unique • Relational • Dynamic	• Physical • Psychosocial • Spiritual • Socio-economic	Surrogate terms: • Survivor • Sufferer • Exceptional patient • Cancer outcomes • All lived experiences Related terms: • Quality of life • Coping • Cure • Adaptation • Adjustment
Doyle, 2008 (243)	Cancer survivorship	Rodgers	43 (1975-2006)	A process beginning at diagnosis and involving uncertainty...a life-changing experience with a duality	• Cancer diagnosis	• Process beginning at diagnosis • Uncertainty • Life-changing experience • Duality of positive and	• Physical health • Psychological health • Social health • Spiritual health	Surrogate terms: • Cancer survivor • Living after a cancer diagnosis Related term: • Quality of life

				of positive and negative aspects, and is unique to the individual but has some universality.		negative aspects • Individual experience with universality		
Hebdon et al., 2015 (244)	Cancer survivor and cancer survivorship	Walker & Avant	30 (1987-2013)	An individual who has a diagnosis of malignancy, has lived through a challenging experience, has positive and negative consequences related to their disease and whose experience is individualised. Survivor is the individual experience of a person living with a history of cancer.	• Cancer diagnosis • Cancer treatment • Being alive	• Living with a history of malignancy • Lived through a difficult experience such as cancer treatment • Impacted in positive and negative ways by the experience • In the follow-up phase of their cancer treatment • Their experience is personal and contextual.	• Does not survive unaffected • Experiences physical, emotional, financial and social challenges • Needs support from external sources • Positive outcomes include improved self-advocacy, a sense of well-being, and victory of overcoming a challenge.	N/A

				Survivorship denotes the general needs of individuals after primary cancer treatment completion.				
Drury et al., 2017 (289)	Cancer survivorship (in the context of CRC)	Rodgers	85 (2006-2016)	An individual, life-changing process, punctuated by uncertainty and a duality of positive and negative outcomes affecting quality of life. CRC survivors experience specific concerns arising from the management of their disease.	• Symptoms of disease • Cancer diagnosis	• Process which begins at diagnosis • Uncertainty • Life-changing experience • Duality of positive and negative aspects • Individual experience of illness and recovery • Navigating systems and resources	• Physical health • Psychological health • Social health • Spiritual health • The constellation of met and unmet survivorship needs	Surrogate terms: • Living beyond cancer • Life after cancer • Living with cancer • Survival • Cancer survivor • Remission Related terms: • Quality of life • Health behaviour • Illness perception • Symptom burden • Survivor identity • Psychological distress • Post-traumatic stress • Coping • Adaption

								• Adjustment • Continuity of care • Unmet need
Wood, 2018 (245)	Transition to cancer survivorship	Rodgers	63 (1985-2017)	A turning point after completion of treatment for a cancer diagnosis, with movement to an undefined and variable time period characterised by liminality, being in-between points of time after treatment and life as a cancer survivor.	• Health status • Cancer diagnosis • Completion of treatments / remission • Identity as “patient” / personal self-concept • Post-treatment state (physical / psycho-social) • Coping styles / adaptability • Expectation / perception / attitudes / beliefs / values • Socio-economic / cultural factors	• Turning point • Variable time period • Liminality • Changes • Multi-dimensional distress • Passage	• New needs (unmet) • Continued multi-dimensional distress • Reforming identity / sense of self • Beginning process for healing and adaptation • New focus on wellness • Developing self-efficacy • Quality of life • Growth / stagnation / transformation	Surrogate terms: • Re-entry • After treatment • Post-treatment • Trajectory • Change • Change-over • Switch • Shift • Gap • Transformation • Transcendence • Conversion • Transition • Process • Threshold • Disjuncture • Survivorship process • Transition experience • Survivorship experience

de Oliveira et al., 2018 (246)	Cancer survivorship	Rodgers	39 (2000-2014)	A universal, multifactorial, and dynamic concept, begins at diagnosis and continues until the end of life. A specific phase exists along the cancer continuum after the end of primary treatment... refers to an individual and heterogeneous disease... encompasses two domains (the survivor and culturally congruent care).	• Cancer diagnosis	• Liminality of the process (change in life plans, dualities, reflections on life, change of identity) • Culturally congruent care (individual experience, control of symptoms, the need for support, quality of care)	• Quality of life • Personal growth	Surrogate terms: • Cancer survivor • Long term survivorship • The one who is living after cancer diagnosis Related terms: • Survival • Cancer rehabilitation

Key: NR = not reported; N/A = not applicable; CRC = colorectal cancer.

3.5.4 Results on the categorisation of cancer survivors

Only one study developed an evidence-based categorisation (113). De Rooij et al. undertook a USA cross-sectional survey on self-reported healthcare needs of participants with a history of early-stage cancer on curative-intent treatment or in long-term follow-up (113). Four clusters were identified including low needs (42.1%), mainly physical needs (15.8%), mainly psychological needs (19.5%), and both physical and psychological needs (22.6%).

3.5.5 Results on the perception of cancer survivors towards the term

3.5.5.1 Evidence syntheses on cancer survivor identity

Three relevant evidence syntheses were identified (90, 247, 248). Cheung and Delfabbro's (90) 2015 systematic review explored acceptance of the cancer survivor term by individuals diagnosed with cancer, associated factors and outcomes, and included 23 articles (which described seven quantitative, nine qualitative and eight mixed methods unique studies). The review showed a variety of methods were used to assess cancer survivor endorsement, and the pooled results found an almost equally divided distribution of acceptance (53.6% endorsed the identity, 46.4% did not) (90).

Costa et al.'s (247) 2019 scoping review of 47 articles of preferred labels across healthcare contexts included eight quantitative and mixed methods articles focusing on cancer survivors, which were all included in Cheung and Delfabbro's review (90). Five showed a preference for the survivor identity.

Greenblatt and Lee (248) completed a systematic mapping review of 22 papers in 2018 on cancer survivorship identity post-treatment. These included two quantitative, 11 qualitative, and two mixed methods studies, four reviews, and three conceptual articles. Dominant discourses of the cancer survivor concept included sharing personal journeys, personal growth, and an individual responsibility to fight cancer (248).

3.5.5.2 Studies assessing acceptance of the cancer survivor identity

Table 6 summarises quantitative results from 15 articles and 17 studies (249-259, 277, 290, 292, 293) that assess acceptance / endorsement of the cancer survivor

identity by individuals with a history of cancer. In addition to 10 articles (253-259, 277, 290, 292) included in Cheung and Delfabbro's review (90), the table includes another five articles (249-252, 293). One article with duplicate results was not included (291). Thirty-five qualitative articles (92, 260-276, 278-288, 294-299) were also reviewed. Since Cheung and Delfabbro's review (90), sixteen qualitative studies exploring cancer survivor identity have been published (260-268, 280-282, 285-288), and eight relevant others were identified (269, 279, 283, 284, 294-297).

Samples varied in cancer type, stage and treatment status, and had diverse results. Twenty-three studies (from 22 articles) examined populations with mixed cancer types (92, 252, 256-258, 260, 261, 265-269, 272-274, 280, 282, 284, 290, 292, 295, 298), but in 15 studies breast cancer was the most common type (92, 252, 257, 258, 260, 265, 267, 268, 272-274, 280, 282, 290). Seventeen other studies involved participants with a history of breast cancer (251, 253, 254, 256, 262, 264, 270, 271, 275, 277, 279, 286, 287, 293, 294, 296, 299), three prostate cancer (250, 253, 259), three colorectal cancer (249, 255, 283), three gynaecological cancers (276, 281, 288), one lung cancer (285), one urological cancers (263), and one haematological malignancies (278). Cancer stage at diagnosis was described in 19 studies (250-253, 255, 256, 258, 259, 261, 264, 270, 271, 277, 279, 283, 286, 288, 290, 299), and most participants did not have distant metastases. Six studies stated that most respondents had no evidence of disease (92, 249, 265, 268, 286, 293). Samples also differed in participant treatment status: 29 studies recruited participants who had completed primary treatment (92, 250, 253, 254, 257, 259, 260, 262-265, 267-273, 275, 276, 279-281, 286-288, 290, 293, 294); 15 studies included people on treatment (249-252, 256, 266, 275, 282-285, 288, 294, 296, 299), although participants not on treatment were typically still the majority (249, 250, 252, 282, 288). White participants were the majority in 28 studies (92, 249, 251-254, 256-258, 260, 262, 268, 271, 272, 274-277, 279, 281, 284, 285, 288, 290, 291, 293, 295, 298). Only eight studies focused on other racial or ethnic groups (264, 265, 270, 273, 280, 282, 286, 287), and 15 studies did not specify these characteristics (250, 253, 255, 259, 261, 263, 266, 267, 269, 278, 283, 292, 294, 296, 299).

Cheung and Delfabbro demonstrated various endorsements of the cancer survivor identity (90). The additional studies reinforced the concepts of "embracing" (identifies as survivor and accepts its dominant image) (249, 263, 267, 268, 280-

283, 288), “constructive” (identifies as survivor but selects its meaning) (264, 266, 285, 288), “ambiguous” (unsure) (261, 266, 268, 283, 294), “resisting” (dislikes the term and label) (249, 261, 262, 264, 268, 280, 281, 283-285, 288, 295), and “non-salient” (indifferent / unconsidered) (249, 268, 280) (90, p.762). Cheung and Delfabbro also concluded that endorsement was greater in those with a history of breast cancer (77.9%) compared to prostate cancer (30.6%) (90), which was reinforced by subsequent studies. In Dalton et al.’s (251) survey, 58% of 70 men with breast cancer liked the term, whereas Jahnen et al. (250) showed that only 16.8% of 3347 men who had completed primary treatment for prostate cancer endorsed the term.

Associations with identification or rejection of cancer survivor were also described by Cheung and Delfabbro (90) and supported by the newer studies. Accepting the term was linked to viewing it as appropriate (267, 288) or optimistic (252, 279, 282, 288, 296), and facilitation by healthcare professionals (267) or the cancer survivor community (252, 265, 282, 296). Particular factors associated with acceptance include mental wellbeing, coping, risk of recurrence, follow-up care, and engagement in cancer-related activities (90). Table 6 highlights other associated factors.

Conversely, reasons for rejecting the identity included finding the term inappropriate (252, 262, 263, 280, 281, 283-285, 288), especially for people with incurable cancer (281, 283-285), feeling undeserving of the term (261-263, 280, 281, 288, 295), and disliking labels (252, 264, 279, 280, 283, 285, 295, 296). Two studies found that those still on treatment were less likely to embrace cancer survivor (249, 252). One study which included a small proportion of participants with advanced disease found this group identified less with and felt less positively about the term ($p<0.01$) (252). Similarly, those who perceived a higher risk of recurrence (256), or had experienced recurrence (250), were less likely to identify.

Table 6: Primary research quantitative studies assessing the acceptance of cancer survivor as an identity.

Author, country, year	Study type	Sample size <i>n</i> , sex %, mean age, racial group %	Cancer type and stage	Anti-cancer tx status	Time since dx (mean)	Method of evaluating perception of CS	Outcomes relating to acceptance of CS	Factors associated with acceptance of CS
Wee et al., Canada, 2022 (249)	Cross-sectional survey	n=539 F:62.7% White: 88.3%	CRC: 100% No evidence of disease: 69.4%	Completed tx: 77.4% On tx: 22.6%	NR	Rate agreement with statements about relating to and seeing themselves as CS.	Relate to CS: Completed tx: 75% On tx: 46.7% See themselves as CS: Completed tx: 79.5% On tx: 43.8%	Completed tx (v. on tx): More likely to relate to CS (aOR=4.0; 95% CI 2.38-6.67) More likely to see themselves as CS (aOR=5.26; 95% CI 3.22-9.09; $p<0.0001$) Dx age ≥ 50 years (v. <50 years): More likely to relate to CS (aOR=1.88; 95% CI 1.20-2.96; $p<0.0001$) Higher health-related quality of life score: Relating to CS ($p=0.004$) Seeing themselves as CS ($p=0.001$)

Jahnen et al., Germany, 2021 (250)	Cross-sectional survey	n=3347 M:100% 78.1 years	Prostate: 100% Grade 2: 70.3%	Completed primary tx: 100% On tx: 12.9%	15.6 years (post-surgery)	Choose most suitable cancer-related identity.	Endorsed CS: 16.8%	Age >70≤80 (OR 1.47; 95% CI 0.98–2.22) Age >80 (OR 2.11; 95% CI 1.39–3.20) Biochemical recurrence during follow-up (OR 1.97; 95% CI 1.49–2.61) Perceived severity of disease (high) (OR 1.86; 95% CI 1.44–2.40) Benefit finding (high) (OR 1.89; 95% CI 1.48–2.40) <i>Negative association:</i> <i>Biochemical recurrence at time of survey</i> (OR 0.68; 95% CI 0.48–0.95) <i>Wellbeing (high)</i> (OR 0.77, 95% CI 0.61–0.99)
Dalton et al., Canada /	Cross-sectional survey	n=70 M:100% 63 years	Breast: 100%	Not on tx: 40%	NR	Rate how much they liked and	Moderately / strongly like: 58%	Greater months since dx (OR 1.02; 95% CI 1.00–1.04, $p=0.05$)

USA, 2021 (251)		White: 94.3%	Stage: I: 32.9% II: 38.6%	On tx: 58.6%		felt like a CS. Choose one label that best describes them.	Endorsed CS: 44%	
Berry et al., USA, 2019 (252)	Cross-sectional survey	n=1,401 F:99% 58.22 years (SD= 11.85) White: 94.9%	Breast: 87.2% Mean stage: 2.39 (SD = 0.73)	Not on tx: 74.6% On tx: 23.6%	NR	Rate agreement with identifying as CS and feelings about CS, and open-ended questions.	Identify as CS: 7-point scale strongly disagree to strongly agree: mean 4.75 (SD = 2). Feelings about the term: 0-100 negative to positive: mean 60.12 (SD = 30.69)	Number of cancer diagnoses ($p<0.05$) <i>Negative association:</i> <i>Receiving active tx ($p<0.01$)</i> <i>More advanced cancer stage ($p<0.01$)</i> <i>Increased age at dx ($p < 0.01$)</i>

Cho and Park, USA, 2015 (290)	Longitudinal survey at baseline (T1) and 1 year (T2)	T1: n=120 F:77.9% 32.59 years (SD= 7.43) White: 93% T2: n=88 F:76.1% 33.63 years (SD= 7.2)	T1: Breast: 25% Lymphoma : 22.5% Thyroid: 15% Stage: I: 22.5% II: 21.7% III: 15.8% T2: Not reported	T1: Completed tx: 100% T2: Completed tx: 100%	T1: 3.83 years (SD = 3.03, range 0–24) T2: 4.71 years (SD = 3.24, range 0–24)	Rate the extent to which they describe themselves as survivor.	T1: Endorsed CS: 55.0% T2: Endorsed CS: 61.9%	Positive self-evaluation (r=0.63, $p<0.001$)
Morris et al., Australia / USA, 2014 (253)	Study 1: Cross-sectional survey	n=514 M:100% 70 years (SD = 8.36)	Prostate: 100%	NR	7.5 years (SD = 4.66)	Endorse one cancer-related identity.	Endorsed CS: 35%	Lower threat appraisal ($p=0.000$) More deliberate rumination ($p=0.042$) Gaining greater understanding of cancer experience through peers ($p=0.041$)
	Study 2: Interviews and	n=160 F:100% 52 years (SD = 7.6)	Breast: 100% Stage	Completed tx: 100%	24 months, (SD = 7.1)	Endorse one cancer-related identity.	Endorsed CS: 44%	More OSG posts ($p=0.048$) Greater feeling of mattering to OSG ($p=0.002$)

	observational data	White: 96%	I: 56% II: 44%		months, range 6-36 months)			Rated OSG as more helpful ($p=0.004-0.01$) Less difficulty relating to OSG ($p=0.002$) Less than college education ($p=0.023$) Received chemotherapy ($p=0.013$)
Jagielski et al., USA, 2012 (277)	Cross-sectional survey	n=629 F:100% White: 91%	Breast: 100% In-situ: 43%	NR	NR (<5 years: 84%)	Do you consider yourself a survivor of breast cancer?	Endorsed CS: 78%	Being told they were cured ($p=0.04$) Believing they had a very good prognosis ($p<0.001$) Higher mental health scores on SF-36 Mental Health subscale ($p=0.002$) Previous chemotherapy ($p=0.01$)
Documet et al., USA, 2012 (254)	Cross-sectional interviews	n=112 F:100% White: 85.71%	Breast: 100%	Completed primary tx: 100%	NR (range 1.53 – 29.36 years)	Do you consider yourself a survivor?	Endorsed CS: 95.5%	NR
Chambers et al., Australia,	Longitudinal survey at baseline (T1) and	n=786, 742 in sub-analysis M:54.2%	CRC: 100% Stage: I: 32.6%	NR	T2: 60 months	Describe themselves in relation to their bowel cancer by	Endorsed CS: 55%	Identifying as CS (v. identifying as a person who has had cancer):

2012 (255)	60 months (T2)		II: 31.7% III: 21.5%			selecting one or more cancer- related identities, or describing an alternative identity at T2.		Higher personal and interpersonal growth at T1 and T6 ($p<0.001$) Higher acceptance at T1 ($p=0.013$) and T6 ($p<0.01$) Higher life satisfaction at T6 ($p<0.05$)
Kelly et al., USA, 2011 (256)	Study 1: Cross- sectional survey	Study 1: n=201 F:80.6% 47.8 years (SD = 14.5) White: 85.5%	Personal history of cancer: 30.3% No history of cancer: 69.7%	NR	NR	Do they consider themselves to be a CS, and should someone who has not been diagnosed with cancer be known as a CS.	Endorsed CS: 22.5% If a person had not been diagnosed with cancer, they would not consider them a CS: 84.1%	Prior history of cancer ($p<0.001$) Female gender ($p<0.001$) Less education ($p<0.001$) Higher comparative risk ($p=0.026$).
	Study 2: Cross- sectional survey	n=113 F:100% 58.9 years (SD = 10.4)	Breast: 100% Stage: I: 11.5%	Mixture of completed tx and on tx.	<1year post-dx: 54.9%	Do they believe they are a cancer patient or survivor and	Endorsed CS: 69%	Dx 2-5 years previously (v within 1 year) (OR 13.4; 95% CI 4.2-42.7; $p<0.001$)

		White: 96.5%	II: 13.3%			the difference.		Considered recurrence risk to be lower (v higher) (OR 5.2; 95% CI 1.2-21.6; $p=0.02$) Ductal cancer subtype ($p<0.01$)
Helge- son, USA, 2011 (293)	Cross- sectional inter- views	n=240 F:100% 58.58 years (SD = 8.95) White: 96%	Breast: 100% No evidence of disease: 80.4%	Completed tx: 100%	10.58 years	Calculated measure of “survivor centrality” (293, $p=0.518$) (extent to which breast cancer is central to identity) including agreement with CS.	Mean survivor centrality score (5- point scale) = 3.58 (SD = 0.82).	Higher survivor centrality related to: Younger age ($r=-0.27$, $p<0.001$) Positive illness valence ($r=0.13$, $p=0.05$)
Park et al., USA, 2009 (257)	Cross- sectional survey	n=168 F:64.3% 46.34 years (SD = 6.29) White: 89%	Breast: 47% Prostate: 12%	Completed primary tx: 100%	3.5 years (SD = 1.7)	Rate how much cancer- related identities describe them.	Endorsed CS: 83%	Engagement in some cancer- related activities (various, $p<0.01-0.05$) Higher levels of positive affect ($p<0.01$) and post-traumatic growth ($p<0.01$)

								Lower levels of negative affect ($p<0.01$) <i>Negative association: Education</i> ($r=-0.19, p<0.5$)
Deimling et al., USA, 2007 (258)	Study 1: Cross-sectional inter-views	n=50 F:86% White: 68%	Breast: 36% CRC: 18%	NR	0-5 years: 44%	Do they consider themselves to be any, all or none from a list of cancer-related identities.	Endorsed CS: 90%	More likely to cope using instrumental strategies ($r=0.26, p<0.05$) Earlier endorsement associated with: Lower anxiety ($r=0.41, p<0.01$) Lower depression ($r=0.47, p<0.01$)
	Study 2: Longitudinal inter-views (from baseline)	n=321 F:59.2% White: 62.3%	Breast: 41.4% CRC: 29.9% Prostate: 28.7% Stage: Local: 56.7% Regional: 27.7%	NR	6-10 years: 44.9%	Do they consider themselves to be any, all or none from a list of cancer-related identities.	Endorsed CS: 86%	Undergone more tx types ($r=0.13, p<0.05$) Undergone chemotherapy ($r=0.11, p<0.05$) <i>Negative association: Prostate cancer</i> ($r=-0.22, p<0.01$) <i>More current cancer-related symptoms</i> ($r=-0.20, p<0.01$) <i>Radiation therapy</i> ($r=-0.13, p<0.05$)

Bellizzi and Blank, USA, 2007 (259)	Cross-sectional survey	n=490 M:100% 69.7 years (SD = 7.8)	Prostate: 100% Gleason score 5-7: 75%.	Completed tx: 100%	46.7 months (range 1-8 years)	Choose which term best describes them in relation to their prostate cancer.	Endorsed CS: 25.9%	Positive affect ($p=0.001$)
Deber et al., Canada, 2005 (292)	Cross-sectional survey	n=606	Breast: 33.3% Prostate: 33.3% Non-cancer: 33.3%	NR	NR	Rate how much they like being referred to as survivor.	Breast cancer: Strongly or moderately like: 21.8% Prostate cancer: Strongly or moderately like: 0.5%	NR

Key: tx = treatment; dx = diagnosis; CS = cancer survivor; F = female; M = male; CRC = colorectal cancer; OSG = online support group; NR = not reported; aOR = adjusted odds ratio; OR = odds ratio; CI = confidence interval; p value = probability value significant at $p<0.05$; SD = standard deviation; r = Pearson correlation coefficient.

3.5.5.3 Studies assessing the meaning of cancer survivor and cancer survivorship according to people who have or had cancer

Thirty-two studies explored the meaning of cancer survivor according to participants (92, 249, 251, 252, 254, 256, 258, 260-262, 264-269, 271-275, 278, 280-282, 285, 286, 288, 291, 294, 296, 298), and nine studies explored the meaning of cancer survivorship (260, 261, 266, 270, 271, 275, 279, 281, 287). Seven studies used the terms interchangeably (254, 260, 265-267, 281, 286). Box 4 summarises the categories identified for cancer survivors, most commonly describing a cancer survivor as someone who is alive, who no longer has cancer, or who has undergone / won a battle. Box 5 shows the categories identified in describing cancer survivorship, divided into either a process or an outcome.

Box 4: The meaning of cancer survivors according to individuals with a history of a cancer diagnosis.

Factual

- Cancer-free (92, 251, 252, 254, 256, 262, 264, 266, 268, 271-275, 278, 281, 285, 288, 294)
- Free of cancer-related symptoms (258, 265) / looks recovered (274)
- Treatment completed (249, 251, 252, 256, 258, 265, 267, 271, 278, 285, 288, 291, 294)
- Certain treatments completed, such as chemotherapy (92, 249, 262, 268, 298)
- Time-defined (252, 254, 256, 258, 260, 264, 271-273, 278, 280, 291, 294, 298)
- 5 years post-diagnosis / without recurrence (252, 254, 256, 258, 260, 271, 272, 278, 288, 294)
- Alive (249, 251, 252, 256, 258, 262, 265-268, 271, 273, 274, 278, 281, 294, 298)
- Not going to die (249, 260, 265, 285)
- High risk of death (252, 274, 280)

Battle/war

- Underwent a battle (249, 254, 260, 262, 265, 266, 268, 269, 273, 274, 278, 285, 286, 288) / won the fight (252, 256, 272, 275, 294, 296)
- Overcame a traumatic / life-threatening experience (92, 252, 256, 261, 262, 268, 271, 272, 275, 278, 280, 281, 285, 288, 294, 298)
- Interchangeable with victim (268, 269, 296)

State of mind

- Positivity / optimism (249, 258, 260, 268, 271, 282, 288, 294, 298)
- Negativity (249) / reminder of cancer (262, 264, 269, 280, 285)
- Strength (249, 252, 254, 256, 266, 275, 278, 286, 296)
- New outlook / identity (92, 249, 254, 260, 268, 274, 275, 286)
- Faith / God's will (254, 258, 264, 267, 282)
- Sense of luck (254, 260, 272, 274, 278, 285, 288, 298)
- Sense of control (262)
- Lack of control (272, 286)
- Temporary / transitional state (92, 265, 272, 286)
- Just another problem (260, 278) / meaningless (249, 278)

Community

- Member of a group (92, 249, 252, 254, 262, 268, 269, 272-275, 278, 282, 288, 294, 296)
- Support from family / others (278)

Lifestyle

- Return to normality (251, 252, 254, 262, 264, 265, 272, 273)
- Positive lifestyle changes (271, 275, 278, 286, 288, 294, 298) / compliance (282)
- Quality of life (285)
- Helping others (254, 265, 271-274, 286, 288, 294, 296)

Box 5: The meaning of cancer survivorship according to individuals with a history of a cancer diagnosis.

A process

- Ongoing struggle (286, 287) / battle (266, 275)
- Personal (266, 286) and / or relational (286) change
- Reintegration (266)
- Time-defined process (260, 279)

An outcome

- Back to normality (265)
- New normal (270, 279, 287)
- New identity (261, 266, 270, 279, 286)
- Overcame a life-threatening experience (261, 270, 279) / battle (270, 275)
- Treatment completed (260, 265)
- New purpose (286) / altruism (270)
- Joining a club (279)

3.6 Discussion

This review aimed to explore the evidence for the meaning of cancer survivors and cancer survivorship by identifying the evidence for the development of definitions and classifications, and the perceptions of individuals who are described as cancer survivors towards these terms. Ultimately the studies in this review differed in describing when survivorship starts, and who should be described as a cancer survivor, showing cancer survivorship to be a continuously changing concept requiring reassessment. This could have important implications for resource and service development for people who have or had cancer (158).

The primary research studies aiming to define cancer survivors / cancer survivorship with professional experts were limited, but the most common definition aligned with the period following diagnosis. Despite this, the majority of primary studies on cancer survivor identity recruited individuals post-treatment, and one of the three evidence syntheses focused entirely on the post-treatment period. Likewise, the interpretations of these participants about the meaning of cancer survivor terminology were diverse, but the idea that an individual must be cancer-free to be defined as a cancer survivor was especially common. An individual's understanding of the meaning of a term greatly influences endorsement (281), and results show this is variable across studies, so the term may alienate the many people with cancer who do not subscribe to the all-encompassing definition (90, 248). The terminology therefore requires refinement and agreement about its application across settings, which should be guided by the perspectives of people described by the terms.

Advances in oncology and improved prognostic outlooks have necessitated updates on Mullan's seasons of survivorship (96). Although a number of experts have proposed additional phases (97, 99, 103) or categories (91, 95) of cancer survivors, these have been subjective, and there is no evidence of consensus or application in academic or clinical practice. One study proposed classifying cancer survivors by self-assessed healthcare needs to direct clinical services, but focused only on individuals with curative-intent cancer (113). Although the concept is potentially transferable, this is an example of the impact of the lack of standardised definitions within research. Essentially, there is a paucity of evidence-based classification which limits how services can be tailored to best care for people who have or had cancer.

Importantly, this review shows that studies researching the perceptions of cancer survivors towards the term have largely recruited white participants from the USA with a history of early-stage breast cancer post-primary treatment. Therefore, studies are not representative of the heterogeneous group encompassed by the Cancer Nation description, where individuals with any cancer type, stage or prognosis are cancer survivors (75). Notable groups lacking evaluation are individuals on anticancer treatment and individuals with advanced / progressive disease. This issue has been noted previously (259, 275), particularly since these groups may be less likely to support the term (91, 252). Additionally, different cultural and ethnic backgrounds require unique considerations (247, 250, 276, 300); a greater variety of countries and ethnicities have recently been studied (250, 263-265, 267, 270, 273, 280, 282, 287), although diversity remains limited. Furthermore, public advocacy for cancer survivor terminology is likely lower outside of the USA (250), where the majority of studies were conducted. Although certain factors associated with endorsement have been demonstrated, their relevance to the scope of people with a history of cancer is unknown. The generalisability of previous findings about the acceptability and interpretation of cancer survivor is therefore restricted.

There is also uncertainty about the consequences of applying this terminology. Firstly, it is unclear whether patient preferences vary between directly addressing someone or referring to them (247). Secondly, the effect of terminology on healthcare, such as treatment behaviours, quality of care (247, 266, 271), or engagement with services (251, 268, 271) is ultimately unknown. Language may be important in the way participants manage illness and uncertainty (269), so individual agency in both accepting and rejecting cancer survivor are valid (262). Healthcare professionals should practice with this awareness, whilst recognising their own potential influence on an individual's identity (261). Thirdly, although endorsing cancer survivor terminology can be associated with mental wellbeing (90, 248-250, 255, 257-259, 263, 277, 290), it has also been suggested that it risks psychological harm (252). Finally, the importance of this debate overall must be considered. For example, in one survey of 539 people who have or had cancer, approximately half (51.6%) deemed the choice of term to be important (249). Given the uncertain impact, it may be argued that appropriate sensitivity should be applied universally.

Many assert that cancer survivor terminology will continue to be used given its influence across social, advocacy and funding levels (271, 275), but the lack of consensus on its definition and categorisation has created ambiguity in research, its interpretation and application. Indeed, a review of 14 cross-sectional surveys found no standard question / method to identify cancer survivors (301), which has likely influenced the variety of study samples (90), as well as the results themselves (252, 290). Similarly, this review has demonstrated a lack of standardisation in the approach to identifying if people who have or had cancer endorse the term.

3.7 Strengths and limitations

This review used a systematic approach (230, 234, 235). The multiple independent reviewers reduced bias and error at each stage (234), and its inclusion of different study designs from a variety of healthcare contexts increases its significance. Importantly, it highlights research gaps worthy of exploration.

Nevertheless, studies meeting the inclusion criteria may not have been identified, including studies not in the English language. The heterogeneity of study designs is a drawback, preventing direct comparison. Additionally, the research available for inclusion was particularly limited regarding categorisation, and the lack of diversity in samples assessing the cancer survivor identity has been discussed previously. Primary research articles have not been appraised, so the generalisability and weight of findings are unconfirmed, and the conclusions do not equate to recommendations for clinical guidelines / policies (232, 235).

3.8 Conclusion

The cancer survivor term was never intended to be a label because it was acknowledged that it would not be endorsed universally (75). Nevertheless, survivorship terminology is widely used in education, research and clinical care, and its ambiguity causes confusion and even alienation, so its application needs to be reconsidered. Evidence supporting its application to any individual with a history of cancer from the point of diagnosis is mixed, and interpretation and acceptance of the term remain varied. To date, the variety of studies on the perception of cancer survivors towards the term do not reflect the views of

individuals on anticancer treatment and individuals with advanced / progressive cancer across cancer types and geographical areas. Future studies should incorporate these participants so that research and clinical practice can integrate their perspectives. Consensus studies should agree which definitions and categorisations to apply, if not universally at least contextually, and incorporate these into service model development.

Chapter 4: PRiSM project: Specialist Palliative Care's Role in Cancer Survivorship Model: European e-Delphi study on the role of specialist palliative care services in cancer survivorship

4.1 Abstract

Background

Specialist palliative care services (SPCS) provide holistic care for individuals with health-related suffering and those close to them. Historically, SPCS have cared for people with advanced cancer, but SPCS now also provide early palliative care for certain individuals on anticancer treatment. However, most people on anticancer treatment, especially maintenance regimens, do not have access to SPCS. Similarly, most people deemed in remission or “cured” do not have access either. Many of these individuals still have significant unmet needs, including poor symptom control (i.e. physical, psychological). It is broadly accepted that cancer survivorship begins at the time of diagnosis and continues until the end of life, so all individuals previously described may be classed as cancer survivors. This study aims to create consensus opinion among European experts about the role of SPCS in the different cohorts of cancer survivors, especially those who are not generally referred to SPCS.

Methods

The PRiSM project (Specialist Palliative care's Role in Cancer Survivorship Model) was an electronic Delphi study. The study involved purposive sampling of European specialist palliative care (SPC) and oncology (ONC) experts to form two separate groups who simultaneously undertook the same Delphi process. Each group included professional experts and people with lived experience of cancer. The process was undertaken via the online platform Welphi®. Round 1 included 105 questions / statements developed from literature reviews, and questions in subsequent rounds were modified / added according to participant feedback. Three successive rounds were undertaken about the definition and core functions of SPCS, application of cancer survivor terminology, categories of individuals with cancer or a history of cancer, and the extended role of SPCS for individuals with cancer or a history of cancer. The process was terminated when consensus (pre-

defined as $\geq 75\%$ within each group) and stability were reached for the majority of statements. Spearman's Rank Order Correlation determined stability, and the Chi square test for goodness of fit compared group outcomes.

Results

Eighty-six SPC experts representing nineteen countries / regions entered the study, and eighty participants completed all three rounds. Fifty-four ONC experts entered the study, representing seventeen countries / regions, and forty-nine completed the process. Outcomes were achieved for 166 statements. Stable consensus between the rounds was achieved for 93 statements for both groups, with an additional 14 in the SPC group, and nine in the ONC group. All results showed stability between two rounds. The opinions of the two expert groups differed significantly regarding 57 statements, but only 13 of these statements reached consensus in one group but not the other.

Conclusion

European SPC and oncology experts reached consensus that cancer survivor terminology should be applied to people post-treatment with no evidence of disease, and that application to people with active cancer should be reconsidered. They also felt that pragmatic (factual) categories may be more useful in terms of providing tailored care for people who have or had cancer. Consensus statements were also generated on the specific role of SPCS in supporting people with stable disease and people living beyond cancer, particularly regarding pain management. The study also highlights key areas of contention within and between the SPC and ONC groups. These results will help to inform a new model of care.

4.2 Introduction

4.2.1 Background

Earlier diagnoses, innovative new anticancer treatments, and improved access to multidisciplinary cancer care has led to increased cancer survival (78). Moreover, it is projected that there will be 28 million new cancer cases worldwide every year by 2040, in line with population growth and ageing, i.e. an increase of 54.9% from 2020 (223). Collectively, this means that healthcare faces the expanding problem of people living longer with the potential physical, psychological and social effects of cancer and its treatment, whether they no longer have evidence of disease, or live with advanced / metastatic disease. Importantly, the novel anticancer treatments still have unclear long-term / late effects, symptom clusters and prognostic impact (129, 130). Supporting these holistic needs of people living “with, through and beyond cancer” (102, p.1) therefore requires attention to ensure that people who benefit from the improvements in cancer survival can also enjoy this time with an improved quality of life (78).

4.2.2 Survivorship care needs for people who have or had cancer

As previously outlined, cancer survivorship refers to the physical, psychological, social and economic issues affecting an individual with a history of cancer (80), and the IOM described the essential components of survivorship care as prevention (of late effects and second / recurrent cancers), surveillance (for late effects and cancer), intervention (for consequences of cancer and its treatment) and care coordination (18). Studies have repeatedly demonstrated that many people deemed in remission or cured (i.e. post-treatment and “living beyond cancer” (102, p.6)) warrant survivorship care as they have significant unmet needs across physical, psychosocial, financial and informational domains (114, 116). These health-related problems may relate to the cancer, cancer treatment, and / or another chronic disease, and encompass a range of issues, such as pain, sexual dysfunction, psychological distress, fear of cancer recurrence, financial and occupational problems, and educational needs (176).

However, identifying the end of treatment has become increasingly challenging (81) and it has been argued that the traditional view of applying survivorship only to the curative-intent post-treatment phase is inappropriate, particularly given the

emerging group of people living longer with advanced or metastatic oncological or haematological disease (6, 302). These individuals can have a variety of experiences, particularly in response to novel anticancer treatments (303). They may experience cancer as a chronic disease (80), with periods of disease stability and progression, where further anticancer treatment may be appropriate, with an array of potential outcomes (302, 304). They can also suffer unique burdensome physical, psychological, social, financial and informational problems (305), and particularly struggle with uncertainty about the future and fear of cancer progression (302). Similarly, their caregivers have distinctive unmet needs, particularly within psychological and support domains (305). Survivorship care has therefore expanded to include this heterogeneous group of individuals living with “malignancies that are treatable but predominantly incurable” (6, p.312). Although the appropriateness of the application of survivorship terminology to this group has been debated (302), such needs are the main driving force behind the growing advocacy for this approach (302, 304, 306), amid suggestions that current systems are not designed to provide adequate support (304).

Indeed, given the potentially complex and variable trajectory of a person with advanced / metastatic cancer, MASCC and ASCO developed standards and practice recommendations for quality survivorship care for this group (6). The standards include person-centred care; coordinated and integrated care; evidence-based and comprehensive care; evaluated and communicated care; accessible and equitable care; sustainable and resourced care; and research and data-driven care. Designed to guide stakeholders, the practice recommendations aim to inform clinical care, research and policy development.

4.2.3 Cancer survivorship terminology

As explored in Chapters 1 and 3, issues surrounding cancer survivorship terminology remain unresolved. A major area of contention is the application of “cancer survivors” to individuals “from the time of diagnosis through the balance of life” (17), or to people who have completed primary therapy with curative intent (76, 77). A similar debate exists for “cancer survivorship”, with some organisations suggesting that it should span the time following diagnosis (83), whereas the original IOM report described it as “the period following first diagnosis and treatment and prior to the development of a recurrence...or death” (18) (pp.23).

Consequently, there is ambiguity surrounding the definitions and application of these terminologies.

Furthermore, it has been suggested that the term cancer survivor should not be routinely used, given its everyday connotation (i.e. that the related event / episode has ended) (17, 88), and its potential negative psychological impact, projecting the need for individuals to appear stronger than they may feel (91). There is also suggestion that increasing numbers of healthcare professionals dislike the term (84). As Chapter 3 demonstrates, many studies have sought the views of people with a history of cancer about this terminology and identified a breadth of interpretations and endorsements (90). However, most studies have excluded people on anticancer treatment (with an uncertain prognosis), and especially people with advanced / progressive disease (with a limited prognosis). Intuitively, these groups may be more reticent about this terminology. Given its North American origins (75), it has also been suggested that support for the terminology may be less outside of the USA (250). Despite these concerns, cancer survivorship terminology continues to be widely applied within the domains of education, research, and clinical practice. Application of such labels (particularly when the meaning is unclear) can impact treatment aims, decisions and the wellbeing of people who have or had cancer (94).

4.2.4 Categorisation of people who have or had cancer

As well as semantics, there is the issue that the problems encountered by people with early cancer are somewhat different from those seen in people with advanced cancer, and again somewhat different from individuals with no evidence of disease. Furthermore, interventions that may be entirely appropriate to manage people with active cancer may be less appropriate in people with no active cancer, e.g. opioid analgesics for chronic pain control (135). Thus, from a clinical (and research) perspective, there is an imperative to categorise people with cancer or a history of cancer. Additionally, this will support the development of appropriate / tailored services for these various cohorts of people.

The evolution of groups of cancer survivors and phases of cancer survivorship was discussed in Chapter 1. In summary, Mullan (96) first described cancer survivorship as three phases: 1) acute survival, encompassing diagnosis and

treatment; 2) extended survival, upon completion of treatment, including surveillance, and 3) permanent survival, following cure. Updates have been suggested as the complexity of people who have or had cancer has evolved. Miller et al. (97) introduced the transitional phase (from active treatment to observation), and further detail has been added to the extended and permanent phases (97). Subsequently, an additional chronic phase (living with cancer for a prolonged time) (98) and an end-of-life phase were proposed (99). Some centres use alternate person-first terms (that is, “person with” a disease (307, p.1053)) to describe survivorship stages, which may be more acceptable than cancer survivor terminology (90). The University of Texas / MD Anderson Cancer Center (102) developed the “living with, through and beyond cancer” terminology (p.1), which relates to on-treatment, post-treatment and long-term survivorship phases. This categorisation is popular, although there remains some ambiguity about these three phases. The most useful terms to describe groups accessing services or within research should be sought to improve clarity and accessibility.

4.2.5 Specialist palliative care services and survivorship care

As previously defined, SPCS are specialist teams that provide holistic care for individuals with health-related suffering and those close to them (22, 23). Chapters 1 and 2 demonstrated that SPCS have traditionally been involved in the care of people with advanced / progressive cancer, although they are increasingly involved in the care of people earlier in the cancer trajectory, including those receiving anticancer therapies (“early palliative care”) (10). Importantly, MASCC / ASCO recommend that people affected by advanced or metastatic cancer “receive timely referral to specialist palliative care (depending on needs evaluated using palliative need assessment tools) for assessment, management, or co-management from diagnosis” (6, p.313). The scope of SPC input for these individuals is therefore potentially wide, but the unique problems faced by individuals living with cancer for a prolonged time require different strategies from those with a limited prognosis (135). Additionally, the longevity of input and types of support potentially required have unclear implications for SPC service structure. The relevant expertise and specific role of SPCS for this group therefore requires clarification.

Given the breadth of unmet needs of people living beyond cancer, it has also been suggested that SPC may have a role in providing support for this group (135). The narrative review in Chapter 2 explored this idea, showing that previous articles suggested that a palliative care (i.e. holistic) approach should at least be applied (173, 192), whereas other articles support actual SPC involvement for targeted interventions (170, 173, 195, 215, 308), or broader aspects such as care coordination and advance care planning (169, 188). In particular, it has been suggested that SPCS have a role in managing people with chronic cancer treatment-related pain (and / or problems with opioid abuse), given the relative expertise of SPC in managing cancer-related pain, including opioid prescribing (200, 213, 309). However, there is great diversity in SPCTs regarding membership, services and availability (206), and a paucity of evidence to support the suggestions about their potential role (192).

Lack of clarity on these issues is impacting education, research, policy and ultimately service provision and clinical care. Interpretation is further compounded by the variation in survivorship terminology application to different cohorts of people who have/had cancer.

4.3 Aims and objectives

The PRiSM project (Specialist Palliative Care's Role in Cancer Survivorship Model) aims to develop European expert consensus about the role of SPC for people with cancer or a history of cancer, especially those who do not typically access SPC. The expert groups are professional experts and non-professional experts (people with lived experience / patient advocates) in SPC and oncology. The objectives are specified in Box 6. Clarifying nomenclature and formalising groups of people who have or had cancer will help to direct service provision, and achieving consensus on the role of SPC for these groups will help to identify the most appropriate ways to improve the quality of life of people who have or had cancer, as well as prioritise resource allocation.

Box 6: PRiSM study objectives.

Primary objective

To develop expert consensus on the role of SPC for individuals with a history of a cancer diagnosis who have no evidence of disease from groups of professional and non-professional SPC and oncology experts.

Secondary objectives

To develop expert consensus on the definition and general core functions of SPCTs (from groups of professional and non-professional SPC and oncology experts)

To develop expert consensus on who should be described as cancer survivors

To develop expert consensus on categories of individuals with cancer or a history of a cancer diagnosis

To develop expert consensus on the role of SPC for categories of individuals with cancer or a history of a cancer diagnosis

To identify the barriers to increasing the scope of provision of SPCS for individuals with cancer or a history of a cancer diagnosis

4.4 Rationale for study design

4.4.1 Delphi methodology

The PRiSM project is a Delphi study; a research technique where participants complete survey rounds aiming to build consensus (310). Delphi processes seek to deal with controversial issues and diverse opinions (310), particularly when evidence is limited or conflicting (311), asserting that aggregation of expert ideas can enhance individual judgement and produce a collective opinion, which is deemed superior to that of an individual expert (312-314). Delphi studies are also recommended in palliative care research (310), particularly in the development of best practice recommendations (312, 315), organisational frameworks and resource allocation (316-318). The Delphi technique was therefore appropriate for

this study to generate consensus statements about the role of SPCS in cancer survivorship since the surrounding knowledge, assumptions and demands are still evolving (310).

4.4.1.1 Types and characteristics of Delphi studies

There are numerous types of Delphi studies, including conventional (where experts complete questionnaire rounds, the first consisting of open-ended questions and the remaining nominal questions seeking to identify agreement with the accuracy or priority of statements); modified (encompassing numerous potential changes in project design and delivery, particularly in questionnaire development); and policy (describing a forum to generate ideas / options rather than consensus) (312, 314, 319-321). Although there are variations in application, the usual technique involves the anonymous participation of subject experts in an iterative process, where each round is informed by results of the previous one (310, 314, 322).

4.4.1.2 Expert panel

Expert selection for Delphi panels is key to study validity (314). They should have the knowledge to inform a respected opinion (310, 313, 319, 323, 324). Ideally the panel should also represent appropriate scientific / academic disciplines, clinical expertise, and those with practical and personal experience, allowing interdisciplinary and transdisciplinary exchange of ideas (325). People with lived experience / patient advocates contribute particularly important and relevant perspectives (326).

4.4.1.3 Sample size

Ten to fifty participants have been recommended for Delphi surveys (312). However, at least thirty from the same discipline are needed for sufficient representation (312, 315) and rigorous statistical analysis. It has been suggested that sample sizes over thirty are not necessarily higher quality (313, 319, 323), and indeed larger panels are associated with lower response rates (327).

4.4.1.4 Rounds and questions

The style of questions in Delphi surveys can vary between qualitative and quantitative according to study objectives (321, 328). In the conventional process, qualitative Round 1 questions can effectively engage experts in generating ideas, using outputs to develop statements for subsequent rounds. Quantitative questions in Round 1 are generally based on critical literature reviews, and participants are usually asked to rate their level of agreement with certain statements. The choice of scale significantly influences consensus results (329), with a Likert scale commonly endorsed to force participants to commit to a particular level (310, 314, 319, 324). Typically, participants are also given the opportunity to suggest improvements / alterations to statements.

Piloting is recommended to assess factors that can impact response rates, including length, clarity, and usability, and to identify potentially leading statements (314, 327). Once the study has commenced, at least three rounds are considered acceptable to achieve consensus (discussed further below) (314, 322, 330). Results are fed back anonymously to participants in each subsequent round in a process of “controlled feedback” (315, p.119), expanding panellists’ existing knowledge / views, and providing the opportunity to adjust responses, reducing outlying results and developing convergence (325). Descriptive statistics (frequencies) are commonly used for controlled feedback in healthcare Delphi studies (315, 325), (311). Subsequent rounds then include a modified questionnaire including new standardised statements developed from answers from previous rounds (315, 325).

4.4.1.5 Consensus and stability

There is no standardised definition of consensus in Delphi studies (311, 331), but specifying how consensus is achieved from the outset is recommended for methodological rigour (310, 314, 331). Generally consensus is defined either as a measure of dispersion (i.e. a gathering around median responses with minimal divergence (313)), unanimous agreement (332), or an acceptance of ratings higher than a previously determined percentage of participants (323) (ranging from 51-80% (333)). Presentation of consensus also involves highlighting the issues that were removed due to high opposition (323), as well as issues where

consensus was not achieved (314). There are no guidelines on actions to take when consensus is not achieved (332).

Consensus should also demonstrate stability, i.e. no significant difference between responses in two successive rounds (332). Stability may be present within different levels of agreement. Both stability and a pre-specified level of agreement should be obtained for meaningful consensus (312, 315, 332, 334).

Furthermore, both stability and consensus should be used to decide study termination (330). Once stable consensus is achieved, or no further consensus or new information gained, the study should be terminated (rather than using a pre-defined number of rounds) (312).

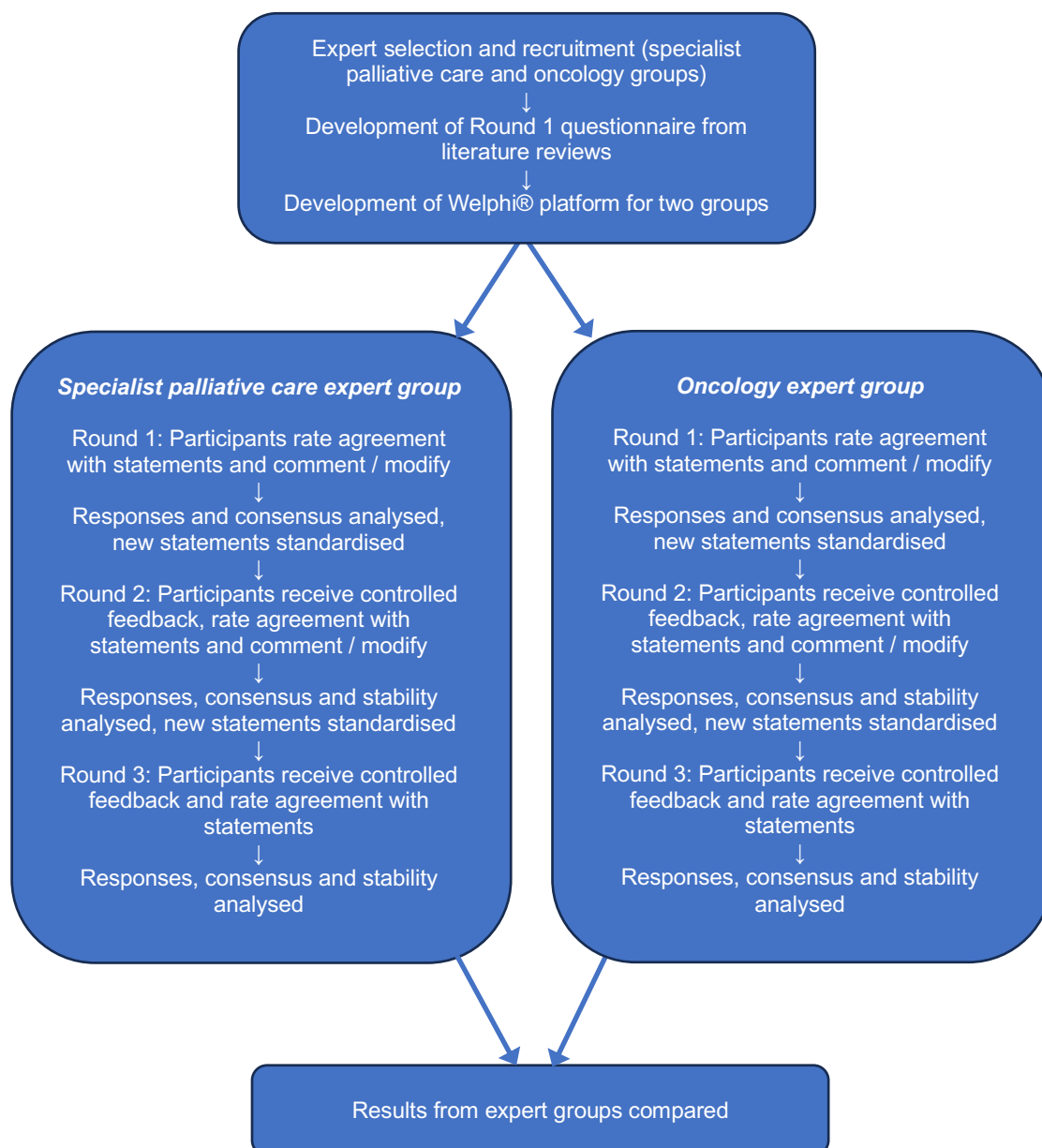
4.4.2 PRiSM study methodology

This study is reported according to the Guidance on Conducting and REporting DElphi Studies (CREDES) in palliative care (310).

4.4.2.1 Process

The PRiSM project was an electronic Delphi (e-Delphi) study where participants provided anonymous feedback on relevant statements over three rounds with the aim to obtain (or not) stable consensus about the individual statements (Figure 5). The process was carried out from April to June 2024 via the Welphi® online platform (Lisbon, Portugal) (335). The study employed a modified Delphi technique since the first round consisted of statements developed from reviews of the medical literature (314).

Figure 5: Flowchart showing PRiSM e-Delphi process.



4.5 Expert panel

4.5.1 Expert selection

This study identified two separate European expert groups from specialist palliative care (SPC) and oncology (ONC), each including professional experts and Patient and Public Involvement (PPI) representation (people with lived experience and patient advocates, or non-professional experts). The criteria for expert selection is outlined in Box 7. Participants were excluded if they did not reside in a European country or have adequate English language proficiency to complete the written informed consent and e-Delphi processes. A variety of

geographical locations across Europe were targeted for recruitment to maximise diversity of opinion and limit the unintentional transfer of ideas between participants (314). It was anticipated that SPC and ONC would have different views, so participants were categorised into either group and the same processes were carried out simultaneously for each group (314). Furthermore, dividing the groups in this way may lead to more reliable outcomes for certain objectives and focused problems (315).

Box 7: Criteria for expert selection.

- Individuals with leadership roles in relevant professional and non-professional organisations (and associated national organisations / member societies)*
- Individuals highlighted from a background literature review that focused on the role of SPCS in cancer survivorship
- Individuals with European expertise in palliative care and / or oncology in clinical and / or academic and / or other relevant settings, particularly cancer survivorship
- Individuals recommended by those meeting previous criteria

*Relevant professional organisations include:

- European Association for Palliative Care (EAPC)
- European Cancer Organisation (ECO)
- European Oncology Nursing Society (EONS)
- European Society for Medical Oncology (ESMO)
- Multinational Association for Supportive Care in Cancer (MASCC)

4.5.2 Sample size

The number of experts throughout Europe in these categories is unknown, so the target sample size was at least thirty participants for effective statistical analysis (312, 315). Given the purpose and complexity of this study, fifty could be

considered more ideal (314), especially to achieve sufficient representation from across Europe and its forty-four countries. More than fifty participants were therefore recruited to each group to widen representation, and account for probable attrition across rounds.

4.5.3 Sampling

Purposive sampling was primarily used, which assumes that the researcher's knowledge about the population can be used to choose the sample (336). Potential participants were identified by contacting relevant professional organisations (including patient advocacy groups with an interest in cancer survivorship), by inviting the first or corresponding author from relevant published articles in peer-reviewed journals identified from a literature review (135), or through personal contact. Those who agreed were also asked to identify other individuals with relevant expertise (snowball sampling (322)).

4.5.4 Recruitment

Potential participants were contacted via email (the email invite can be found in Appendix 3a), provided with a Participant Information Leaflet outlining the study design, commitment, and rationale (Appendix 3b), and asked to return a study-specific Consent Form (Appendix 3c). Upon entering the study, baseline information was collected about their age, sex, and country of residence (Appendix 3d). Professional experts were asked to identify either ONC or SPC as their main specialty, to select their health profession from a predetermined list (e.g. medical, nursing, physiotherapy, etc.) (337) and to state their job title / role. Non-professional experts were asked to identify their affiliated patient advocacy group.

4.6 Description of methods

4.6.1 Questionnaire development

Round 1 included a series of 105 questions / statements based on previous literature reviews on the role of SPCS for people living beyond cancer (Chapter 2) (135) and cancer survivorship terminology (Chapter 3). The contents of subsequent rounds were informed by round 1 results. Despite this being a

common approach for Delphi surveys, there is little guidance about questionnaire development (311). Predominantly qualitative questionnaires focus on the generation of ideas and agreement rather than stability, and may involve greater steering from researchers, potentially increasing the risk of bias (311, 315). Alternatively, appropriate use of literature to inform questionnaires can increase study validity, but presenting information, and particularly citations, can also influence opinion and bias (314). In the end, information was selected for inclusion following critical literature reviews.

Round 1 included different styles of questions. To determine participants' preferred definitions for "palliative care", "specialist palliative care" and "cancer survivors", participants selected fixed-choice options or presented an alternative. Otherwise, participants were asked to rate their level of agreement with certain statements and to comment / modify those statements, generating ideas to influence subsequent rounds. A Likert scale (strongly disagree, moderately disagree, neither agree nor disagree, moderately agree, strongly agree) was used (310, 314), with a neutral middle point included given the uncertainty around the topic and the probable diversity of direct experience. Finally, some free-text response questions were provided to allow participants to share viewpoints not covered elsewhere. Limiting participant contributions so that Round 1 was not entirely qualitative controlled the volume of data given the large number of participants, whilst also capturing a breadth of views (333).

Round 1 questions were piloted on a multidisciplinary group of SPC academic staff in Ireland, leading to adjustments of some words / phrases for clarity. Once the questionnaire was prepared on the Welphi® platform, a further trial of the survey instrument was undertaken, leading to minor platform usability alterations.

4.6.2 Rounds

Participants entered one of two simultaneous Delphi processes (SPC or ONC), where questions in each round were identical. Participants were emailed personalised links via the online platform to access each round's questionnaire. Three iterative rounds were completed, each open for two weeks, with another week in between. Participants received controlled feedback from their group (described below), and were given the opportunity to select their level of

agreement using the five-part Likert scale and comment on new statements. Reminder emails were sent to non-responders via the platform towards the deadline to encourage participation, and all participants were notified about round closure.

The questions for Round 1 are provided in Appendix 3e, encompassing four sections:

1. Definition and core functions of Specialist Palliative Care
2. Definition of “cancer survivor”
3. Categorisation of individuals with cancer or a history of cancer
4. Extended role of Specialist Palliative Care for individuals with a history of cancer.

4.6.3 Controlled feedback

Group results were shared anonymously with the same group’s participants in each subsequent round (315, 325) (but not the other group). If the question was in the previous round, the participant’s previous answer was highlighted in a shaded box, whilst the whole group percentages for each response were also displayed. Sharing frequencies is a recommended and easily understood approach (322).

4.6.4 Questionnaire modification and dropping criteria

Rounds 2 and 3 included both original and new / modified statements based on participant responses (314, 315, 325). Pragmatic dropping criteria were applied: questions that had achieved stable agreement were excluded as either stable consensus was achieved, or it was deemed that modifications would not further impact the outcome (332). Round 3 therefore did not include those statements with stable consensus after rounds 1 and 2. A small number of statements were also dropped after undergoing minor modification, and no useful additional information would be gleaned by carrying them forward.

4.6.5 Closing criteria, consensus and stability

A systematic review of Delphi study methods identified 75% as the median threshold to define consensus (331), and so this study pre-defined consensus within each expert group as $\geq 75\%$ participants having moderate or strong agreement, moderate or strong disagreement, or a neutral stance. This parameter has been supported by other Delphi studies used to inform guideline development (338). Stability of responses between rounds was determined by statistical analysis (described below), to identify if the association between the ratings of each panel on an item from two rounds was significantly different from zero (330). Stability and consensus were used to decide study termination (330), i.e. once stable consensus between rounds was achieved for a majority of statements, or stable agreement was achieved and further consensus was unlikely (312, 332).

4.6.6 Response rate

High response rates improve credibility (339), and at least 70% is considered ideal (340), so response rate was considered for each round. Personalised emails before and after each round and timely completion reminders, as well as the incentive of acknowledgement in study publications, were used to encourage participation (322).

4.7 Ethical responsibilities

Ethical approval was received from Trinity College Dublin Faculty of Health Sciences Research Ethics Committee on 27th March 2024 (project number 2786) (Appendix 4a), and supported by Our Lady's Hospice & Care Services Research Committee (Appendix 4b). The study was registered on the Comet Initiative database (available from: <https://www.comet-initiative.org/Studies/Details/3097>).

Participation was "quasi-anonymous" (341); participants were identifiable by the researchers but blinded from others to minimise social pressure and reduce bias (310, 333). Upon entering the study they were given a unique identifier code, only accessible by one researcher, which was used for group allocation and to encourage participation of non-responders (although their specific answers were not identifiable). A secure online platform Welphi® (Lisbon, Portugal) (335) was used to secure anonymity of this process.

4.8 Analysis

A combination of qualitative and quantitative analyses were applied (312). All results are reported (those that did and those that did not reach consensus).

4.8.1 Qualitative analysis

Qualitative analysis of participant comments on questions / statements was undertaken using content analysis, which is a systematic and transparent process to identify patterns and produce universal descriptions (342, 343) (and which is commonly used in Delphi round 1 analysis) (333). Conceptual content analysis was used, which examines the existence / frequency of selected terms in the data, both explicitly (counting words / phrases) and implicitly (implying the same idea) (343). Findings were used to determine changes between rounds.

Qualitative comments were transposed to Microsoft Excel and independently reviewed by two researchers (AT and AD). Coding rules were agreed (342, 343): phrases were used as the unit of analysis; all statements would be coded; and the frequency of concepts would be counted. Preliminary coding categories were also defined as changes to wording, changes / additions to content, new content, and opinion / explanatory statements. Two researchers improved the reproducibility / inter-rater reliability (342), and following independent review the researchers collaboratively reviewed each category, from which modified and new statements were developed to include in subsequent rounds.

4.8.2 Quantitative analysis

4.8.2.1 Descriptive statistics

Descriptive statistics were generated using Microsoft Excel for sample age, sex, country of residence and professional discipline. Crude figures of response, completion and drop-out rates were recorded for each round for transparency. Frequencies of answers (percentages) for various ratings of agreement for each question and statement in each round were also determined via the Welphi® platform.

4.8.2.2 Statistical analysis

Statistical tests were carried out using Statistical Package for the Social Sciences (SPSS) version 29.0.2.0.

4.8.2.2.1 Levels of agreement

Trends towards consensus and stability across rounds are indicated by increasing percentage agreements, decreasing frequency of comments and a convergence of rankings (334). Frequencies of results for each level of the Likert scale for statements in each round (324, 344) were used to determine if consensus (pre-defined as $\geq 75\%$ within each group) was achieved. Majority describes occasions when over 50% of respondents agree (332) and plurality occurs when a larger portion of responses (but under 50%) reach agreement (332). Bipolarity occurs when participant responses are divided equally (332). Disagreement refers to when responses cannot be aligned into any of these aforementioned criteria (332). Although representing lack of consensus, such outcomes are also considered important.

Although it has been suggested that little change in frequency of responses assumes stability of results between rounds (345), statistical tests improve the validity and objectivity of analysis (330). Dajani et al. proposed using the Chi-square (χ^2) test for stability (332), but this has been criticised for assessing the independence of the rounds from responses instead (334). Means and standard deviations have also been suggested as measurements of convergence (346), but this study used ordinal groups (via Likert scale options) rather than numerical scales. Finally, parametric statistical analysis (such as the Pearson correlation coefficient) is only recommended when the data follows a normal distribution (330), which is not typical in ordinal / categorical results, and so non-parametric analytical methods were applied (330).

Non-parametric methods recommended to analyse stability between Delphi rounds include the McNemar change test, Spearman's Rank Correlation Coefficient and the Wilcoxon Paired Signed-Ranks T Test (330). The McNemar change test requires dichotomous options, and the Wilcoxon paired signed ranks T test requires the generation of mean sum ranks (330, 347). Spearman's rank correlation coefficient (ρ) (between ratings on an item from two consecutive

rounds) was therefore chosen since it can be applied to ordinal responses (which can be ranked) and is relatively unaffected by outliers (330, 347). Correlation is the extent of a linear relationship between two variables, including the strength and direction (347), and the null hypothesis is that there is no monotonic association between the two rounds. (Monotonic refers to the situation where the size of one variable increases as the other increases, or decreases (347)). The critical value of a hypothesis test (such as the correlation coefficient), for a particular sample size and level of significance, stated with results, is used to determine if the null hypothesis is rejected (348). However, statistical significance gives little information about the strength of correlation (347). It is generally accepted that values between 0.80 and 1.00 suggest a very strong association, between 0.50 and 0.80 moderate association, between 0.2 and 0.5 fair association, and under 0.2 poor association (349, 350). Cautious interpretation is nevertheless advised given the variety of ranges suggested in the literature and between disciplines (349).

4.8.2.2.2 Comparison between groups

The Chi-square (χ^2) test for goodness of fit was used to compare final results from the two expert groups (351). Particularly useful for categorical variables (352), it was considered a pragmatic approach to determine significant differences between group outcomes. The Mann-Whitney U Test is another non-parametric test to assess for differences between two independent groups (351). Although it can be applied to categorical variables, it would compare ranks across categories and ultimately the median ranking, which was not the outcome of interest in this study. The independent samples t-test was also unsuitable since the variable data is neither continuous nor normally distributed (351). The Chi-square (χ^2) goodness of fit test was therefore chosen to compare the proportion of the ONC group that agreed with statements compared to the proportion of the SPC comparison group.

Adjustment of the probability (p) value using Bonferroni's correction was considered (353), but correcting for multiplicity when undertaking comparison statistical tests is debated (354, 355). The risk of type I error (concluding that a significant difference exists when it does not) increases with the number of tests (355), so "experiment-wise" error correction would reduce its likelihood in this

study. However, it may be argued that correction is not required as it may increase the risk of type II error (failing to identify a significant difference where one exists), ignoring potentially important outcomes and reducing the power of the test (355). Bonferroni's correction is therefore not recommended for Chi-square goodness of fit test, since reducing the chance of a type I error would increase the chance of a type II error, and the risk of spurious results (355).

4.9 Results

4.9.1 Study sample

Sixty-two professional organisations were contacted and invited to recommend individuals to participate. Five international organisations and 18 national organisations responded. Authors from four papers identified from literature reviews were contacted, and four authors responded. Fifteen PPI / patient advocacy groups were also invited, and three responded. Other participants were recommended by those who consented.

Ninety SPC experts from various disciplines agreed to participate, and 86 returned the consent form, representing nineteen countries / regions. Four were non-professional experts (people with lived experience and patient advocates). Eighty participants completed all three rounds. Sixty-one ONC experts agreed to participate, and 54 returned the consent form, representing seventeen countries / regions. Five were non-professional experts. Forty-nine completed all three rounds. Participant demographics are presented in Table 7. Table 8 shows retention rates across rounds.

Table 7: Personal demographics of recruited participants in each expert group.

	Specialist palliative care expert group (n = 86)		Oncology expert group (n = 54)	
Sex n (%)	Female	45 (52%)	Female	31 (57%)
	Male	41 (48%)	Male	23 (42%)
Age	Median - 52yr (range: 33-68yr)		Median – 50yr (range: 31-70yr)	

Country of residence n (%)	Austria	3 (3%)	Belgium	1 (2%)
	Belgium	1 (1%)	Cyprus	1 (2%)
	Denmark	6 (7%)	Denmark	1 (2%)
	France	5 (6%)	France	4 (7%)
	Germany	6 (7%)	Germany	1 (2%)
	Greece	1 (1%)	Ireland	6 (11%)
	Ireland	15 (17%)	Italy	6 (11%)
	Italy	3 (3%)	Netherlands	6 (11%)
	Malta	2 (3%)	Norway	3 (6%)
	Netherlands	2 (3%)	Poland	1 (2%)
	Norway	5 (6%)	Portugal	4 (7%)
	Poland	6 (7%)	Serbia	1 (2%)
	Portugal	4 (5%)	Slovenia	1 (2%)
	Romania	2 (3%)	Spain	2 (4%)
	Serbia	1 (1%)	Sweden	2 (4%)
	Spain	5 (6%)	Switzerland	3 (6%)
	Sweden	3 (3%)	United Kingdom	11 (19%)
	Switzerland	3 (3%)		
	United Kingdom	13 (15%)		
Type of expert	Professional	82 (95%)	Professional	49 (91%)
	Non-professional	4 (5%)	Non-professional	5 (9%)
Discipline (professional experts) n (%)	Healthcare professional	82 (95%)	Healthcare professional	49 (91%)
	- physician	59 (69%)	- physician	36 (66%)
	- nurse	16 (19%)	- nurse	8 (15%)
	- pharmacist	2 (2%)	- physiotherapist	2 (4%)
	- dietitian	1 (1%)	- pharmacist	1 (2%)
	- medical manager	1 (1%)	- psychologist	1 (2%)
	- medical scientist	1 (1%)	- skin therapist	1 (2%)
	- occupational therapist	1 (1%)		
	- psychologist	1 (1%)	Non-professional	
			- cancer patient advocacy group members	5 (9%)
	Non-professional			

	- Public and Patient Involvement group members	4 (5%)	

Table 8: Retention rates across rounds.

		Round 1 n (%)	Round 2 n (%)	Round 3 n (%)
Number of participants completing / number of participants approached	SPC	84/86 (98%)	81/84 (96%)	80/81 (99%)
	ONC	53/54 (98%)	52/53 (98%)	49/52 (94%)
Reason for attrition		No response 3 (2%)	No response 2 (1%) Leave 1 (1%) IT issues 1 (1%)	No response 3 (2%) Time commitment 1 (1%)

Key: SPC = specialist palliative care expert group; ONC = oncology expert group.

4.9.2 Participant comments

In the SPC group in round 1, participants made 527 comments about the original statements. Seventy suggested changes to wording, 248 suggested changes / additions to content, 49 suggested new statements / content, and 160 provided general explanations for their opinion. In round 2, participants made 182 comments. Five suggested changes to wording, 98 suggested changes / additions to content, six suggested new statements, and 73 provided general explanations. Regarding free-text responses, the SPC group provided 52 in round 1 (two about wording, 25 content additions, six new content and generic explanations), and 69 in round 2 (six about wording, three content additions, 12 new content and 48 generic explanations).

In the ONC group in round 1, participants made 243 comments about the original statements. Thirty-four suggested changes to wording, 100 suggested changes /

additions to content, 37 suggested new content / statements, and 72 provided general explanations. In round 2, participants made 105 comments. Ten suggested changes to wording, 44 suggested changes / additions to content, 9 suggested new statements, and 42 provided general explanations. The ONC group provided 32 free-text responses in round 1 (one content addition, 24 new content and 7 generic explanations) and 28 in round 2 (five about wording, seven new content and 16 generic explanations).

4.9.3 Questionnaire changes between rounds

In round 2, 37 new statements and 20 modified statements were added. One new section on the extended role of SPCS for individuals with stable advanced or metastatic cancer was also included, which had six questions and 52 new statements. Additional information was made available for two statements. Nine statements were excluded and replaced with modified statements. Six questions relating to definitions were also removed, as it was not aimed to build consensus on these, but instead determine the most popular choice for use in this study and the extent of agreement. Additionally, the option to suggest “other” statements was removed if utilised in the previous round.

In round 3, 56 statements were excluded as they had achieved consensus and stability, or had stability and it was deemed that further iterations would not lead to consensus. One modified statement was included, and the wording of seven questions was modified based on participant feedback. Additional information was made available for three statements.

4.9.4 Group responses

Group responses for each statement across rounds, and stability between rounds, are reported in Appendix 5, Supplementary Tables S1a-e and S2a-e.

In the SPC group, after round 2, consensus was achieved for 41 statements, a majority insufficient for consensus was reached for 12 statements (10 majority agreement, two majority disagreement), and three statements showed plurality. After round 3, consensus was achieved for an additional 66 statements, a majority

insufficient for consensus for 29 statements (16 agreement, 13 disagreement), and 15 statements showed plurality.

In the ONC group, after round 2, consensus was achieved for 39 statements, a majority insufficient for consensus was reached for 14 statements (12 majority agreement, two majority disagreement), and three statements showed plurality. After round 3, consensus was achieved for an additional 63 statements, a majority insufficient for consensus for 35 statements (25 agreement, 10 disagreement), and 12 statements showed plurality.

Overall, outcomes were achieved for 166 statements. In the SPC group, consensus was achieved for 107 statements, a majority insufficient for consensus for 41 statements, and 18 statements showed plurality. In the ONC group, consensus was achieved for 102 statements, a majority insufficient for consensus for 49 statements, and 15 statements showed plurality.

4.9.5 Stability between rounds

In the SPC group, for a significance level of 0.05 and 81 participants (round 2), the critical value is 0.184, and for 80 participants (round 3), the critical value is 0.185 (see section 4.8.2.2.1 Levels of agreement for explanation of critical value).

Responses between rounds 1 and 2 demonstrated very strong association (ρ 0.80-1.0) for 22 statements, moderate association (ρ 0.50-0.79) for 32 statements, and fair association (ρ 0.2-0.49) for two statements. Responses between rounds 2 and 3 demonstrated very strong association (ρ 0.80-1.0) for 56 statements and moderate association (ρ 0.50-0.79) for 54 statements. No statement demonstrated poor association between rounds (ρ <0.2). Regarding the statements that reached consensus, 31 of these demonstrated very strong association between rounds, 74 of these moderate association, and two fair association.

For the ONC group, for a significance level of 0.05 and 52 participants (Round 2), the critical value is 0.231, and for 49 participants (Round 3), the critical value is 0.238. Responses between rounds 1 and 2 demonstrated very strong association (ρ 0.80-1.0) for 33 statements, moderate association (ρ 0.50–0.79) for 21 statements, and fair association (ρ 0.2-0.49) for two statements. Responses between rounds 2 and 3 demonstrated very strong association (ρ 0.80-1.0) for

59 statements, and moderate association (ρ 0.50 – 0.79) for 51 statements. No statement demonstrated poor association between rounds (ρ <0.2). Regarding the statements that reached consensus, 42 of these demonstrated very strong association between rounds, 58 of these moderate association and two fair association.

The study was terminated after round 3 since stable consensus had been achieved for a majority of statements, and stable agreement for the rest, making it unlikely that further consensus would be reached.

4.9.6 Definitions of palliative care and specialist palliative care

The majority of experts (63.1% SPC group and 69.8% ONC group) favoured the WHO's definition of palliative care (see Box 8) (20). Only 26.2% of the SPC group and 24.5% of the ONC group selected the IAHPHC definition (22), whilst 10.7% of the SPC group and 5.7% of the ONC group preferred other national / regional definitions. Table 9 shows the extent to which the groups agreed with the wording / content of the two former definitions.

Equally, the majority of experts (82.1% SPC group, 81.1% ONC group) selected the EAPC's description of SPC as their preferred definition (Box 8) (23). Table 9 displays the extent of agreement. 17.9% of the SPC group and 18.9% of the ONC group selected other definitions from journal articles and American organisations.

Box 8: Definitions of palliative care and specialist palliative care.

- (1) The World Health Organization (WHO) definition of palliative care:
“Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual” (20).
- (2) The International Association for Hospice and Palliative Care (IAHPHC) definition of palliative care: “Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe

illness and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers.” (22, p.755)

(3) The European Association for Palliative Care (EAPC) definition of specialist palliative care: “Specialist palliative care is provided by specialised services for patients with complex problems not adequately covered by other treatment options. Specialist palliative care services require a team approach, combining a multi-professional team with an interdisciplinary mode of work. Team members must be highly qualified and should have their main focus of work in palliative care.” (23, p.686)

Table 9: Extent of agreement of expert groups with definitions of palliative care and specialist palliative care.

		SD	MD	N	MA	SA
(1) WHO definition of PC	SPC (%)	6	4	3	25	62
		10		3	87	
	ONC (%)	2	3	0	25	70
		5		0	95	
(2) IAHPHC definition of PC	SPC (%)	8	8	6	39	39
		16		6	78	
	ONC (%)	2	6	1	57	34
		8		1	91	
(3) EAPC definition of SPC	SPC (%)	2	7	3	30	58
		9		3	88	
	ONC (%)	2	6	2	45	45
		8		2	90	

Key: WHO = World Health Organization; IAHPHC = International Association for Hospice and Palliative Care; EAPC = European Association for Palliative Care; SPC = specialist palliative care expert group; ONC = oncology expert group; PC = palliative care; SD = strongly disagree; MD = moderately disagree; N = neutral; MA = moderately agree; SA = strongly agree.

4.9.7 Core functions of specialist palliative care services

Tables 10 and 11 show the statements regarding core functions, current SPC knowledge and skills, and areas requiring further education / training that reached consensus in both groups (n = 46), the SPC group only (n = 6), and the ONC group only (n = 3). (Complete results can be found in Appendix 5 Tables S1a and S2a.)

Table 10: Consensus statements on core functions, knowledge and skills of SPCS.

Statement reaching consensus	% SPC group	% ONC group	Agreement between groups
Expert group agrees that the following are “core functions” of SPCS			
Management of pain	97	98	$\chi^2 = 0.082$; $p = 0.775$
Management of other physical symptoms	97	96	$\chi^2 = 0.353$; $p = 0.553$
Management of psychological problems	97	96	$\chi^2 = 0.353$; $p = 0.553$
Emotional support (patient)	96	98	$\chi^2 = 0.489$; $p = 0.484$
Emotional support (family)	95	96	$\chi^2 = 0.144$; $p = 0.704$
Spiritual support	83	72	$\chi^2 = 4.484$; $p = 0.034$
Social assistance	82	61	$\chi^2 = 15.684$; $p < 0.001$
Co-ordination of care	89	96	$\chi^2 = 2.883$; $p = 0.090$
Advance care planning	97	98	$\chi^2 = 0.489$; $p = 0.484$
End-of-life care	96	100	N/A

Bereavement care	92	81	$\chi^2 = 7.109$; $p = 0.008$
Research	97	93	$\chi^2 = 0.726$; $p = 0.394$
Education (other healthcare professionals)	99	100	N/A
Expert group agrees that SPCS should manage the following types of pain:			
Acute cancer-related pain*	93	94	$\chi^2 = 0.234$; $p = 0.629$
Acute cancer treatment-related pain*	85	92	$\chi^2 = 2.211$; $p = 0.137$
Chronic cancer-related pain**	93	96	$\chi^2 = 1.017$; $p = 0.313$
Chronic cancer treatment-related pain**	86	96	$\chi^2 = 4.355$; $p = 0.037$
Chronic cancer / cancer treatment-related pain – in collaboration with the multidisciplinary chronic pain team	97	96	$\chi^2 = 0.503$; $p = 0.478$
Individuals with cancer / cancer treatment-related pain and a previous history of opioid misuse / abuse / addiction	94	98	$\chi^2 = 1.503$; $p = 0.220$
Individuals with cancer / cancer treatment-related pain and ongoing problems of opioid misuse / abuse / addiction	91	96	$\chi^2 = 1.907$; $p = 0.167$
Individuals with chronic cancer / cancer treatment-related pain and a previous history of opioid misuse / abuse / addiction – in collaboration with the multidisciplinary chronic pain team	89	90	$\chi^2 = 0.058$; $p = 0.810$
Individuals with chronic cancer / cancer treatment-related pain and ongoing problems of opioid misuse / abuse / addiction – in collaboration with the multidisciplinary chronic pain team	89	94	$\chi^2 = 1.306$; $p = 0.253$

Individuals with cancer / cancer treatment–related pain and a previous history of opioid misuse / abuse / addiction – in collaboration with addiction services	93	94	$\chi^2 = 0.134$; $p = 0.714$
Individuals with cancer / cancer treatment–related pain and ongoing problems of opioid misuse / abuse / addiction – in collaboration with addiction services	91	96	$\chi^2 = 1.355$; $p = 0.244$
Expert group agrees that SPCS should manage the following types of non-pain symptoms / physical problems:			
Acute cancer-related symptoms / physical problems*	94	87	$\chi^2 = 4.475$; $p = 0.034$
Acute cancer treatment-related symptoms / physical problems*	87	79	$\chi^2 = 2.309$; $p = 0.129$
Acute symptoms / physical problems related to non-cancer causes*	77	74	$\chi^2 = 0.251$; $p = 0.617$
Chronic cancer-related symptoms / physical problems**	95	96	$\chi^2 = 0.144$; $p = 0.704$
Chronic cancer treatment-related symptoms / physical problems**	88	93	$\chi^2 = 1.110$; $p = 0.292$
Chronic symptoms / physical problems related to non-cancer causes**	65	81	$\chi^2 = 6.611$; $p = 0.010$

Key: SPC = specialist palliative care expert group; ONC = oncology expert group; SPCS = specialist palliative care services; % group bold = subthreshold 75% i.e. consensus was not reached in that expert group; p value bold = Chi square (χ^2) test for goodness of fit and one degree of freedom comparing agreement between groups was significant at a level of ≤ 0.05 ; *duration <3 months (356); **duration ≥ 3 months (356).

Table 11: Consensus statements about current knowledge and skills of SPCS and areas requiring further education / training.

Statement reaching consensus	% SPC group	% ONC group	Agreement between groups
Expert group agrees that SPCS generally have the knowledge and skills to manage the following:			
Acute cancer-related pain*	99	94	$\chi^2 = 8.894$; $p = 0.003$
Acute cancer treatment-related pain*	95	94	$\chi^2 = 0.066$; $p = 0.798$
Acute pain related to non-cancer causes*	61	83	$\chi^2 = 10.193$; $p = 0.001$
Chronic cancer-related pain**	100	94	N/A
Chronic cancer treatment-related pain**	86	96	$\chi^2 = 4.355$; $p = 0.037$
Chronic pain related to non-cancer causes	62	78	$\chi^2 = 5.499$; $p = 0.019$
Individuals with cancer / cancer treatment-related pain and a previous history of opioid misuse / abuse / addiction	85	93	$\chi^2 = 3.029$; $p = 0.082$
Individuals with cancer / cancer treatment-related pain and ongoing problems of opioid misuse / abuse / addiction	78	94	$\chi^2 = 7.537$; $p = 0.006$
Acute cancer-related symptoms / physical problems*	98	87	$\chi^2 = 24.929$; $p < 0.001$
Acute cancer treatment-related symptoms / physical problems*	94	97	$\chi^2 = 19.306$; $p < 0.001$
Acute symptoms / physical problems related to non-cancer causes*	78	72	$\chi^2 = 1.143$; $p = 0.285$
Chronic cancer-related symptoms / physical problems**	95	96	$\chi^2 = 0.066$; $p = 0.798$

Chronic cancer treatment-related symptoms / physical problems**	89	86	$\chi^2 = 0.239$; $p = 0.625$
Regarding pain management, expert group agrees that SPCS services should have more education and / or appropriate training in the following areas:			
Interventional pain techniques	92	91	$\chi^2 = 0.240$; $p = 0.877$
Physiotherapy interventions	93	78	$\chi^2 = 15.784$; $p < 0.001$
Occupational therapy interventions	82	74	$\chi^2 = 2.768$; $p = 0.096$
Transcutaneous electrical nerve stimulation (TENS), scrambler therapy	80	73	$\chi^2 = 1.306$; $p = 0.253$
Psychological and behavioural therapies / interventions	92	90	$\chi^2 = 0.122$; $p = 0.727$
Pharmacological interventions in addiction recovery	84	75	$\chi^2 = 2.420$; $p = 0.120$
Regarding management of non-pain symptoms / physical problems, expert group agrees that SPCS should have more training in the following areas:			
Assessment of acute side effects of anticancer treatment (especially novel anticancer treatments)	99	77	$\chi^2 = 171.000$; $p < 0.001$
Management of acute side effects of anticancer treatment (especially novel anticancer treatments)	96	84	$\chi^2 = 21.066$; $p < 0.001$
Assessment of chronic / long-term effects of anticancer treatment (especially novel anticancer treatments)	99	85	$\chi^2 = 64.474$; $p < 0.001$
Management of chronic / long-term effects of anticancer treatment (especially novel anticancer treatments)	97	86	$\chi^2 = 14.763$; $p < 0.001$

Assessment of late / delayed effects of anticancer treatment (especially novel anticancer treatments)	99	79	$\chi^2 = 139.592$; $p < 0.001$
Management of late / delayed effects of anticancer treatment (especially novel anticancer treatments)	96	82	$\chi^2 = 28.487$; $p < 0.001$

Key: SPC = specialist palliative care expert group; ONC = oncology expert group; SPCS = specialist palliative care services; % group bold = subthreshold 75% i.e. consensus was not reached in that expert group; p value bold = Chi square (χ^2) test for goodness of fit comparing agreement between groups was significant at a level of ≤ 0.05 ; *duration <3 months (356); **duration ≥ 3 months (356).

4.9.7.1 Lack of consensus

A majority of both groups (insufficient for consensus) agreed with the following statements: rehabilitation is a core function of SPCS; SPCS should manage acute pain related to non-cancer causes; SPCS should manage chronic pain related to non-cancer causes; SPCS should manage chronic symptoms / physical problems related to non-cancer causes, that SPCS have the knowledge and skills to manage chronic symptoms / physical problems related to non-cancer causes; and that SPCS should have more education and / or appropriate training in acupuncture / acupressure, complementary therapies, and psychosocial and behavioural interventions in addiction recovery.

4.9.8 Definition of cancer survivors

Consensus was achieved in both expert groups regarding the ESMO definition (76), but not the NCI definition (17) (Box 9 and Table 12). Moreover, the majority in both groups stated that the ESMO definition was their preferred definition, i.e. 54.8% (n = 46) SPC group and 50.9% (n = 27) ONC group (76). Only 26.2% (n = 22) of the SPC group and 35.8% (n = 19) of the ONC group selected the NCI definition as their preference (17). Six (7.1%) of the SPC group, and three (5.7%) of the ONC group, preferred an alternative definition. However, 10 (11.9%) of the SPC group, and four (7.5%) of the ONC group preferred no definition, that is, that the term cancer survivor should not be used in clinical practice.

Box 9: Definitions of cancer survivor.

(1) National Cancer Institute (NCI): “An individual is considered a cancer survivor from the time of diagnosis through the balance of life. There are many types of survivors, including those living with cancer and those free of cancer” (17).

(2) European Society for Medical Oncology (ESMO): “Patients with a diagnosis of cancer who are managed with curative intent, from completion of active therapy (despite eventually on or off maintenance therapy) to long-term follow-up” (76, p.1121).

Table 12: Expert groups’ agreement with standard definitions of cancer survivor.

		SD	MD	N	MA	SA
(1) NCI	SPC (%)	26	18	12	23	21
		44		12	44	
	ONC (%)	12	19	12	17	40
		31		12	57	
(2) ESMO	SPC (%)	1	6	10	43	40
		7		10	83	
	ONC (%)	6	8	6	40	40
		14		6	80	

Key: NCI: National Cancer Institute; ESMO: European Society for Medical Oncology; SPC: specialist palliative care expert group; ONC: oncology expert group; SD: strongly disagree; MD: moderately disagree; N: neutral; MA: moderately agree; SA: strongly agree

4.9.9 Groups described as cancer survivors

Table 13 shows the statements about who should be called a cancer survivor that reached consensus in both expert groups (n = 7), the SPC group only (n = 1), and the ONC group only (n = 1). (Complete results can be found in Appendix 5 Tables S1b and S2b.)

Table 13: Consensus statements on groups defined as cancer survivors.

Statement reaching consensus	% SPC group	% ONC group	Agreement between groups
Expert group <u>agrees</u> that the following groups should be called cancer survivors:			
Individuals who have just completed anticancer treatment, and have no known cancer present.	75	83	$\chi^2 = 2.000$; $p = 0.157$
Individuals who completed anticancer treatment at least 1 year beforehand, and have no known cancer present.	73	89	$\chi^2 = 6.441$; $p = 0.011$
Individuals who completed anticancer treatment at least 5 years beforehand, and have no known cancer present.	90	95	$\chi^2 = 0.995$; $p = 0.319$
Individuals who completed anticancer treatment at least 10 years beforehand, and have no known cancer present.	88	96	$\chi^2 = 2.773$; $p = 0.096$
Expert group <u>disagrees</u> that the following groups should be called cancer survivors:			
All individuals with cancer.	82	79	$\chi^2 = 0.294$; $p = 0.588$
Individuals who are still receiving anticancer treatment with curative intent.	77	53	$\chi^2 = 49.133$; $p < 0.001$
Individuals who are still receiving anticancer treatment with palliative intent.	85	77	$\chi^2 = 16.641$; $p < 0.001$
Individuals who have progressive/worsening cancer, and have no other anticancer treatment options.	87	87	$\chi^2 = 1.300$; $p = 0.254$
Family members, friends, and caregivers of individuals with cancer or a history of cancer.	94	89	$\chi^2 = 3.071$; $p = 0.080$

Key: SPC = specialist palliative care expert group; ONC = oncology expert group; SPCS = specialist palliative care services; % group bold = subthreshold 75% i.e.

consensus was not reached in that expert group; p value bold = Chi square (χ^2) test for goodness of fit for one degree of freedom comparing agreement between groups was significant at a level of ≤ 0.05 .

4.9.9.1 Lack of consensus

A majority of both groups (67% SPC and 58% ONC) disagreed that individuals who have just completed anticancer treatment and still have some known cancer present should be defined as “cancer survivors” ($\chi^2(1) = 1.030$; $p = 0.310$). For the statement “no individual should be called a “cancer survivor” i.e. the term should not be used”, 45% of the SPC group disagreed and 69% of the ONC group disagreed ($\chi^2(1) = 0.249$; $p = 0.618$).

4.9.10 Categories of individuals with cancer or a history of cancer

Participants were presented with three categorisations to inform a model of care (Box 10). Table 14 shows those that the expert groups determined to be useful with a consensus majority; the living with, through and beyond cancer categorisation (102), and a novel categorisation of groups of individuals who have or had cancer. (Complete results can be found in Appendix 5 Tables S1c and S2c.)

Box 10: Categorisations of people who have or had cancer.

(1) Seasons of survivorship (97)

- Acute survivorship (Diagnosis, staging and treatment.)
- Transitional survivorship (The transition from active treatment to careful observation and the emotional, social, and medical adaptations that occur.)
- Extended survivorship (A diverse group who are who are (1) alive and "living with cancer" but requiring ongoing treatment for recurrent, active, and often advanced disease; (2) in a complete remission that requires ongoing therapy; or (3) in a complete remission and with a favourable prognosis
- Permanent survivorship (A diverse group of 4 subgroups including (1) survivors who are "cancer-free but not free of cancer," (2) survivors who are

cancer-free but continue to have significant "fall-out" from cancer and its treatment including psychosocial, medical, financial, or legal sequelae, (3) survivors who go on to develop second cancers which may be unrelated to the first cancer or its treatment, or may be more likely due to genetic or environmental factors, and (4) survivors who later develop cancers that are secondary to the initial treatment.).

(2) Living with, through and beyond cancer categorisation (102)

- Living with cancer (Begins with diagnosis. The focus is on treatment, getting rid of the cancer, if possible, or controlling the cancer to the point where you can live with it long term.)
- Living through cancer (The period after treatment when you are at risk of your cancer returning (recurrence). This is also a time of rehabilitation.)
- Living beyond cancer (Post-treatment and long-term survivorship.)

(3) Groups of individuals with cancer or a history of cancer

- Individuals with cancer before the start of primary anticancer treatment
- Individuals with cancer on anticancer treatment with "curative intent" (primary or other)
- Individuals with cancer on anticancer treatment with "palliative" / non-curative intent (primary or other)
- Individuals with cancer not on anticancer treatment on "watch and wait" / active monitoring
- Individuals with cancer not on anticancer treatment with advanced / progressive disease and no further anticancer treatment options
- Individuals with a history of cancer who have completed anticancer treatment and have no evidence of disease, on active oncology follow-up (some risk of recurrence)
- Individuals with a history of cancer who have completed anticancer treatment and have no evidence of disease, not on active oncology follow-up (low risk of recurrence)

Table 14: Consensus statements on useful categorisations of people with cancer or a history of cancer.

Categorisation reaching consensus	% SPC group	% ONC group	Agreement between groups
Expert group agrees that the following classifications for groups of individuals with cancer or a history of cancer are useful:			
Living with, through and beyond cancer categorisation (102)	84	91	$\chi^2 = 1.577$; $p = 0.209$
Groups of individuals with cancer or a history of cancer (see Box 10)	89	79	$\chi^2 = 5.327$; $p = 0.021$

Key: SPC = specialist palliative care expert group; ONC = oncology expert group; SPCS = specialist palliative care services; p value bold = Chi square (χ^2) test for goodness of fit for one degree of freedom comparing agreement between groups was significant at a level of ≤ 0.05 .

4.9.10.1 Lack of consensus

Consensus was not achieved in either expert group about the so-called seasons of cancer survivorship (97). A majority (65%) of the SPC group disagreed with the categorisation, and the ONC group demonstrated a bimodal distribution (47% agreed, 40% disagreed) ($\chi^2(1) = 40.540$; $p < 0.001$).

4.9.11 *Extended role of specialist palliative care for individuals with a history of cancer who have completed anticancer treatment and have no evidence of disease*

Table 15 shows the statements regarding the extended role of SPCS for individuals with a history of cancer who have completed anticancer treatment and have no evidence of disease (i.e. individuals living beyond cancer) that reached consensus in both groups (n = 14), the SPC group only (n = 5), and the ONC group only (n = 2). (Complete results can be found in Appendix 5 Tables S1d and S2d.)

Table 15: Consensus statements on the extended role of SPCS for individuals with a history of cancer who have completed anticancer treatment and have no evidence of disease.

Statement reaching consensus	% SPC group	% ONC group	Agreement between groups
Expert group <u>agrees</u> that SPCS should have a role in supporting the following components of care:			
Management of pain	76	81	$\chi^2 = 1.150$; $p = 0.284$
Management of other physical symptoms / problems	73	75	$\chi^2 = 0.223$; $p=0.637$
Expert group <u>disagrees</u> that SPCS should have a role in supporting the following components of care:			
Prevention of second cancers	89	87	$\chi^2 = 9.577$; $p = 0.002$
Surveillance for recurrence or second cancers	88	90	$\chi^2 = 0.825$; $p = 0.364$
Managing financial problems ("financial toxicity")	79	68	$\chi^2 = 11.367$; $p < 0.001$
Expert group <u>agrees</u> that SPCS generally have the knowledge and skills to support the following components of care:			
Management of pain	88	92	$\chi^2 = 0.843$; $p = 0.359$
Management of other physical symptoms / problems	86	84	$\chi^2 = 0.266$; $p = 0.606$
Management of psychological distress	83	81	$\chi^2 = 0.134$; $p = 0.715$
Supporting caregivers	78	69	$\chi^2 = 1.849$; $p = 0.174$
Expert group <u>disagrees</u> that SPCS generally have the knowledge and skills to support the following components of care:			
Prevention of second cancers	90	92	N/A

Surveillance for recurrence or second cancers	86	88	$\chi^2 = 4.185$; $p = 0.041$
Managing financial problems ("financial toxicity")	76	47	$\chi^2 = 0.047$; $p = 0.829$
Expert group <u>agrees</u> that the following are barriers to extending the input of SPCS to this group:			
Financial resources	82	71	$\chi^2 = 4.027$; $p = 0.045$
Human resources	90	81	$\chi^2 = 5.388$; $p < 0.020$
Time resources	85	85	$\chi^2 = 0.019$; $p = 0.892$
Lack of relevant education and training	81	62	$\chi^2 = 11.770$; $p < 0.001$
Misperceptions about the nature of palliative care	76	75	$\chi^2 = 0.038$; $p = 0.846$
Type of service:			
Expert group <u>agrees</u> that:			
A dedicated multidisciplinary specialist team is required	89	87	$\chi^2 = 0.045$; $p = 0.832$
SPCS should be an extended member of this team i.e. support with relevant problems / issues	74	88	$\chi^2 = 4.978$; $p = 0.026$
Expert group <u>disagrees</u> that:			
SPCS should not contribute to this team	80	83	$\chi^2 = 0.002$; $p = 0.962$
SPCS should lead this team	76	80	$\chi^2 = 0.058$; $p = 0.810$

Key: SPC = specialist palliative care expert group; ONC = oncology expert group; SPCS = specialist palliative care services; % group bold = subthreshold 75% i.e. consensus was not reached in that expert group; p value bold = Chi square (χ^2) test for goodness of fit comparing agreement between groups was significant at a level of ≤ 0.05 .

4.9.11.1 Lack of consensus

A number of statements did not reach consensus (although some still reached a majority). Results of the Chi square (χ^2) test for goodness of fit are reported where there was a difference in the overall trend between the SPC and Onc groups.

Role of SPCS in supporting components of care

SPC group

The *majority agreed* that SPCS should have a role in:

- management of psychological distress (72%).

The *majority disagreed* that SPCS should have a role in:

- surveillance of physical "late effects" (late effects are the new onset of treatment-related problems) (66%)
- surveillance of psychological distress (66%)
- rehabilitation (66%)
- supporting occupational issues / return to work (70%)
- supporting caregivers (51%)
- coordination between specialists and primary care providers (63%)
- developing survivorship care plans (SCPs) (57%) (defined as a plan provided after completion of acute treatment that "should contain information regarding both physical and psycho-social impacts of cancer and cancer treatment, and aim at organising their management, as well as the cancer patient's rehabilitation, through access to relevant services and interventions" (357, p.7)).

There was *no majority* reached for the following:

- managing "fear of cancer recurrence" (49% agreed, 43% disagreed).

Onc group

Distinct from the SPC group, the *majority agreed* that SPCS should have a role in:

- surveillance of physical “late effects” (53%, $\chi^2(1) = 10.828$; $p < 0.001$)
- surveillance of psychological distress (59%, $\chi^2(1) = 17.767$; $p < 0.001$)
- management of psychological distress (67%).
- supporting caregivers (55%, $\chi^2(1) = 4.656$, $p = 0.031$).
- coordination between specialists and primary care providers (57%, $\chi^2(1) = 19.246$; $p < 0.001$)).

Distinct from the SPC group, a *majority disagreed* that SPCS should have a role in:

- managing “fear of cancer recurrence” (51%, $\chi^2(1) = 0.291$; $p = 0.589$)
- supporting occupational issues / return to work (62%).

There was *no majority* reached for the following:

- rehabilitation (45% disagreed, 43% agreed)
- developing SCPs (49% disagreed, 43% agreed).

Knowledge and skills

SPC group

The *majority agreed* that SPCS generally have the knowledge and skills to support:

- surveillance of physical “late effects” (58%)
- surveillance of psychological distress (64%)
- managing “fear of cancer recurrence” (54%)
- coordination between specialists and primary care providers (72%).

The *majority disagreed* that SPCS generally have the knowledge and skills for:

- supporting occupational issues / return to work (67%)
- developing SCPs (52%).

There was *no majority* reached for the following:

- rehabilitation (43% agreed, 34% disagreed).

Onc group

Similar to the SPC group, the *majority agreed* that SPCS generally have the knowledge and skills to support:

- surveillance of psychological distress (61%)
- managing “fear of cancer recurrence” (59%)
- coordination between specialists and primary care providers (61%).

The *majority disagreed* that SPCS generally have the knowledge and skills for:

- supporting occupational issues / return to work (53%)
- developing SCPs (51%).

There was *no majority* reached for the following:

- surveillance of physical "late effects" (43% disagreed, 39% agreed)
- rehabilitation (39% agreed, 33% disagreed).

Barriers

SPC group

The *majority agreed* that the following were barriers to extending the input of SPCS to this group:

- lack of willingness from palliative care professionals (56%)
- lack of willingness from oncology professionals (60%).

There was *no majority* reached for the following:

- lack of willingness from GPs (42% agreed, 17% disagreed)
- lack of willingness from patients and families (44% agreed, 31% disagreed).

Onc group

The *majority agreed* that the following were barriers to extending the input of SPCS to this group:

- lack of willingness from oncology professionals (67%)
- lack of willingness from GPs (57%, $\chi^2(1) = 5.926$; $p = 0.015$).

There was *no majority* reached for the following:

- lack of willingness from palliative care professionals (48% agreed, 17% disagreed)
- lack of willingness from patients and families (42% agreed, 23% disagreed).

Type of service

SPC group

The *majority disagreed* with the following statement:

- SPCS should be a core member of this team i.e. routinely involved in care (52%).

Onc group

There was no majority reached for the following statement:

- SPCS should be a core member of this team i.e. routinely involved in care (43% agreed, 49% disagreed).

4.9.12 Extended role of specialist palliative care for individuals with stable locally advanced or metastatic cancer.

Table 16 shows statements that reached consensus in both groups (n = 24), the SPC group only (n = 2) and the ONC group only (n = 3) regarding the extended role of SPCS for individuals with stable locally advanced or metastatic cancer, and levels of agreement. (Complete results can be found in Appendix 5 Tables S1e and S2e.)

Table 16: Consensus statements on the extended role of SPCS for individuals with stable locally advanced or metastatic cancer.

Statement reaching consensus	% SPC group	% ONC group	Agreement between groups
Expert group <u>agrees</u> that SPCS should have a role in supporting the following components of care:			
Surveillance of physical symptoms / problems	91	84	$\chi^2 = 3.470$; $p = 0.062$
Surveillance of psychological distress	92	84	$\chi^2 = 3.470$; $p = 0.062$
Management of pain	100	100	N/A
Management of other physical symptoms / problems	100	96	N/A
Management of psychological distress	100	98	N/A
Support for cultural, spiritual and religious needs	87	75	$\chi^2 = 6.440$; $p = 0.011$
Supporting caregivers	91	87	$\chi^2 = 0.729$; $p = 0.393$
Care coordination between specialists and primary care providers	73	80	$\chi^2 = 1.236$; $p = 0.266$
Advance care planning	98	98	$\chi^2 = 0.042$; $p = 0.837$
Expert group <u>disagrees</u> that SPCS should have a role in supporting the following components of care:			
Prevention of second cancers	74	88	$\chi^2 = 1.842$; $p = 0.175$
Surveillance for cancer spread, recurrence or second cancers	53	84	$\chi^2 = 9.144$; $p = 0.002$
Expert group <u>agrees</u> that SPCS generally have the knowledge and skills to support the following components of care:			
Surveillance of physical symptoms / problems	95	89	$\chi^2 = 2.794$; $p = 0.095$

Surveillance of psychological distress	95	94	$\chi^2 = 0.130$; $p = 0.718$
Management of pain	99	100	N/A
Management of other physical symptoms / problems	99	98	$\chi^2 = 0.211$; $p = 0.646$
Management of psychological distress	98	94	$\chi^2 = 2.638$; $p = 0.104$
Support for cultural, spiritual and religious needs	78	65	$\chi^2 = 4.178$; $p = 0.041$
Supporting caregivers	88	85	$\chi^2 = 0.143$; $p = 0.705$
Care coordination between specialists and primary care providers	81	81	$\chi^2 = 0.082$; $p = 0.775$
Advance care planning	94	100	N/A
Expert group <u>disagrees</u> that SPCS generally have the knowledge and skills to support the following components of care:			
Prevention of second cancers	77	74	$\chi^2 = 1.124$; $p = 0.289$
Expert group <u>agrees</u> that the following are barriers to extending the input of SPCS to this group:			
Financial resources	86	90	$\chi^2 = 0.529$; $p = 0.467$
Human resources	91	100	N/A
Time resources	90	94	$\chi^2 = 0.819$; $p = 0.366$
Misperceptions about the nature of palliative care	87	86	$\chi^2 = 0.010$; $p = 0.919$
Type of service:			
Expert group <u>agrees</u> that			
A dedicated multidisciplinary specialist team is required	89	94	$\chi^2 = 1.306$; $p = 0.253$
SPCS should be a core member of this team i.e. routinely involved in care	83	85	$\chi^2 = 0.351$; $p = 0.554$

SPCS should be an extended member of this team i.e. support with relevant problems / issues	79	83	$\chi^2 = 0.717$; $p = 0.397$
Expert group <u>disagrees</u> that:			
SPCS should not contribute to this team	98	98	N/A

Key: SPC = specialist palliative care expert group; ONC = oncology expert group; SPCS = specialist palliative care services; % group bold = subthreshold 75% i.e. consensus was not reached in that expert group; p value bold = Chi square (χ^2) test for goodness of fit and one degree of freedom comparing agreement between groups was significant at a level of ≤ 0.05 .

4.9.12.1 Lack of consensus

A number of statements did not reach consensus (although some still reached a majority). Results of the Chi square (χ^2) test for goodness of fit are reported where there was a difference in the overall trend between the SPC and Onc groups.

Role of SPCS in supporting components of care

SPC group

The *majority agreed* that SPCS should have a role in:

- rehabilitation (74%)
- supporting occupational issues / return to work (60%).

There was *no majority* reached for the following:

- managing financial problems ("financial toxicity") (50% agreed, 30% disagreed)
- health promotion (48% agreed, 21% disagreed)
- developing SCPs (36% agreed, 22% disagreed).

Onc group

The *majority agreed* that SPCS should have a role in:

- rehabilitation (73%)

- supporting occupational issues / return to work (53%)
- health promotion (71%)
- developing SCPs (63%).

There was *no majority* reached for the following:

- managing financial problems (“financial toxicity”) (47% agreed, 28% disagreed).

Knowledge and skills

SPC group

The majority agreed that SPCS generally have the knowledge and skills to support:

- rehabilitation (56%).

The majority disagreed that SPCS generally have the knowledge and skills for:

- surveillance for cancer spread, recurrence or second cancers (66%).

There was *no majority* reached for the following:

- supporting occupational issues / return to work (50% agreed, 29% disagreed)
- managing financial problems (“financial toxicity”) (44% agreed, 30% disagreed)
- health promotion (24% agreed, 37% disagreed)
- developing SCPs (21% agreed, 41% disagreed).

Onc group

Similar to the SPC group, the *majority agreed* that SPCS generally have the knowledge and skills to support:

- rehabilitation (57%).

The *majority disagreed* that SPCS generally have the knowledge and skills for:

- surveillance for cancer spread, recurrence or second cancers (74%)
- health promotion (53%).

There was *no majority* reached for the following:

- supporting occupational issues / return to work (39% agreed, 49% disagreed, $\chi^2(1) = 2.469$; $p = 0.116$)
- managing financial problems (“financial toxicity”) (26% agreed, 47% disagreed, $\chi^2(1) = 5.908$; $p = 0.015$)
- developing SCPs (47% agreed, 28% disagreed, $\chi^2(1) = 19.261$; $p < 0.001$).

Barriers

SPC group

The *majority agreed* that the following were barriers to extending the input of SPCS to this group:

- lack of relevant education and training (68%)
- lack of willingness from oncology professionals (67%).

There was *no majority* reached for the following:

- lack of willingness from palliative care professionals (45% agreed, 46% disagreed)
- lack of willingness from GPs (45% agreed, 25% disagreed)
- lack of willingness from patients and families (33% agreed, 28% disagreed).

Onc group

The *majority agreed* that the following were barriers to extending the input of SPCS to this group:

- lack of relevant education and training (71%)
- lack of willingness from palliative care professionals (51%)
- lack of willingness from oncology professionals (63%)

- lack of willingness from GPs (61%).

There was *no majority* reached for the following:

- lack of willingness from patients and families (47% agreed, 37% disagreed).

Type of service

SPC group

There was no majority reached for the following statements:

- SPCS should lead this team (47% agreed, 42% disagreed)
- the same team should provide care for both groups (23% agreed, 38% disagreed).

Onc group

The majority agreed with the following statement:

- the same team should provide care for both groups (51%, $\chi^2(1) = 9.427$; $p = 0.002$).

There was no majority reached for the following statements:

- SPCS should lead this team (36% agreed, 39% disagreed, $\chi^2(1) = 1.786$; $p = 0.181$).

4.9.13 Comparison of expert groups

For a significance level of 0.05 and one degree of freedom, the critical value is 3.841 for the Chi square (χ^2) test to compare the levels of agreement between the two expert groups for the final statements.

Outcomes differed significantly for 57 relevant statements ($p < 0.05$), but this was only relevant to 13 of the 23 statements that reached consensus in only one group (see Appendix 5, Table S3 for comparisons for all statements).

Fourteen statements reached consensus in the SPC group but not ONC, seven of which had a significant difference:

- spiritual support is a core function of SPCS ($\chi^2(1) = 4.484$; $p = 0.034$)
- social assistance is a core function of SPCS ($\chi^2(1) = 15.684$; $p < 0.001$)
- disagreeing that individuals who are still receiving anticancer treatment with curative intent should be called “cancer survivors” ($\chi^2(1) = 49.133$; $p < 0.001$)
- disagreeing that SPCS should have a role in managing financial problems (“financial toxicity”) ($\chi^2(1) = 11.367$; $p < 0.001$) for people who have completed anticancer treatment and have no evidence of disease
- identifying financial resources ($\chi^2(1) = 4.027$; $p = 0.045$) as a barrier to extending the role of SPCS to individuals with a history of cancer who have completed anticancer treatment and have no evidence of disease
- identifying lack of relevant education / training ($\chi^2(1) = 11.770$; $p < 0.001$) as a barrier to extending the role of SPCS to individuals with a history of cancer who have completed anticancer treatment and have no evidence of disease
- agreeing that SPCS generally have the knowledge and skills to support the cultural, spiritual and religious needs of individuals with stable locally advanced or metastatic cancer ($\chi^2(1) = 4.178$; $p = 0.041$).

Nine statements reached consensus in the ONC group but not SPC, six of which had a significant difference:

- SPCS generally have the knowledge and skills to support acute pain related to non-cancer causes ($\chi^2(1) = 10.193$; $p = 0.001$)
- SPCS generally have the knowledge and skills to support chronic pain related to non-cancer causes ($\chi^2(1) = 5.499$; $p = 0.019$)
- SPCS should have a role in managing chronic symptoms / physical problems related to non-cancer causes ($\chi^2(1) = 6.611$; $p = 0.010$)
- individuals who completed anticancer treatment at least 1 year beforehand and have no known cancer should be called “cancer survivors” ($\chi^2(1) = 6.441$; $p = 0.011$)

- SPCS should be an extended member of the team that supports individuals who have completed anticancer treatment and have no evidence of disease ($\chi^2(1) = 4.978$; $p = 0.026$)
- disagreeing that SPCS should have a role in surveillance for cancer spread, recurrence or second cancers for individuals with stable locally advanced or metastatic cancer ($\chi^2(1) = 9.144$; $p = 0.002$).

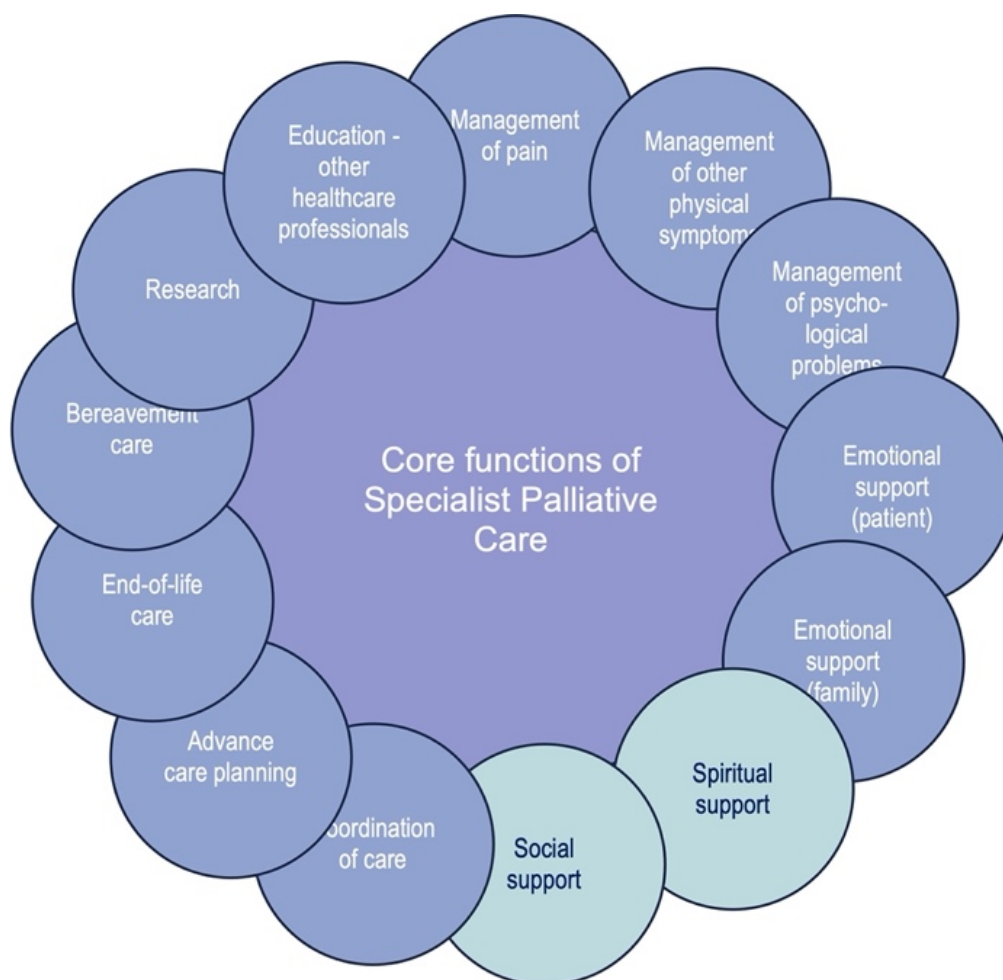
4.10 Discussion

This unique e-Delphi process has generated important information from European experts about the potential role of SPCS for people who have or had cancer, and will be utilised in the development of a European-focused model of care. It is the first study clarifying expert opinion in this area, and also highlights key areas of contention that exist within and between these groups.

4.10.1 Definition and core activities of SPCS

Both expert groups largely agreed with the widely used definitions of palliative care (WHO (20) and IAHP (22)) and SPC (EAPC (23)). The e-Delphi reiterated the core functions of SPCS, presented in Figure 6, and there was good concordance between the two expert groups. The only exceptions were the provision of spiritual support (consensus in SPC group but not the ONC group), and the provision of social assistance (consensus in SPC group but not the ONC group). Importantly, there is much overlap between these and the unmet needs of individuals living with, through and beyond cancer (175, 176).

Figure 6: Consensus-based core functions of SPCS.



Key: Blue circles = consensus reached in both SPC and ONC groups; green circles = consensus reached in SPC group only.

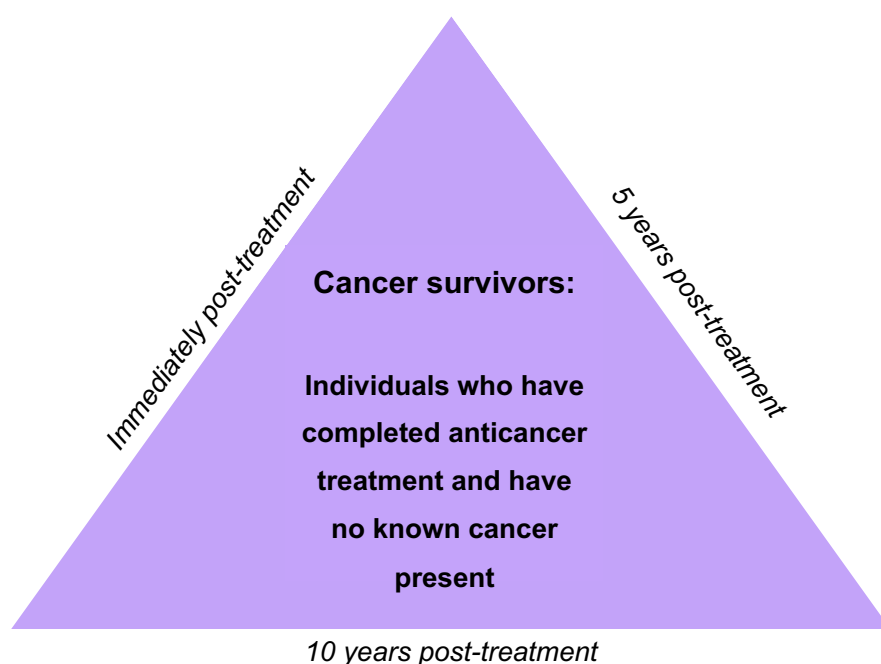
Notably both groups agreed that acute and chronic pain and other physical symptoms related to cancer and its treatment should be included. In terms of chronic cancer-related / cancer treatment-related pains, there was not only consensus that this was a core function of SPCS, but that these services already had the knowledge and skills to undertake this role (in collaboration with chronic pain teams). Furthermore, this role should include people with a previous history, or ongoing problems, related to opioid abuse / addiction (in collaboration with addiction services). An obvious absence of consensus related to the management of chronic non-cancer related pain or other physical problems, showing the lack of clarity regarding the contribution of SPC to non-malignant pain, and the probable current variation in service provision.

4.10.2 Definition and categorisation of cancer survivors

This e-Delphi process has reiterated ongoing issues / concerns around cancer survivor terminology amongst European SPC and oncology professionals. Importantly, both expert groups agreed with (and preferred) ESMO's functional definition of cancer survivors (individuals post curative-intent treatment) (76), as opposed to the NCI definition (or alternative definitions). Indeed, the SPC group was divided between agreement and disagreement with the NCI's all-encompassing definition of cancer survivors (17). Such lower agreement with the NCI definition (17) may reflect a lower acceptability of this interpretation outside of North America, as has been previously suggested (250).

Both expert groups reached consensus agreement that individuals post-treatment with no evidence of disease (immediately, and after 5 and 10 years) should be called cancer survivors (Figure 7). Relatedly, there was also consensus in both expert groups that the term cancer survivor should not be applied to all individuals with cancer, and specifically not to individuals who are still receiving anticancer treatment with palliative intent, to individuals who have progressive / worsening cancer and no other anticancer treatment options, and to family members, friends, and caregivers of individuals with cancer or a history of cancer (145).

Figure 7: Consensus statements on who should be defined as cancer survivors.



Importantly, certain learned groups (non-European in composition) do apply survivorship terminologies to individuals with advanced or metastatic cancer (6), although it remains uncertain whether people with advanced / metastatic cancer themselves are supportive of these terms (91, 252, 302). It should be noted that there was a general discomfort about the term cancer survivor amongst both expert groups (based upon free text feedback during the Delphi process), and interestingly no statement on care provision / components that used survivorship terminology reached consensus support. One participant stated, “I think to use cancer survivor to describe this group could be distressing and actually insulting”. Indeed, another found the very title of the study (PRiSM) challenging, commenting, “Since I disagree with this definition (of cancer survivorship), it is difficult to answer questions (that relate to it)”. Indeed, these results suggest that its application to people who currently have cancer should be reconsidered.

One of the persuasive arguments for not having an all-inclusive definition relates to the fact that people with cancer or a history of cancer are extremely heterogeneous, and that whilst there are many generic problems, there are also highly specific problems relating to the individual’s cancer subtype, disease status, treatment history (current, previous), and their expected outcome (control, “cure”). Indeed, this explains the support from the expert groups for the broader living with, through, and beyond cancer categorisation to describe a person’s phase of illness (102), and equally the new factual classification developed during the process, grouping individuals with cancer or a history of cancer according to anticancer treatment status, treatment intent, and evidence of disease (see Table 14). However, it is acknowledged that such clear identification of treatment intent (curative or palliative) may also be challenging in the current era of novel anticancer treatments (358).

4.10.3 Extended role of SPCS for individuals with a history of cancer who have completed anticancer treatment and have no evidence of disease

Importantly, both expert groups reached consensus that SPCS should have a role in supporting pain management for people with a history of cancer and no evidence of disease. This aligns with previous suggestions / local initiatives (193-197, 199), and recommendations from oncology organisations (88, 203). Moreover, there was similar consensus for chronic cancer-related / cancer

treatment-related non-pain symptoms. This is the first demonstration of expert consensus opinion in this area, and particularly between two relevant expert groups. This has important implications regarding the scope of SPC clinical involvement for this area of contention.

Despite identifying that SPCS have the knowledge and skills to support this group in other areas, pain management was the only component that reached consensus in both groups. SPC involvement may therefore be more related to service capacity than skills. Importantly, the SPC group disagreed that they had the knowledge and skills to support other components of care, such as coordination of care, surveillance for recurrence or second cancers, and prevention of second cancers (but these were not identified as areas requiring education or training). Furthermore, the SPC group disagreed that dealing with financial toxicity was within their remit (or ability). These are important ideas in refining and limiting sensible scope of practice for SPCS for this group, and also highlight that SPC interventions are generally viewed in relation to management of issues rather than prevention.

The type of service that should support this group is another fundamental finding. A multidisciplinary specialist team has been previously endorsed by certain guidelines (76, 88, 139). Both groups of experts agreed that there needed to be a dedicated multidisciplinary team (MDT) to support individuals living beyond cancer, and that while SPCS should contribute to this team, they should not lead this team. The ideal team is likely a broad group of many specialties, including but not restricted to oncology and primary care. Importantly, the team should include persons with expertise in non-SPC core functions (e.g. cancer prevention, financial toxicity).

However, significant barriers were identified to SPCS supporting this cohort of people, including misperceptions about palliative care (see section 4.10.6 Misperceptions about palliative care), limited financial resources, and limited human (and time) resources. In addition, the need for further education / training was also seen as a major barrier. SPCS could only extend care to non-traditional groups like long-term cancer survivors without compromising care to traditional groups if all of these barriers are overcome.

4.10.4 Extended role of SPCS for individuals with stable locally advanced or metastatic cancer

Both expert groups agreed that SPCS should have a larger role for this group, reaching consensus that SPCS should support eight components of care, predominantly focusing on symptom assessment and management, and that SPCS generally already have the relevant knowledge and skills (Table 16). This is unsurprising, given the historical association of SPCS with symptom management in advanced disease, and the previous contribution of SPC professionals in defining quality care standards for this group (6). However, what this study adds is detail beyond referral “depending on needs” (6, p.313). Considering the core functions of SPCS, the scope of SPC involvement for this group is potentially wide, but these results clarify issues where SPCS have relevant skills, better defining how to provide support, promoting SPC ownership regarding the extent, and directing services within finite resources.

Importantly, both expert groups agree that SPC involvement regarding physical symptoms should relate to cancer and cancer treatment-related issues. For example, the role of SPCS in chronic pain is specified as pain relating to cancer or its treatment, with particular consideration of the risk of analgesic drug addiction / misuse, and in collaboration with addiction services and chronic pain teams. Furthermore, the role of SPCS again lies within intervention for consequences of cancer and its treatment, not in areas such as cancer surveillance and prevention, or care coordination (18). Both expert groups also agree that a dedicated MDT is required to support people who have advanced / metastatic cancer, in which SPCS should have either a core or extended role. The introduction of such clarity into a care model could direct SPC clinical services more effectively, particularly since financial, human and time resources were all identified as barriers to service provision.

4.10.5 Areas for education

Although results identified that SPCS generally have the competence for their core functions and the components of care where they should offer support (e.g. management of pain and other physical symptoms), areas where further training would be beneficial were also identified.

The management of chronic pain in individuals living beyond cancer is fundamentally different from the approach used in people with advanced cancer (i.e. typical palliative care patients) (217), and the SPC group especially identified the need for further education / training in non-pharmacological interventions (e.g. psychological / behavioural techniques, TENS / scrambler therapy), interventional techniques, and pharmacological interventions for the treatment of addiction. Indeed, analgesic drug dependency / abuse is a greater concern for people living longer, especially if there is no evidence of disease (196) and SPCS do not have universal competence in assessment and management of such areas (197), since additional skills are required (196, 220).

Similarly, the experts identified the need for further education / training in the assessment / management of long term, and delayed, effects of cancer treatments. Certainly, if SPC is expected to expand services to support this group of people who have or had cancer, which is growing in number and complexity, training will need to be altered accordingly. These results should influence considerations about SPC training programmes and service integration.

4.10.6 Misperceptions about palliative care

Public, professional and patient misperceptions about SPC remain widespread, particularly its association with the end of life (30, 191). Relatedly, these were identified as a barrier to SPCS service extension in both the aforementioned groups, and will require careful explanation if relevant stakeholders are to understand the relevance and appropriateness of SPCS. Effective educational strategies to promote understanding of other healthcare professionals, patients and those close to them need to be identified and implemented.

4.10.7 Areas of disagreement

The two separate panels could have been combined into one, but judgements often differ between such groups (359). Certainly, the two expert groups differed in some important areas, e.g. the SPC group disagreed that cancer survivor should be applied to individuals who are still receiving anticancer treatment irrespective of treatment intent, whereas the ONC group only disagreed that cancer survivor

should be applied to individuals who are still receiving anticancer treatment with palliative intent.

The statements that reached consensus in one group but not the other with a significant difference also highlight important areas that would benefit from inter-specialty discussion, in order to align understanding about SPC's relevant skills and services. The holistic nature of SPC is one area, with SPC placing greater emphasis on social and spiritual aspects of care. Expectations about the knowledge and role of SPCS in supporting non-cancer related issues also varied. Interestingly, ONC believed SPCS generally have the knowledge and skills required to manage acute and chronic non-cancer pain, whereas SPCS identified lack of training as a barrier to extending services for these problems. This reinforces the necessity to reconsider SPC training content, as well as clarity of SPC referral criteria. Additionally, the ONC group had a clearer idea about the extent of SPC team involvement for people with no evidence of disease (an extended member of the multidisciplinary specialist team), and although the SPC expert group agreed that they generally had the knowledge and skills for this role, and that they should contribute (to pain management), consensus about their level of involvement within the team was not achieved. An extended team role is likely the most pragmatic and supported option, and would enable flexible SPC input according to local skills and resources.

4.10.8 Areas where consensus is lacking

Consensus remains lacking in both SPC and ONC groups in some key areas. Relating to the care of individuals living beyond cancer, this included surveillance of psychological distress, managing "fear of cancer recurrence", rehabilitation, supporting occupational issues / return to work, supporting caregivers, and development of SCPs (Appendix 5, Tables S1d and S2d). Although psychological, caregiver and social support have previously been proposed (169, 188), these ideas are not supported by consensus expert opinion in this study (although disagreement was not displayed either).

Similarly, there remains lack of consensus about the role of SPCS for people with stable advanced / metastatic disease, including leadership of the MDT, and SPC knowledge and provision of certain components of care, including health

promotion, rehabilitation, developing SCPs, and support for occupational and financial issues (Appendix 5, Tables S1e and S2e). These areas could therefore be considered according to local resources, particularly where SPCS already have relevant skills, but results from this study do not identify these as priorities for education or clinical application.

Both expert groups also showed divided opinion about whether the same team should support these components of care for individuals with a history of cancer who have completed anticancer treatment and have no evidence of disease, and for individuals with stable locally advanced or metastatic cancer. This likely represents two cohorts within each expert group, so uncertainty remains about expert opinion on this aspect of service structure.

Consensus is not typically reached for all items in a Delphi study (311), and differences in opinion may be attributed to variations in personal values, personal experience, specialty / qualification and exposure to the issues (321, 360), as well as questionnaire structure and presentation (and whether written in the participant's native language) (361). Indeed, one participant commented that they felt their language limitation may have affected their ability to suggest alternative phrasing. Moreover, the word "survivor" likely has different cultural and linguistic interpretations (250). Additionally, given the anonymised process, it is impossible to ascertain trends within the groups, which may be relevant in study generalisability (311). Furthermore, it should be noted that since consensus can be defined differently, the choice of parameter has important implications as it may change the results (311). There are no guidelines for when consensus is not achieved (332), but face-to-face meetings may be a useful additional procedure (where necessary).

Alternative methods to measure and develop consensus, such as the nominal group technique, hybrid methods, informal meetings or consensus conferences (362, 363) would have been less flexible and efficient, increasing participant burden, and likely would have reduced the panel's geographical diversity, given the variety of time zones (314, 322, 323). Other methods also lack anonymity, increasing the risk of bias (particularly given the potentially contentious issues explored in this study). However, it has also been argued that Delphi processes do not provide the opportunity for discussion (324).

4.10.9 Reliability, validity and trustworthiness issues

4.10.9.1 Reliability

Reliability refers to the consistency of a measurement (364): the extent to which a repeated measurement remains the same, its stability over time, or similarity of measurements within a given time (365). Inter-rater reliability (equivalence) (364) is particularly difficult to determine with Delphi studies as this would require resource-intensive recruitment of further panels to undertake alternative / parallel questionnaires, ascertaining if the same results would be produced (322, 333). Although this study had two panels, they were not comparable as they represented different expert groups. It would also likely be inappropriate to repeat the process at a later date to determine reliability, since participant opinions will be altered by increased knowledge and experience (321, 366). Furthermore, reliability is ultimately impacted by the personal and situational biases of panellists, so results are never completely generalisable (366). However, consistency within the study (and therefore reliability) was demonstrated by stability of results between rounds, with all final statements having moderate or strong stability. Many Delphi studies do not assess stability (367), improving this study's reliability.

4.10.9.2 Validity

Validity refers to the accuracy of the study in determining its outcome (364). This can be external (generalisability, that is the extent to which results can be applied to other settings) or internal, which is measured in different ways, including content validity (adequacy of coverage of the topic), construct validity (adequacy of a theoretical inference from the measurement) and criterion validity (concurrent or predictive; adequacy in correlating with or predicting similar measurements through other methods) (364). In this study, expert group opinion is assumed to have higher validity than individual opinion (321). Such a modified Delphi study with nominal / ordinal questions may also have superior content validity than one with an entirely qualitative first round, where bias may be higher (321, 368).

The feedback process supported construct validity as participants could consider / check previous results, with successive rounds assuming concurrent criterion-related validity (321). Additionally, controlled feedback prevented participants from becoming overwhelmed with new information, which in itself can affect consensus

(333). However, it has also been argued that the influence of group think (a cognitive bias where consensus is reached to maintain harmony without critical reasoning (369)) can create the “bandwagon effect” (where individuals join the perceived majority (370)), and that high levels of agreement might reflect this phenomenon (371).

4.10.9.3 Trustworthiness

Since reliability and validity are difficult to measure in Delphi studies, it has been recommended to apply approaches used to test rigour in qualitative studies instead (321, 328, 333). Trustworthiness refers to credibility (believability and accuracy), dependability (stability of results), confirmability (objectivity / neutrality) and transferability (generalisability) (336, 372). The credibility of this study is increased by the expertise of the panellists (324), as well as the numerous rounds and feedback process, which can be considered member checking (333, 373). The diversity of the panel improves transferability and dependability, with the latter supported further by statistical tests proving stability between rounds. The transparent study methodology and reporting reinforces its confirmability, and the anonymisation of participants from each other reduced participant bias, supporting neutrality.

4.10.10 Strengths and limitations

The strengths of this study are the transparent, robust methodology (315, 322). The questionnaire was developed from critical literature reviews and the opportunity for free text responses was provided where possible, including the opportunity for participant responses to limit potential researcher biases, and promote alternate / contradictory suggestions (312, 324). Clear processes were employed in analysing and presenting group responses, particularly regarding consensus, stability, and terminating criteria (315).

The expert groups were quite large, and quite diverse in nature (countries, disciplines, experience), which increased the scope and representation of results (315). The variety of age, sex, and affiliation was also influential (374), as such cognitive diversity promotes robust outcomes (311), whilst anonymity minimised bias and dominant influence from certain group members (315, 322).

The study also uniquely included representation from PPI / patient advocacy groups. The contribution of PPI in research is increasingly supported (311), yet guidelines on identifying and incorporating their preferences into survivorship care are lacking (375, 376). Hence, inclusion in this study is particularly valuable. Indeed, Delphi studies that are able to build consensus between professionals and patient advocates can support information exchange and prevent misunderstandings, helping to identify the best way forward (325).

Attrition is often high in e-Delphi studies (315), and at least 70% retention per round is recommended to ensure rigour (340). This study's high response / completion rate (over 90%) therefore improves the project's credibility (339). Notably, this is generally higher than other studies, where median responses are reported to be 72-92% in the first round and 87-90% in the last (311). Furthermore, the large sample size (for a Delphi study) reduced the impact of non-responders on results (312).

However, the study has limitations. A Delphi study's constructivist nature (knowledge development through reflection and active construction (377)) is inherently limiting (310), with findings representing one group of experts at one time (321), so results must not be overinterpreted (333). Indeed, potential differences relating to geographic location or discipline within the group remain unknown. The study panels were skewed towards western European countries, and physicians, which may have influenced results. Greater representation from non-clinical professional experts (such as management) may have been valuable (311), and from PPI / patient advocacy groups (who are more likely to change their views during the Delphi process (325)).

Additional research should corroborate these results (333). The opinions of people who have or had cancer should be sought regarding cancer survivor terminology, particularly those on treatment, and those with advanced / metastatic cancer, who have been underrepresented in previous research, especially within Europe. A selected diverse expert group with patient advocacy representation should build upon the care-related consensus statements generated (310), before application within a model of care.

Finally, this study does not deal with the roles of oncology and primary care practitioners, which will both differ and overlap to some extent with the suggested

roles of SPCS. Given the expanding need for prevention and surveillance (through primary care, and to an extent oncology) and anticancer treatment delivery (through oncology), these services cannot absorb the increasing burden of cancer-related unmet needs, especially as complexity also grows. Collaboration and coordination between services is essential.

4.10.11 Implications of study

4.10.11.1 Clinical services and care provision

This is the first study clarifying expert opinion about the role of SPCS for people with stable advanced / metastatic cancer and people living beyond cancer. These results will help to determine the most appropriate role for SPCS towards improving the quality of life of people who have or had cancer within the constraints of their skills and resources. While the process was undertaken in Europe, the findings are likely to be relevant in other jurisdictions.

4.10.11.2 Research and education

The anticipated impact is effective knowledge translation to develop a European expert consensus-based model of care, to be evaluated in feasibility studies and RCTs. Areas for educational development in SPC curricula have also been identified, relevant to current and recommended extended practice. Additionally, misperceptions about the role of SPCS equating to end of life care continue to be impactful, and pose a barrier to service extension. Other healthcare professionals, as well as people who have or had cancer, require greater clarification if such service extension is to be understood.

4.10.11.3 Resources and policy

Any increase in SPC service provision will ultimately require greater resources. It is asserted that SPCS do not currently have the capacity for service expansion without compromising the care already provided (215), and so dedicated funding and resources will be necessary (169), which will need to be supported and sustained by changes in healthcare policy (192).

4.11 Conclusion

The ongoing care of people who have or had cancer has become a major healthcare (and health economic) issue in Europe and beyond. Currently, these groups of individuals have unmet needs, which need to be addressed in optimal, achievable and cost-effective ways. Improving this situation will require major changes in healthcare policy, service funding, service provision (including novel models of care), and training of healthcare professionals. Importantly, services need to be tailored to the relevant population, and take into consideration the locally available resources (and their training / experience).

In this unique e-Delphi process, European oncology and specialist palliative care experts demonstrated agreement that the term cancer survivor should be applied to people who have completed anticancer treatment and have no evidence of disease, and that application to people with active cancer should be reconsidered. They also felt that pragmatic (factual) categories may be more useful in terms of providing tailored care for people who have or have had cancer. Consensus statements have also been generated about the core functions of SPC, and their potential extended role for individuals with a history of cancer and no evidence of disease, and individuals with stable locally advanced / metastatic cancer. These will be used to develop an expert consensus-based European model of care for the role of SPCS for people who have or had cancer.

Chapter 5: Palliative care and Oncology Survey on Terminology (POST): what do individuals known to palliative care and oncology services think about the terminology used to describe them?

5.1 Abstract

Introduction

The choice of words used to describe people with cancer is a divisive issue. One of the most widely used definitions from the NCI states that, “an individual is considered a cancer survivor from the time of diagnosis through the balance of life. There are many types of survivors, including those living with cancer and those free of cancer”. This definition is widely quoted, and often used in clinical practice and research. Anyone with cancer, or a history of cancer, may thus be described as a cancer survivor. However, the perception of people with active cancer towards the term is largely unexplored.

The aim of this study is to determine the perceptions of heterogeneous groups of people with cancer regarding the terminologies used to describe them, in particular cancer survivor, and identify associated personal and clinical characteristics.

Methods

This was a multicentre, cross-sectional, survey-based observational study. A study-specific questionnaire was developed based on literature reviews and revised according to feedback from professional experts and PPI representatives. The two target groups were people with cancer known to specialist palliative care (SPC group), and people with cancer on anticancer treatment (Onc group). Convenience sampling was used, and people known to hospice units, community or hospital palliative care services, and / or oncology services (inpatient or outpatient) across Ireland and the UK were invited to participate by their clinical teams between September 2023 and October 2025. Participants completed the paper-based questionnaire by themselves or supported by the researcher. Data analysis was carried out using SPSS. Descriptive statistics were used to describe participant characteristics and preferences regarding different terminologies. The Mann-Whitney U test compared views between the SPC and Onc groups. Binary logistic regression was applied within two models (A: personal characteristics; B:

clinical / cancer-related characteristics) to identify factors associated with dislike of the term cancer survivor.

Results

The questionnaire was completed by 1328 people with cancer (610 in SPC group; 718 in Onc group). The samples varied in gender, relationship status, educational attainment, ECOG status, and cancer diagnosis. The majority had a White ethnic background. Most SPC participants were not on anticancer treatment (60.7%), and most Onc participants were receiving palliative-intent treatment (62.5%).

Overall, 618 (46.5%) disliked being described as a cancer survivor, 401 (30.2%) liked the description, and 309 (23.3%) were neutral. Controlling for other personal demographics, living in Ireland (OR 2.134 (95% CI 1.690-2.694), $p<0.001$) and high educational attainment (OR 1.422 (95% CI 1.071-1.889), $p=0.015$) were associated with disliking the term. Controlling for other clinical characteristics, SPC group status (OR 1.388 (95% CI 1.081-1.782), $p=0.010$) and ECOG status ≥ 2 (OR 1.289 (95% CI 1.008-1.649), $p=0.043$) were associated with disliking the term, and having a cancer diagnosis within the “other” cancer type category (OR 0.581 (95% CI 0.409-0.827), $p=0.003$) was negatively associated. Other factors had significance within certain regional subgroups. Cancer survivor was the only terminology which showed a significant difference between group opinions ($U = 253265.500$; $p<0.001$). “Oncology patient” was the most favoured term in both SPC (liked by 48.5%) and Onc (liked by 52.6%). Most participants considered the choice of term to be important (65.6%).

Conclusion

In this unique survey-based study, more people with cancer known to SPCS, and more people with cancer on anticancer treatment, disliked being described by the term cancer survivor compared to the proportions that liked the term. This suggests that application of cancer survivor to people with active cancer should be reconsidered, and that other terms, such as oncology patient, may be more acceptable within these groups.

5.2 Introduction

The choice of words to describe people with cancer has long been debated (90, 247), and individual preferences vary between healthcare settings / contexts and illnesses / diseases (247). The common and familiar word patient used to be universally applied to people using healthcare services (247). However, current perspectives associate it with passivity or lack of control (378), and it is considered more acceptable amongst people undergoing treatment rather than beyond (291). Alternative phrases including client, consumer, customer and service user may be more empowering by promoting balance between people and their healthcare providers (379), but these can also be inappropriate across healthcare settings with variable resources since they suggest choice / control (which is not always the case). There has also been movement away from disease-first language such as cancer patient to person-first language (that is, “person with” (307, p.1053)) in clinical as well as academic settings, with the aim to improve patient-clinician relationships, trust and confidence (307). Indeed, the term “living with cancer” (102, p.6) has been particularly advocated for being more accurate and positive (84), and is considered acceptable, appropriate and useful by the individuals themselves (285, 380), although the phrase lacks conciseness and may be challenging to translate (381). Nevertheless, it has been further supported by the popularised phrase “living with, through and beyond cancer” (102, p.1) which describes the whole time after a cancer diagnosis (102). As previously discussed, cancer survivorship can also be used to describe this period.

Chapters 1 and 3 have demonstrated the lack of standardised meaning attributed to cancer survivor terminology. In summary, historically a cancer survivor was someone still alive five years after diagnosis (227). Following the suggestion from Cancer Nation (75), a cancer advocacy organisation, that cancer survivors included anyone living with or beyond cancer, other organisations adopted this idea, leading to one of the most widely used definitions applied in clinical and academic practice from the NCI (17). This states that, “an individual is considered a cancer survivor from the time of diagnosis through the balance of life. There are many types of survivors, including those living with cancer and those free of cancer” (17). Thus, anyone with cancer, or a history of cancer, meets the criteria to be a cancer survivor. This includes individuals who are still receiving anticancer treatment (irrespective of treatment intent), and people with advanced cancer,

including those receiving palliative care. Indeed, recent years have seen growing advocacy for survivorship care for people with advanced / metastatic disease (302, 304, 306).

It has been highlighted previously that cancer survivor was not designed to be a label since not everyone with a history of cancer would subscribe to it (17). Its use has certainly divided opinion, and a previous systematic review used pooled results of forced-choice questions to demonstrate the split between those who endorsed (53.6%) and rejected (46.4%) the identity (90). However, as Chapter 3 revealed, the perception of people towards the term has been sought for a variety of groups (90, 247, 249), but only a minority of studies included individuals on anticancer treatment (249-252, 256, 266, 275, 282-285, 288, 294, 296, 299). Even so, when included, they remained under-represented (249, 250, 252, 282, 288), and were only rarely analysed separately (249, 285). No previous study has assessed the perceptions of people with cancer known to SPCS, who likely have advanced / progressive disease (and may be on anticancer treatment, or have no further treatment options). Importantly, individuals are likely to subscribe to different identities at different times (279, 290), and so results from previous studies cannot be generalised to other groups. Nevertheless, the term's widespread use continues in education, research and clinical practice, risking the alienation of individuals who do not endorse the term.

5.3 Aims and objectives

The Palliative care and Oncology Survey on Terminology (POST) seeks to better understand the views of heterogeneous groups of people with cancer on anticancer treatment (with an uncertain prognosis), and especially people with advanced / progressive disease (with a limited prognosis) towards the terms used to describe them, in particular cancer survivor. It is hypothesised that most of these individuals will moderately or strongly dislike the NCI's definition of cancer survivor (17) and the term being applied to them. Results would have important implications for the ongoing application of cancer survivorship terminology. The specific objectives are outlined in Box 11.

Box 11: POST study objectives.

Primary objective

To determine the perceptions of individuals with cancer known to SPCS, and individuals with cancer on anticancer treatment, regarding the term cancer survivor.

Secondary objectives

To determine the perceptions of these individuals about which groups of people with cancer or a history of cancer should be known as cancer survivors.

To determine the perceptions of these individuals about the NCI's widely used definition of cancer survivor (17).

To determine the association between perception towards the term cancer survivor and phase of cancer illness (including anticancer treatment type / intent), cancer diagnosis and performance status.

To determine the association between perception towards the term cancer survivor and personal demographics including country of residence, age, gender, relationship status, educational attainment, and ethnicity.

To determine the perceptions of these individuals towards the terms patient, client, consumer, customer, service user, oncology patient, cancer patient, patient with cancer, and person living with cancer.

To identify the level of importance these individuals attribute to the terms used to describe them.

5.4 Methods

This study is reported according to the Checklist for Reporting Of Survey Studies (CROSS) (382).

5.4.1 Study design

This was a multicentre, cross-sectional survey-based observational study carried out in six sites in Ireland and 19 sites in the UK. A study-specific English language questionnaire was developed and revised according to feedback from professional experts and PPI representatives. The two target groups were people with cancer known to SPCS, and people with cancer on anticancer treatment.

5.4.2 Data collection methods: questionnaire

5.4.2.1 Rationale for choice of questionnaire

As discussed in Chapter 3, the perceptions of people towards the term cancer survivor have previously been explored through various quantitative and qualitative methodologies for other target groups. A study-specific questionnaire was chosen as the data collection tool to enable more individuals to participate and produce comparable factual and attitudinal results of adequate power. Additionally, since this study recruited individuals with cancer known to SPCS and individuals with cancer on anticancer treatment, a short one-off questionnaire sought to minimise participant burden.

5.4.2.2 Questionnaire content

The questionnaire consisted of a researcher section (two questions) and three participant sections (22 questions). All participants completed the same questionnaire but were separated into two groups according to inclusion criteria: Group 1; individuals with cancer known to SPCS (hereafter in this chapter referred to as SPC group), and Group 2; individuals on anticancer treatment (hereafter in this chapter referred to as Onc group). Some overlap between the two groups was anticipated. The questionnaire is provided in the Case Report Form (CRF) in Appendix 6a.

5.4.2.2.1 Researcher section

The researcher completed two questions on current anticancer treatment, and, if applicable, current anticancer treatment intent. Options were based on cancer treatment types as defined by the NCI (383) and the WHO (384), and cancer

treatment / systemic anticancer therapy drug regimen intent categories from the National Health Service (UK) data model and dictionary (385), with feedback from collaborators working in oncology.

5.4.2.2.2 Participant sections

The questionnaire had three participant sections: personal and clinical / cancer-related demographics, general terminologies, and cancer survivor terminology.

Section 1: Personal and clinical / cancer-related characteristics

Participants were asked their country of residence, age, gender, relationship status, highest educational attainment and ethnicity, their cancer diagnosis, and to determine their own Eastern Cooperative Oncology Group (ECOG) Performance Status (PS) (Box 12) (386). CRFs were amended for the UK for educational attainment and ethnicity questions, given the different educational systems and standards for recording ethnicity.

Box 12: ECOG PS (386).

- | |
|---|
| <p>0 - Fully active, able to carry on all pre-disease performance without restriction</p> <p>1 - Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work</p> <p>2 - Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours</p> <p>3 - Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours</p> <p>4 - Completely disabled. Cannot carry on any selfcare. Totally confined to bed or chair</p> |
|---|

Section 2: Questions on general terminologies

Participants were asked their opinion about being described as a patient, client, consumer, customer, service user, oncology patient, cancer patient, patient with cancer, and person living with cancer, by selecting a response from a Likert scale (options: strongly dislike, moderately dislike, neutral, moderately like, or strongly like). Participants were then asked the importance they attribute to the choice of term used to describe them as someone who uses healthcare services, selecting from another five-point Likert scale (options: very unimportant, slightly unimportant, neither important nor unimportant, slightly important, very important).

Section 3: Questions on cancer survivor

Participants were asked to select which of the following groups, in their opinion, should be called cancer survivors: a) any individual with a diagnosis of cancer; b) individuals who are still receiving anticancer treatment; c) individuals who have just completed anticancer treatment, and still have some known cancer present; d) individuals who have just completed anticancer treatment, and have no known cancer present; e) individuals who completed anticancer treatment at least 1 year beforehand, and have no known cancer present; f) individuals who completed anticancer treatment at least 5 years beforehand, and have no known cancer present; g) individuals who completed anticancer treatment at least 10 years beforehand, and have no known cancer present; h) individuals who have progressive / worsening cancer, and have no other anticancer treatment options; i) the term should not be used for any individual.

Participants were then provided with the definition of cancer survivor according to the NCI (17) and asked how much they liked the definition and being described as a cancer survivor themselves, using the same Likert scale as section 2 (options from strongly dislike to strongly like). Finally, participants were asked if they had any comments about the term cancer survivor (open-ended item).

5.4.2.3 Questionnaire design

The questionnaire was designed using recommendations for survey development in medical education and research (387-392), as well as outcomes from the

scoping review of the meaning and acceptance of cancer survivor (Chapter 3). As previously noted, there is great heterogeneity in the methods used to determine endorsement of terminology used to describe people with cancer, and the study populations in POST had not been targeted before, so a study-specific questionnaire was developed.

5.4.2.3.1 Content design

The researcher section regarding anticancer treatment status and treatment type was included since there is limited evidence about differences in opinion towards cancer survivor according to these factors. Treatment intent has not been specified in previous studies (249-252, 256), but likely has relevance since the anticipated outcome of treatment (that is, to be cured or not) has the potential to impact perceptions. Indeed, expectations surrounding the risk of cancer recurrence have proven to be influential (256, 277). Earlier research also demonstrated that receiving chemotherapy can be linked to positive endorsement of cancer survivor (253, 258, 277), whereas those who had undergone radiation therapy were less likely (258), and so current cancer treatment type was also collected.

Regarding section 1, previous studies have shown there are significant associations with individuals' perceptions about medical terminologies and age (249, 250, 252, 293) and gender (256). The relevance of relationship status (260, 262, 263, 267), socioeconomic status (260, 263, 267) and ethnic background (247, 250, 276, 300) have also been proven. These factors would also determine sample diversity. The ethnicity section was localised according to regional standards; Ireland as defined by the Central Statistics Office Ireland (393) and UK by the Office for National Statistics (394).

To determine participants' socioeconomic status (such as income, housing status and occupation), the European Commission's European Socio-economic Groups classification (395) was considered too burdensome and intrusive. Educational attainment was selected since it is commonly included in formal socioeconomic evaluations and typically correlates with other indicators (396, 397). Self-reported and easily measured, it is also more likely to be disclosed than other domains such as income (397). Additionally, other studies have demonstrated that

endorsement of cancer survivor is associated with lower educational attainment (256, 257, 296). The United Nations Educational, Scientific and Cultural Organisation's International Standard Classification of Education (ISCED) 2011 (398) is acceptable to allow participants to self-report educational attainment and to generate cross-comparable data using a recognised categorical system (Box 13). Localised descriptions for each code of educational attainment were developed using resources from national educational organisations / official educational policies, with feedback from collaborators from each region (including educational experts). The Department of Education (399) and Department of Further and Higher Education, Research, Innovation and Science (400) were used for Ireland, and the UK Government national curriculum (401) and Education Scotland (402) were used for the UK.

Box 13: ISCED 2011 (398).

ISCED 0 = Early childhood education

ISCED 1 = Primary education

ISCED 2 = Lower secondary education

ISCED 3 = Upper secondary education

ISCED 4 = Post-secondary non-tertiary education

ISCED 5 = Short-cycle tertiary education

ISCED 6 = Bachelor's degree or equivalent tertiary education level

ISCED 7 = Master's degree or equivalent tertiary education level

ISCED 8 = Doctoral degree or equivalent tertiary education level

Collecting information on cancer type was considered important to identify diversity of sample, particularly since earlier studies have shown that groups differ in their perceptions about cancer survivor according to cancer diagnosis: for example, individuals with prostate cancer (253, 259) identify less with the term compared to individuals with breast cancer (90, 254, 256, 275, 277). PS was collected as the research to date has not assessed the impact of a person's

functional ability on endorsement of cancer survivor. The ECOG PS (386) scale ranges from zero (no limitations to function) to four (bedbound) (Box 12) and is widely used to measure PS in people with cancer, including in prognostic estimation (403). Patients and healthcare professionals generally agree on ECOG PS assessments (404), supporting participant self-reporting using the ECOG PS scale in this study (405).

In section two, participants were asked their opinion on terms identified from a literature review on studies assessing the perceptions of individuals about the healthcare terms used to describe them (90, 247, 292). Individuals can simultaneously endorse more than one term, so participants were asked their views on each separately. The level of importance that participants attributed to the choice of term was also evaluated, since evidence of this is limited: a single earlier study identified that 51.6% of people with a history of colorectal cancer (most post-treatment) deemed the choice of term to be important (249). Another five-point Likert scale was utilised, maintaining consistency in question style, with construct-specific responses designed to reinforce the question (390).

Options in section three for groups that should be defined as cancer survivor were developed from Chapter 3's literature review. Notably, the time frames post-treatment subscribe to historical oncology survival statistics (227), as well as the meaning of cancer survivor according to people with a history of cancer (252, 254, 256, 258, 260, 264, 271-273, 278, 280, 291, 294, 298).

The majority of questions were closed questions to enable statistical analysis (391). A free text box is recommended at the end of questionnaires (406), and so a final open-ended item was included for participants to highlight any issues particularly important or relevant to them, and to further understand their perception about cancer survivor through qualitative processes.

5.4.2.3.2 Item design

The items follow principles of effective survey design (387). The questionnaire and its questions were short and straightforward, reducing cognitive demand and error, and maintaining motivation (390, 391, 406). Its three parts also had cognitive similarities, aiding completion. Items were presented as questions (rather than statements) one at a time, largely using positive language (negative language

increases cognitive demand) (387, 391, 407), and there was consistency of measurement purpose and perspective (391). The questions on terminology were also arranged from general to more specific (391), encouraging participants to consider their opinion more deeply, finishing with questions on cancer survivor terminology.

5.4.2.3.3 Item design: responses

A scale incorporates related options that measure the same idea / objective (392), through which participants can express a range of views, whilst maintaining clarity of meaning and improving quality (408, 409), reflecting the range of participant responses more effectively than dichotomous yes / no options (410). Certainly, it has been suggested that a dichotomous approach cannot be applied to cancer-related identities as the notion is more complex (275). Five-point scales are recommended in questionnaires to aid stability and reliability of responses (387, 391, 408), and more options could cause frustration (409). Five options also remain appropriate when conducting the questionnaire verbally / over the phone (411) (an option in this survey). Additionally, verbal labels were chosen rather than numerical responses, promoting standardised meaning / understanding between respondents (412). All scales in the questionnaire also consistently incorporated bipolar options, rather than switching between unipolar and bipolar options (413). The alternative of asking participants to rank preferences would have been more cognitively demanding (414), which was purposefully minimised for the target groups.

The Likert scales asked individuals to choose how much they like / dislike the options, instead of selecting their level of agreement with statements, which is associated with lower quality (415), greater acquiescence bias (the tendency to respond positively irrespective of content (416)) and satisficing (the encouragement of minimal effort (387)). Construct-specific options that relate to the question are more effective approaches at emphasising the question's purpose (407, 412, 414), applied in asking participants about the importance of the issue (Appendix 6a, question 2.10).

The item formats relate to the questions, and a tick all that apply approach was chosen for one question given the list was short and it was likely that most

participants would complete the questionnaire alongside a researcher, especially in the SPC group. Although the question style could have used a forced-choice format (yes / no) for each statement instead to eliminate uncertainty about whether options not selected were missed (414), the approach selected supported ease and remained satisfactory.

5.4.2.3.4 Questionnaire format

The questionnaire was designed to be completed by participants or the researcher, according to participant preference. The intended form of questionnaire delivery influenced its physical layout (391), which can impact response and engagement (406). Consistent formatting and spacing was used for response options, aligning the visual, numeric and conceptual mid-points (387, 414, 417), thus reinforcing the equality of options and reducing visual bias (418). Where possible, options were also in either single rows or columns to minimise confusion (387).

Although it is typical to place the most important questions early in the questionnaire to ensure completion (387), it is also advisable to present sensitive items later (387). Questions regarding cancer survivor were considered both most important and most sensitive (more so than demographic questions, which typically appear at the end of questionnaires (387)). Cancer survivor questions were therefore inserted conclusively, allowing for the development of rapport and engagement before their introduction (419). They also naturally follow the section on generic terms, supporting cognitive flow. The short nature of the survey meant it was unlikely that participants would be too fatigued by section 3 to complete it.

5.4.2.3.5 Questionnaire revision

The questionnaire was reviewed by a group of clinical and academic palliative care and oncology professionals, a number of non-healthcare professionals, and by the Voices4Care (PPI group of the AllHPC), prior to implementation (392). This ensured the questions were appropriate, straightforward and applicable to all potential respondents and completable within the desired timeframe. Minor adjustments were made to two questions to improve clarity, alongside a formatting change.

Development of the survey content could have been supported by interviews or focus groups, in addition to literature reviews (392), and likewise the survey design through cognitive interviewing of potential participants, or a formal pilot phase (391, 392). However, it would have been challenging to recruit additional participants for a pilot, burdensome for the individuals involved, and time-consuming within the study timeline. The formerly described process through the Voices4Care was therefore deemed appropriate for this study.

5.4.3 Sample characteristics

5.4.3.1 Study setting

Participants were recruited through palliative care and oncology services in Ireland and the UK. In Ireland, the study sites were Our Lady's Hospice & Care Services, St James's Hospital, St Vincent's University Hospital, Marymount Hospice, the South East Palliative Care Centre, and the Community Specialist Palliative Care Services Laois / Offaly. One other site was established, but did not contribute to recruitment due to local issues. In the UK, the study sites were Royal Surrey NHS Foundation Trust, Clatterbridge Cancer Centre NHS Foundation Trust, Norfolk and Norwich University Hospitals NHS Foundation Trust, University Hospital Southampton NHS Foundation Trust, Royal Marsden NHS Foundation Trust, Royal Cornwall Hospitals NHS Trust, St Raphael's Hospice, Bury Hospice, St Columba's Hospice Care Edinburgh, Duchess of Kent Hospice, South Oxfordshire Community Palliative Care Hub, Princess Alice Hospice, Hospiscare (Devon), Cornwall Hospice Care, Saint Francis Hospice, St Wilfrid's Hospice, Pilgrims Hospice, Teesside Hospice and Northern Ireland Hospice. Two other sites were established, but did not contribute to recruitment due to local issues.

5.4.3.2 Participants

The study's two target groups and their inclusion and exclusion criteria are outlined in Box 14.

SPC group: Individuals with a diagnosis of cancer known to SPCS

Inclusion criteria:

- Diagnosis of cancer
- Under the care of palliative care services as an inpatient, outpatient, or community patient
- Age ≥ 18 years
- Able to speak / read English (enough to complete questionnaire)

Onc group: Individuals with a diagnosis of cancer receiving anticancer treatment known to oncology services

Inclusion criteria:

- Diagnosis of cancer
- Under the care of oncology services and currently receiving an anticancer treatment regimen of any kind
- Age ≥ 18 years
- Able to speak / read English (enough to complete questionnaire)

Both groups

Exclusion criteria:

- Unable to provide consent
- Unable to complete questionnaire

The reasons for including these groups of individuals in the study have been described above. Individuals in long-term remission were not included as a separate control group since numerous studies have already assessed the perspectives of participants who have completed primary anticancer treatment (92,

250, 253, 254, 257, 259, 260, 262-265, 267-273, 275, 276, 279-281, 287, 290, 293, 294) and / or have no evidence of disease (92, 249, 265, 268, 293). In contrast, there is limited or no data on individuals with advanced disease or those known to SPCS. Additionally, it would have been difficult to identify / recruit people in long-term remission as there are often no dedicated oncology follow-up clinics. The potential was explored through the National Cancer Registry Ireland (NCRI), but this organisation does not hold such data (NCRI, personal email, March 2023). Additionally, other methods of recruitment (e.g. social media, cancer support groups) would be expected to result in a particularly biased sample.

5.4.3.3 Sample size

A sample is a finite number of participants from the study population (420), and its size should be sufficient to allow ethical inference (conclusions about the target population (420)). A similar study from Wee et al. (249) reported that within a group of 122 people with colorectal cancer undergoing anticancer treatment, 56 participants (46.7%) related to the term cancer survivor. It can be assumed that 53.3% did not relate to the term or find it acceptable, and hence that 53.3% did not like the term. A recent study analysing a similar topic and participant group, its results were appropriate to determine the sample size for the POST study (421). It was decided in advance to replace participants who entered the study but did not complete the parts of the questionnaire relevant to the main objectives.

The primary outcome of the POST study was the proportion of individuals within each group that moderately or strongly disliked being described as a cancer survivor. The Onc group in the POST study targeted individuals with a variety of cancer diagnoses on anticancer treatment, so assuming a similar outcome and prevalence to Wee et al.'s study (249), a sample size of 383 participants was selected to provide a 95% confidence interval of +/- 5% for the estimate of the proportion percentage (422-424). It should be noted that there are no analogous results available for the SPC group (individuals with cancer known to SPCS), and so a similar response was assumed. The study therefore aimed to recruit 383 individuals in each group in each country, i.e., 766 in the SPC group, 766 in the Onc group, and 1532 overall.

5.4.3.4 Sampling

Convenience sampling was deemed appropriate given the potentially sensitive nature of the topic (see section 5.4.6 Ethical considerations). In convenience sampling, participants are selected consecutively according to accessibility until the sample size is achieved (420). Any individual known to a service within the inclusion criteria could be invited into the study.

5.4.4 *Survey administration*

5.4.4.1 Recruitment

People known to hospice inpatient units, community palliative care services, hospital palliative care teams and / or oncology services at the study sites listed above were invited to participate by the clinical teams from September 2023 until October 2025. Those who were agreeable were given a Participant Information Leaflet (PIL) (Appendix 6b) and discussed the study with the site researcher before signing a study-specific consent form (Appendix 6c). No incentives were offered for participation. Documentation was adapted according to country and site, and consent was carried out in person at the study site, or via telephone or video conference (with the form returned via post), depending on participant preference or accessibility. Participants then completed a one-off paper Case Report Form (CRF) (Appendix 6a) by themselves or with the researcher.

5.4.5 *Study preparation*

The research team was a group of healthcare professionals working in SPCS or oncology, experienced in undertaking research in these areas and dealing with distress. All researchers attended a meeting with the lead site prior to study commencement where the consent process, study risks, distress protocol and data transfer process were outlined, and the questionnaire was reviewed to minimise inconsistencies in researcher interpretation / understanding (406). Additionally, all researchers had completed training in Good Clinical Practice (425) and data protection regulations (426). Meetings were also held with key members of clinical teams across sites, whose support was required to identify potential participants. Site monitoring was carried out remotely via video conference system.

5.4.6 Ethical considerations

5.4.6.1 Ethical approvals

The study was conducted in accordance with the Declaration of Helsinki (427), and the International Conference on Harmonisation guidance on Good Clinical Practice (425). Institutional Review Board approval was sought for all study sites, outlined in Table 17. Corresponding approval letters can be found in Appendix 7. The study was registered on ClinicalTrials.gov, ID NCT05871996 (available from: <https://clinicaltrials.gov/study/NCT05871996>).

Table 17: Research Ethics Committee outcomes for POST study.

County / region	Research Ethics Committee (REC)	REC Reference ID(s)	Date of full approval
Ireland	St James's Hospital/Tallaght University Hospital Joint Research Ethics Committee	3602	04/12/23
	The Research Ethics Committee of St. Vincent's Healthcare Group	RS23-058	15/09/23
	Clinical Research Ethics Committee of the Cork Teaching Hospitals	ECM 4 (i) 05/03/2024	27/02/24
	Health Service Executive South Eastern Area Research Ethics Committee	24.18	5/6/24
	Health Service Executive Mid-Western Area University of Limerick Hospitals Group Research Ethics Committee	0099	30/9/24
	Health Service Executive Midland Area Research Ethics Committee	RRECB0924AD	25/10/24
UK	London - Surrey Research Ethics Committee	IRAS 328818 – REC REF 23/LO/0834	12/10/2023

	Health and Social Care Research Ethics Committee B	IRAS 338819- REC REF 24- NI-0006-REC	14/02/24

5.4.6.2 Risk assessment

The study was considered low risk with minimal participant burden. Participation was voluntary and written consent was obtained prior to entry. There were no potential adverse impacts on participant health, although they were advised of the risk of discomfort or emotional distress, and that the study could be stopped at any time. If participants became distressed the questionnaire was discontinued, and they were supported appropriately by the researcher with follow-up from the clinical team (if required).

5.4.6.3 Data protection

The study conformed to the General Data Protection Regulations (GDPR) (2018) (426); all data was treated as confidential, and access was restricted to the researchers. Participants were given unique study IDs at the point of entry so data was pseudonymised (426), allowing withdrawal prior to the point of data de-identification. The participant key and paper documentation were securely stored at study sites, and the local research teams uploaded the pseudonymised CRF data onto a secure online platform Research Electronic Data Capture (REDCap) (428). Data checking was encouraged and carried out by local research teams at each site to ensure questionnaire completion and accurate data transfer. Only the lead research team could access the complete dataset. At the end of the study, participant codes were removed from the overall data set, which was stored on a secure hard drive at the overall lead site. Relevant study documentation and data will be securely stored and retained for five years following study completion, when it will be appropriately destroyed.

5.4.7 Analysis: Statistical analysis

Quantitative data analysis was carried out using SPSS software version 30.0.0.0, using similar approaches to comparable studies (249, 250, 252, 277). The data is

presented overall, and / or according to SPC and Onc groups, and country subgroups.

5.4.7.1 Respondent characteristics

Where data was available, recruitment rate was calculated by determining the proportion of people who completed the questionnaire from the total approached by the researchers.

5.4.7.2 Descriptive statistics

The personal and clinical characteristics of participants are presented in tables using counts and proportions for categorical variables, and medians with minimum and maximum for continuous variables. Responses to close-ended questions (Likert scales and tick all that apply) are also presented using counts and proportions.

5.4.7.3 Differences between groups

The Mann-Whitney U Test is a non-parametric test to assess for differences between data from two independent groups by comparing the distribution of ranks, generally reported with median values (351). Although typically used for continuous data, it can be applied to ordinal data (such as the Likert scales used in this study) (429, 430), especially since it does not assume normal distribution (required for the independent samples t-test (351). Although the Chi-square test for independence (which explores relationships between groups with categorical variables) could be used, the importance of ordering of results may be lost, and so rank-based tests are likely more effective for comparisons using ordinal data (429). To control for multiple comparisons and reduce the risk of type I error (concluding that a significant difference exists when it does not), the probability (p) value was adjusted using Bonferroni's correction (353, 355).

5.4.7.4 Relationships among variables

The dependent variable was what respondents thought about being described as a cancer survivor. Binary categorical outcomes were identified representing

whether participants disliked (moderately or strongly) being described as a cancer survivor, and those who answered otherwise.

5.4.7.4.1 Independent variables

Independent variables were chosen based on previous research and clinical importance (see section 5.4.2.3.1 Content design). Regarding personal characteristics, it was predicted that dislike of cancer survivor would be associated with younger age (249, 250, 252), male gender (256), not having a partner (250), higher educational attainment (256, 257, 296), and the most common ethnicity in Ireland and the UK (assuming that European ethnicities may favour the term less than people with North American heritage, and little is known about people from ethnically diverse groups, as described in Chapter 3). Regarding clinical characteristics, it was predicted that dislike of cancer survivor would be associated with SPC group status, cancer types other than breast cancer (90, 254, 256, 275, 277), not being on anticancer treatment, being on palliative-intent compared to curative intent treatment, and having a higher ECOG PS (lower function).

5.4.7.4.2 Bivariate analyses

To identify unadjusted associations with other categorical variables, bivariate analyses were initially undertaken using the Chi-square (χ^2) test for independence (351). Assumptions include independence of study groups, nominal / ordinal variables, mutually exclusive categories within the variables, and at least 80% of cells should have expected frequencies of 5 or more (431). Pearson's chi-square value was reported alongside p-values to determine significance. Where each variable had two categories, Yates' Correction for Continuity was applied, accounting for overestimation in this context (351). If the minimum expected cell frequency assumption was violated, the p-value was determined using Fisher's exact test for variables with two categories (432), and the maximum likelihood ratio Chi-square test for variables with over two categories (431). When a significant difference was observed for variables with more than two categories, adjusted residuals were used to detect which categories contributed to the result (± 1.96 are significant at the 5% level) (433).

Finally, effect size was determined. Effect size refers to the magnitude of the association. The phi coefficient is typically reported for effect size of 2x2 tables but this is unsuitable for larger tables (351). Cramer's V was therefore used for all variables to maintain consistency, accounting for the different degrees of freedom between variables with different numbers of categories (351). Cohen's criteria can generally be applied, but is most appropriate for 2x2 tables (small=0.1, medium=0.3, large=0.50), and larger tables have adjusted thresholds (small=0.07, medium=0.21, large=0.35 for 2x3 tables) (351, 434).

5.4.7.4.3 Logistic regression

Regression is a technique to determine how individual independent variables (categorical or continuous) influence the outcome of another dependent variable (observed event) whilst avoiding confounding factors. The latter can obscure the true association between an independent variable and the outcome because of its own relationship with both, a particular concern in observational studies (435).

The dependent variable in this study was categorical, so logistic regression was indicated (in contrast to multiple regression, which assesses relationships with a continuous dependent variable) (435-437). Logistic regression also requires other assumptions: independence of observations; mutually exclusive and exhaustive categorical variables; adequate sample size; absence of multicollinearity; a linear relationship between continuous independent variables and the logit transformation of the dependent variable (there were no continuous independent variables in this analysis); and absence of influential outliers (435, 437-439).

Multicollinearity exists when independent variables are highly correlated, affecting the model's ability to determine their unique contributions (439). Association measures can be used as a useful screening step when the independent variables are categorical (440, 441), although this is limited in detecting associations between two variables at a time. Therefore, the Chi-square test of independence was used prior to regression modelling (high association determined for statistically significant associations with Cramer's $V > 0.5$ (434)), and removal of the relevant redundant variables was considered (435, 441). Multicollinearity was then checked by design matrix inspection through variance inflation factors (VIF) (measure of how much collinearity influences the variance of regression coefficient

estimates (442)) and condition indices (CI) (measure of stability of regression coefficient estimates (442)), which is commonly undertaken indirectly in logistic regression through linear regression modelling (since this only examines relationships between independent variables and not the dependent variable) (443). The same reference categories were applied as within the logistic regression model, and variables with over two categories were dummy-coded (351). $VIF \geq 5$ and $CI > 30$ were indicative of multicollinearity (442).

An outlier refers to a participant whose actual outcome is considerably different from their predicted outcome, potentially affecting the goodness of fit (435). Outliers can be assessed by examining residuals (the difference between predicted and actual outcomes) (435). In SPSS, the relevant observed groups and predicted probabilities plot generated in logistic regression can be observed alongside a casewise list to detect individual poorly predicted cases (437).

5.4.7.4.3.1 Binary logistic regression

Ordinal logistic regression was considered since hierarchy could be applied to combined dependent variable categories (dislike / neutral / like), and it could be assumed that the independent variables had consistent effect across each cumulative threshold within these categories (proportional odds) (439). However, over 20% of cells in the models had zero frequencies, that is, some categorical combinations were not reflected in participant responses. This remained even when certain categories were pragmatically collapsed (reducing categorical options), particular variables with skewed distributions were excluded (potentially removing the problem), SPC and Onc groups from Ireland and the UK were combined (increasing the sample size), and two models were generated instead of one (personal characteristics, and separately clinical / cancer-related characteristics). Although assumptions were met and the models were deemed significant, the goodness of fit was poor and standard errors were large, so conclusions were likely flawed (444).

Multinomial logistic regression was also trialled (444); it requires a nominal dependent variable with over two categories (351, 438). Similarly, assumptions for the technique held, and despite adequate expected frequencies across included categorical variables, the convergence of the models was again limited by the

absence of certain categorical combinations. Models with three dependent outcomes therefore appeared less suitable for the sample size and independent variables of interest.

Binary logistic regression was therefore used to optimise use of the available data and create models with greater stability and better fit (435). Furthermore, this was appropriate for the primary outcome of interest (determining people who disliked being described as a cancer survivor, from people who felt otherwise). Finally, since models were developed for each of the four groups (SPC and Onc Ireland and UK groups), and the targeted sample size was not reached in all groups, using a dichotomous dependent outcome was most appropriate.

5.4.7.4.4 Model development

Two models were developed to maximise generalisability of outcomes; Model A assessing personal characteristics, and Model B assessing clinical / cancer-related characteristics (435). Additionally, division of variables into two models reduced the likelihood of an overfit model, based on the generally accepted standard that for each independent variable, there should be no fewer than ten outcomes for each dependent variable category (435). The reference group for each variable in the models was determined by the predicted outcome (see section 5.4.7.3.1 Independent variables) (435).

There are three model building approaches: direct (all independent variables are entered simultaneously), hierarchical (variables are prioritised and added sequentially), and stepwise (variables are retained or removed based on statistical criteria) (435, 439). The direct approach was adopted since it was assumed that no variable had greater worth than another (435).

The first model created was for the Onc Ireland group since its target sample size was achieved. The same model was then applied to the other groups, which could be considered internal model validation (435). External validation would involve testing the model in a new study setting (435). However, the purpose of logistic regression in this study was not to develop a model that could help predict an outcome, but rather identify associations with independent variables.

5.4.7.4.5 Interpretation of output

5.4.7.4.5.1 Model fit

The Omnibus Tests of Model Coefficients was used to determine if the overall model was significantly different from the null hypothesis ($p < 0.05$ equates to significance). The Hosmer-Lemeshow Goodness of Fit Test was used to determine how well the model predictions matched the data since it can be easily applied and interpreted, despite being dependent upon group cut-off points ($p \geq 0.05$ equates to good fit) (435).

5.4.7.4.5.2 Individual variables

Results of the outputs of the independent variables in the model are presented as adjusted odds ratios (OR), representing the contribution of that particular variable towards the outcome after adjustment for the other variables in the model, typically reported with 95% confidence intervals (95% CI) as a measure of precision and to determine significance ($p < 0.05$) (435).

5.4.7.4.5.3 Sensitivity analysis

Sensitivity analysis refers to assessing how much the results change according to varied assumptions (437). Sensitivity analyses were not necessary for these models since the outcomes of interest related to identifying factors associated with the binary outcome, not the prediction of that outcome (445).

5.4.8 Analysis: Qualitative analysis

General comments from participants about cancer survivor were analysed using a qualitative descriptive design (446). The process and results for this section are presented in Chapter 6.

5.5 Results – quantitative

5.5.1 Respondent characteristics

From September 2023 to October 2025, 1328 participants completed the questionnaire: 610 participants in the SPC group and 718 participants in the Onc group (693 participants from Ireland and 635 from the UK).

In Ireland, 996 people who met inclusion criteria were approached by the researchers about the study. 708 people completed consent, but only 693 questionnaires were sufficiently completed (15 were incomplete and excluded from analysis). Response rate in Ireland was therefore 69.6%. By subgroup, 460 individuals in the SPC group were approached, 315 completed consent, and 310 completed the questionnaire (response rate 67.4%). Similarly, in the Onc group 536 individuals were approached, 393 completed consent and 383 finished the questionnaire (response rate 71.5%). Reasons for declining to participate included fatigue, lack of interest, and inconvenience. The number approached by clinical staff across all sites was unknown, as details were only retained for individuals approached by researchers. This information was not available for all UK sites.

5.5.2 Participant characteristics

Participant characteristics are outlined in Table 18, according to study group and country. The samples varied in gender, relationship status and educational attainment, but a white ethnic background was most common. Table 18 summarises ethnicities into the most common ethnic background and “other”, but complete results are located in Appendix 8, Supplementary Table S4. No participant selected non-binary / other gender. Most participants in the SPC group had an ECOG status of 2 or higher (76.0%), whereas the majority of participants in the Onc group had an ECOG of 0 or 1 (69.3%). The groups were heterogeneous in terms of cancer type. In both groups, gastrointestinal cancer was most common (29.0% SPC; 25.5% Onc), followed by lung cancer in the SPC group (19.5%), and breast cancer in the Onc group (19.9%). The majority of the SPC group were not on anticancer treatment (60.7%). Most participants in the Onc group were being treated with palliative intent (62.5%), most commonly with chemotherapy (66.9%).

Table 18: Personal and clinical / cancer-related characteristics of POST participants.

	SPC group			Onc group		
	Ireland	UK	Total	Ireland	UK	Total
<i>Number in group</i>	310	300	610	383	335	718
<i>Personal characteristics</i>						
Age median years (range)	68 (22-95)	70 (32-95)	69 (22-95)	59 (27-92)	65 (26 – 89)	61 (26-92)
<i>Gender n (%)</i>						
Female	150 (48.4%)	146 (48.7%)	296 (48.5%)	221 (57.7%)	164 (49.0%)	385 (53.6%)
Male	160 (51.6%)	154 (51.3%)	314 (51.5%)	162 (42.3%)	171 (51.0%)	333 (46.4%)
Non-binary / other	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
<i>Relationship status n (%)</i>						
Single	55 (17.7%)	39 (13.0%)	94 (15.4%)	61 (15.9%)	34 (10.1%)	95 (13.2%)

Married / similar	177 (57.1%)	192 (64.0%)	369 (60.5%)	271 (70.8%)	246 (73.4%)	517 (72.0%)
Divorced / separated	32 (10.3%)	29 (9.7%)	61 (10.0%)	29 (7.6%)	27 (8.1%)	56 (7.8%)
Widowed	46 (14.8%)	40 (13.3%)	86 (14.1%)	22 (5.7%)	28 (8.4%)	50 (7.0%)
<i>Highest educational attainment n (%)</i>						
Less than primary	2 (0.6%)	1 (0.3%)	3 (0.5%)	2 (0.5%)	1 (0.3%)	3 (0.4%)
Primary	58 (18.7%)	1 (0.3%)	59 (9.7%)	30 (7.8%)	0 (0.0%)	30 (4.2%)
Lower secondary	76 (24.5%)	58 (19.3%)	134 (22.0%)	77 (20.1%)	37 (11.0%)	114 (15.9%)
Upper secondary	34 (11.0%)	82 (27.3%)	116 (19.0%)	42 (11.0%)	75 (22.4%)	117 (16.3%)
Post-secondary non-tertiary	23 (7.4%)	46 (15.3%)	69 (11.3%)	38 (9.9%)	60 (17.9%)	98 (13.6%)
Short-cycle tertiary	58 (18.7%)	29 (9.7%)	87 (14.3%)	80 (20.9%)	48 (14.3%)	128 (17.8%)
Bachelor's degree	43 (13.9%)	50 (16.7%)	93 (15.2%)	78 (20.4%)	78 (23.3%)	156 (21.7%)
Master's degree	14 (4.5%)	23 (7.7%)	37 (6.1%)	31 (8.1%)	26 (7.8%)	57 (7.9%)

Doctoral degree	2 (0.6%)	4 (1.3%)	6 (1.0%)	4 (1.0%)	2 (0.6%)	6 (0.8%)
Not otherwise specified	0 (0.0%)	6 (2.0%)	6 (1.0%)	1 (0.3%)	8 (2.4%)	9 (1.3%)
Country n (%)						
Ireland			310 (50.8%)			383 (53.3%)
UK			300 (49.2%)			335 (46.7%)
Ethnicity						
Ethnicity – Ireland n (%)						
White Irish	290 (93.5%)			340 (88.8%)		
Other White	13 (4.2%)			33 (8.6%)		
Other	7 (2.3%)			10 (2.6%)		
Ethnicity - UK (England) n (%)						

English/ Welsh/ Scottish/ Northern Irish/ British		264 (88.0%)			310 (92.5%)	
Other White		14 (4.7%)			10 (3.0%)	
Mixed/ Multiple ethnic groups		4 (1.4%)			2 (0.6%)	
Asian/ Asian British		3 (0.9%)			6 (1.8%)	
Black/ African/ Caribbean/ Black British		1 (0.3%)			6 (1.8%)	
Other ethnic group		0 (0.0%)			1 (0.3%)	
<i>Ethnicity - UK (Northern Ireland) n (%)</i>						
White		14 (4.7%)			0 (0.0%)	
Other		0 (0.0%)			0 (0.0%)	

<i>Clinical / cancer-related characteristics</i>						
<i>ECOG PS n (%)</i>						
ECOG 0	7 (2.3%)	11 (3.7%)	18 (3.0%)	88 (23.0%)	78 (23.3%)	166 (23.1%)
ECOG 1	50 (16.1%)	78 (26.0%)	128 (21.0%)	187 (48.8%)	145 (43.3%)	332 (46.2%)
ECOG 2	78 (25.2%)	87 (29.0%)	165 (27.0%)	85 (22.2%)	71 (21.2%)	156 (21.7%)
ECOG 3	158 (51.0%)	102 (34.0%)	260 (42.6%)	22 (5.7%)	36 (10.7%)	58 (8.1%)
ECOG 4	16 (5.2%)	22 (7.3%)	38 (6.2%)	1 (0.3%)	3 (0.9%)	4 (0.6%)
Not answered	1 (0.3%)	0 (0.0%)	1 (0.2%)	0 (0.0%)	2 (0.6%)	2 (0.3%)
<i>Cancer-related characteristics</i>						
<i>Cancer diagnosis n (%)</i>						
Breast	40 (12.9%)	28 (9.3%)	68 (11.1%)	121 (31.6%)	22 (6.6%)	143 (19.9%)
Endocrine	12 (3.9%)	5 (1.7%)	17 (2.8%)	7 (1.8%)	2 (0.6%)	9 (1.3%)
Gastrointestinal	97 (31.3%)	80 (26.7%)	177 (29.0%)	85 (22.2%)	98 (29.3%)	183 (25.5%)

Gynaecological	33 (10.6%)	26 (8.7%)	59 (9.7%)	23 (6.0%)	30 (9.0%)	53 (7.4%)
Haematological	10 (3.2%)	12 (4.0%)	22 (3.6%)	59 (15.4%)	58 (17.3%)	117 (16.3%)
Head & Neck	16 (5.2%)	14 (4.7%)	30 (4.9%)	14 (3.7%)	19 (5.7%)	33 (4.6%)
Lung	70 (22.6%)	49 (16.3%)	119 (19.5%)	23 (6.0%)	19 (5.7%)	49 (6.8%)
Neurological	3 (1.0%)	7 (2.3%)	10 (1.6%)	0 (0.0%)	4 (1.2%)	4 (0.6%)
Sarcoma	2 (0.6%)	8 (2.7%)	10 (1.6%)	8 (2.1%)	23 (6.9%)	31 (4.3%)
Skin	3 (1.0%)	10 (3.3%)	13 (2.1%)	11 (2.9%)	12 (3.6%)	23 (3.2%)
Unknown primary	0 (0.0%)	7 (2.3%)	7 (1.1%)	1 (0.3%)	0 (0.0%)	1 (0.1%)
Urological	24 (7.7%)	53 (17.7%)	77 (12.6%)	31 (8.1%)	38 (11.3%)	69 (9.6%)
Other	0 (0.0%)	1 (0.3%)	1 (0.2%)	0 (0.0%)	3 (0.9%)	3 (0.4%)
<i>Cancer treatment intent / status n (%)</i>						
Curative-intent	3 (1.0%)	4 (1.3%)	7 (1.1%)	164 (42.8%)	105 (31.3%)	269 (37.5%)

Palliative-intent	121 (39.0%)	112 (37.4%)	233 (38.2%)	219 (52.2%)	230 (68.7%)	449 (62.5%)
Not on treatment	186 (60.0%)	184 (61.3%)	370 (60.7%)			
Current anticancer treatment type n (%)						
Chemotherapy	61 (19.7%)	56 (18.7%)	117 (19.2%)	242 (63.2%)	238 (71.0%)	480 (66.9%)
Hormone Therapy	24 (7.7%)	32 (10.7%)	56 (9.2%)	38 (9.9%)	14 (4.2&)	52 (7.2%)
Immunotherapy	30 (9.7%)	19 (6.3%)	49 (8.0%)	75 (19.6%)	65 (19.4%)	140 (19.5%)
Targeted Therapy	34 (11.0%)	19 (6.3%)	53 (8.7%)	111 (29.0%)	40 (11.9%)	151 (21.0%)
Radiotherapy / Radiation Therapy	9 (2.9%)	17 (5.7%)	26 (4.3%)	16 (4.2%)	40 (11.9%)	56 (7.8%)
Surgery	2 (0.6%)	0 (0.0%)	2 (0.3%)	1 (0.3%)	3 (0.9%)	4 (0.6%)

Key: SPC group = participants with cancer known to specialist palliative care services; Onc group = participants with cancer known to oncology services on anticancer treatment; ECOG PS = Eastern Cooperative Oncology Group Performance Status.

5.5.3 Descriptive results

5.5.3.1 Perceptions towards cancer survivor

Overall, 46.5% (n=618) individuals disliked being described as a cancer survivor (32.8% (n=436) strongly, 13.7% (n=182) moderately). Comparatively, 30.2% (n=401) individuals liked being described by the term (15.3% (n=203) strongly, 14.9% (n=198) moderately), and 23.3% (n=309) felt neutral about the term. Similar attitudes were demonstrated towards the NCI's definition of cancer survivor (17), with 41.5% (n=552) individuals disliking the description (27.3% (n=363) strongly, 14.2% (n=189) moderately), 31.5% (n=418) individuals liking the definition (13.4% (n=178) strongly, 18.1% (n=240) moderately), and 27.0% (n=358) feeling neutral. Table 19 and Figure 8 show the breakdown according to subgroups. Higher proportions disliked both the personal application and the definition in the SPC group than in the Onc group, and in the groups recruited from Ireland compared to the UK.

Correspondingly, Table 20 and Figure 9 show the groups that participants thought should be referred to as cancer survivors. Only minorities selected that any individual with a cancer diagnosis should be called a cancer survivor (SPC 19.8%; Onc 19.1%). Instead, the majority of all groups selected that people who had completed anticancer treatment and had no evidence of disease (irrespective of time since completion) should be called cancer survivors: individuals who have just completed anticancer treatment, and have no known cancer present (SPC 58.4%; Onc 58.8%); individuals who completed anticancer treatment at least 1 year beforehand, and have no known cancer present (SPC 57.7%; Onc 55.0%); individuals who completed anticancer treatment at least 5 years beforehand, and have no known cancer present (SPC 65.7%; Onc 66.0%); and individuals who completed anticancer treatment at least 10 years beforehand, and have no known cancer present (SPC 64.6%; Onc 60.9%).

5.5.3.2 Perceptions towards other terms used in healthcare

Table 21 shows the extent to which participants in each subgroup liked a range of terms used to describe them within healthcare according to subgroup. (Results for all participants combined can be found in Appendix 8 Supplementary Table S5.) Comparisons of proportions of each group that liked and disliked the terms are displayed in Figures 10 and 11 respectively. "Oncology patient" was the most

favoured term in both the SPC group (liked by 48.5%) and the Onc group (liked by 52.6%). The majority of both groups disliked being described as a “client” (70.1% SPC; 69.5% Onc), “consumer” (81.1% SPC; 81.9% Onc), “customer” (85.3% SPC; 82.6% Onc) and “service user” (60.3% SPC; 57.0% Onc). Only minorities disliked being described as a patient (3.5% SPC; 2.2% Onc). There was little difference in views towards the two terms “cancer patient” and “patient with cancer” in either group, although a greater proportion of participants favoured the terms in the SPC group, and most Onc participants otherwise felt neutral (cancer patient: liked by 37.4% SPC; 33.4% Onc; patient with cancer: liked by 40.3% SPC; 35.4% Onc). The term “person living with cancer” was generally liked within both groups (43.4% SPC; 40.1% Onc).

5.5.3.3 Importance of choice of term

The majority of subgroups considered the choice of term used to describe people in healthcare services to be important (Table 22 and Figure 12). Overall, 65.6% (n=871) participants thought the issue was important: 27.9% (n=370) believed it was very important, and 21.2% (n=282) slightly important. Only 13.2% (n=175) respondents considered the choice of words to be unimportant: 7.0% (n=93) very unimportant and 6.2% (n=82) slightly unimportant. The rest were neutral about the issue (21.2%, n=282).

5.5.4 Main findings

5.5.4.1 Differences between groups

Mann-Whitney U tests (U) were carried out to determine differences between the SPC and Onc groups on what they think about being described as a patient, client, consumer, customer, service user, oncology patient, cancer patient, patient with cancer, person living with cancer, and cancer survivor, what they think of the NCI’s definition of cancer survivor, and the importance attributed to the choice of term (Appendix 8 Supplementary Table S6). Five outcomes were significant before Bonferroni’s correction was applied ($p < 0.05$) (353), following which only one outcome had statistical significance ($\alpha = 0.004$): being described as a cancer survivor ($U = 253265.500$; $p < 0.001$).

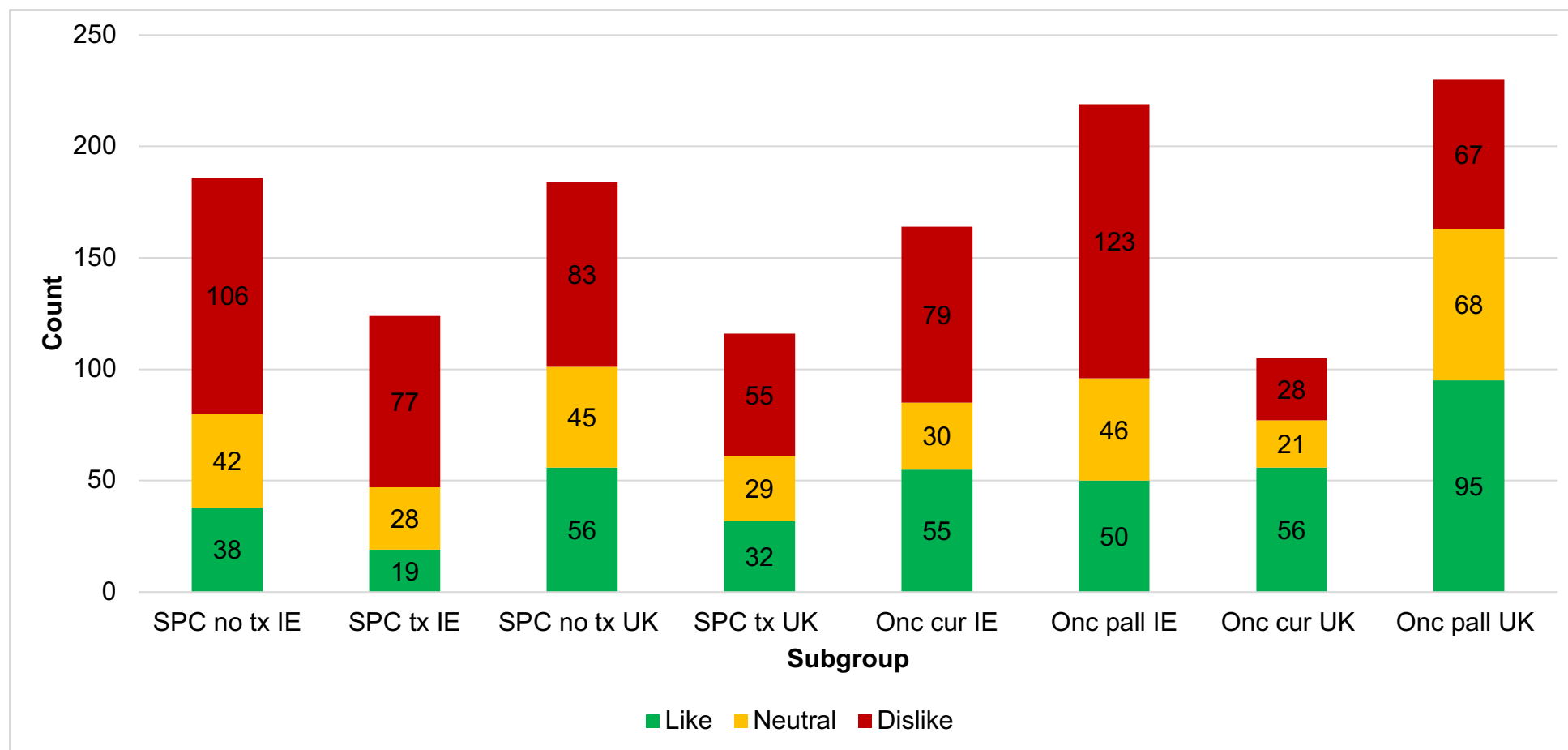
Table 19: Perceptions of participants towards being described as a cancer survivor and the NCI's definition of cancer survivor (17).

	Subgroup		Strongly dislike n (%)	Moderately dislike n (%)	Neutral n (%)	Moderately like n (%)	Strongly like n (%)
Being described as a cancer survivor	SPC	Ireland (n=310)	149 (48.1%)	34 (11.0%)	70 (22.6%)	27 (8.7%)	30 (9.7%)
			183 (59.1%)			57 (18.4%)	
		UK (n=300)	90 (30.0%)	48 (16.0%)	74 (24.6%)	41 (13.7%)	47 (15.7%)
			138 (46.0%)			88 (29.4%)	
		Total (n=610)	239 (39.2%)	82 (13.4%)	144 (23.6%)	68 (11.1%)	77 (12.7%)
			321 (52.6%)			145 (23.8%)	
	ONC	Ireland (n=383)	147 (38.4%)	55 (14.4%)	76 (19.8%)	56 (14.6%)	49 (12.8%)
			202 (52.8%)			105 (27.4%)	
		UK (n=335)	50 (14.9%)	45 (13.4%)	89 (26.6%)	74 (22.1%)	77 (23.0%)
			95 (28.3%)			151 (45.1%)	
		Total (n=718)	197 (27.4%)	100 (13.9%)	165 (23.0%)	130 (18.1%)	126 (17.5%)
			297 (41.3%)			256 (35.7%)	

Definition of cancer survivor	SPC	Ireland (n=310)	116 (37.4%)	29 (9.4%)	92 (29.7%)	41 (13.2%)	32 (10.3%)
			145 (46.8%)			73 (23.5%)	
		UK (n=300)	61 (20.3%)	61 (20.3%)	86 (28.7%)	56 (18.7%)	36 (12.0%)
			122 (40.6%)			92 (30.7%)	
		Total (n=610)	177 (29.0%)	90 (14.8%)	178 (29.2%)	97 (15.9%)	68 (11.1%)
			267 (43.8%)			165 (27.0%)	
	ONC	Ireland (n=383)	141 (36.8%)	47 (12.3%)	88 (23.0%)	61 (15.9%)	46 (12.0%)
			188 (49.1%)			107 (27.9%)	
		UK (n=335)	45 (13.4%)	52 (15.5%)	92 (27.5%)	82 (24.5%)	64 (19.1%)
			97 (28.9%)			146 (43.6%)	
		Total (n=718)	186 (25.9%)	99 (13.8%)	180 (25.1%)	143 (19.9%)	110 (15.3%)
			285 (39.7%)			253 (35.2%)	

Key: SD = Strongly dislike; MD = Moderately dislike; N = Neutral; ML = Moderately like; SL = Strongly like; CS = cancer survivor; SPC = participants with cancer known to specialist palliative care services; Onc = participants with cancer known to oncology services on anticancer treatment.

Figure 8: Stacked bar graph showing what participants think about being described as a cancer survivor according to subgroup.



Key: SPC=participants with cancer known to specialist palliative care services; Onc=participants with cancer known to oncology services on anticancer treatment; no tx=not on treatment; tx=on treatment; cur=curative-intent treatment; pall=palliative-intent treatment; IE=Ireland; UK=United Kingdom.

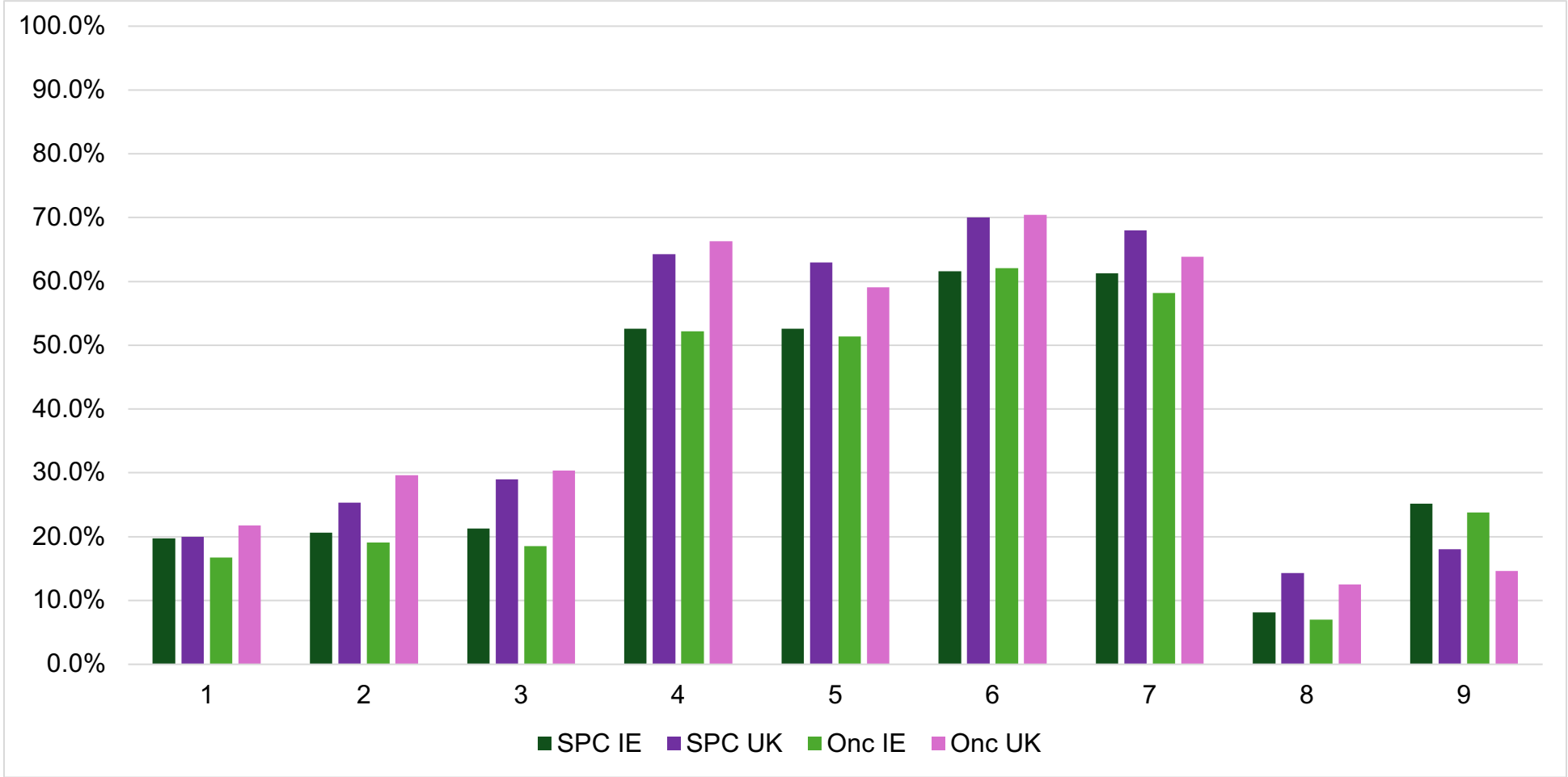
Table 20: Proportions of participants that thought different groups of people with cancer or a history of cancer should be referred to as cancer survivors.

Groups of people with cancer / a history of cancer	SPC			Oncology		
	Ireland (n=310)	UK (n=300)	Total (n=610)	Ireland (n=383)	UK (n=335)	Total (n=718)
1) Any individual with a diagnosis of cancer	61 (19.7%)	60 (20.0%)	121 (19.8%)	64 (16.7%)	73 (21.8%)	137 (19.1%)
2) Individuals who are still receiving anticancer treatment	64 (20.6%)	76 (25.3%)	140 (23.0%)	73 (19.1%)	99 (29.6%)	172 (24.0%)
3) Individuals who have just completed anticancer treatment, and still have some known cancer present	66 (21.3%)	87 (29.0%)	153 (25.1%)	71 (18.5%)	102 (30.4%)	173 (24.1%)
4) Individuals who have just completed anticancer treatment, and have no known cancer present	163 (52.6%)	193 (64.3%)	356 (58.4%)	200 (52.2%)	222 (66.3%)	422 (58.8%)
5) Individuals who completed anticancer treatment at least 1 year	163 (52.6%)	189 (63.0%)	352 (57.7%)	197 (51.4%)	198 (59.1%)	395 (55.0%)

beforehand, and have no known cancer present						
6) Individuals who completed anticancer treatment at least 5 years beforehand, and have no known cancer present	191 (61.6%)	210 (70.0%)	401 (65.7%)	238 (62.1%)	236 (70.4%)	474 (66.0%)
7) Individuals who completed anticancer treatment at least 10 years beforehand, and have no known cancer present	190 (61.3%)	204 (68.0%)	394 (64.6%)	223 (58.2%)	214 (63.9%)	437 (60.9%)
8) Individuals who have progressive/worsening cancer, and have no other anticancer treatment options	25 (8.1%)	43 (14.3%)	68 (11.1%)	27 (7.0%)	42 (12.5%)	69 (9.6%)
9) The term should not be used for any individual	78 (25.2%)	54 (18.0%)	132 (21.6%)	91 (23.8%)	49 (14.6%)	140 (19.5%)

Key: SPC = participants with cancer known to specialist palliative care services; Onc = participants with cancer known to oncology services on anticancer treatment.

Figure 9: Cluster bar graph showing percentages of subgroups that agree that groups of people who have or had cancer should be called cancer survivors.



Key: SPC = participants with cancer known to specialist palliative care services; Onc = participants with cancer known to oncology services on anticancer treatment; IE = Ireland; UK = United Kingdom; see Table 20 for statements 1-9.

Table 21: Perceptions of participants towards being described by a range of terminologies used in healthcare.

Terminology	Subgroup		Strongly dislike n (%)	Moderately dislike n (%)	Neutral n (%)	Moderately like n (%)	Strongly like n (%)
Patient	SPC	Ireland (n=310)	4 (1.3%)	10 (3.2%)	199 (64.2%)	45 (14.5%)	52 (16.8%)
			14 (4.5%)			97 (31.3%)	
		UK (n=300)	2 (0.7%)	5 (1.7%)	109 (36.2%)	74 (24.7%)	110 (36.7%)
			7 (2.4%)			184 (61.4%)	
		Total (n=610)	6 (1.0%)	15 (2.5%)	308 (50.4%)	119 (19.5%)	162 (26.6%)
			21 (3.5%)			281 (46.1%)	
	ONC	Ireland (n=383)	4 (1.0%)	8 (2.1%)	204 (53.3%)	82 (21.4%)	85 (22.2%)
			12 (3.1%)			167 (43.6%)	
		UK (n=335)	1 (0.3%)	3 (0.9%)	130 (38.8%)	65 (19.4%)	136 (40.6%)
			4 (1.2%)			201 (60.0%)	
		Total (n=718)	5 (0.7%)	11 (1.5%)	334 (46.5%)	147 (20.5%)	221 (30.8%)
			16 (2.2%)			368 (51.3%)	

Client	SPC	Ireland (n=310)	114 (36.8%)	101 (32.6%)	75 (24.1%)	12 (3.9%)	8 (2.6%)
			215 (69.4%)			20 (6.5%)	
		UK (n=300)	115 (38.3%)	98 (32.7%)	63 (21.0%)	16 (5.3%)	8 (2.7%)
			213 (71.0%)			24 (8.0%)	
		Total (n=610)	229 (37.5%)	199 (32.6%)	138 (22.7%)	28 (4.6%)	16 (2.6%)
			428 (70.1%)			44 (7.2%)	
	ONC	Ireland (n=383)	164 (42.8%)	117 (30.6%)	71 (18.5%)	20 (5.2%)	11 (2.9%)
			281 (73.4%)			31 (8.1%)	
		UK (n=335)	121 (36.1%)	97 (29.0%)	88 (26.2%)	19 (5.7%)	10 (3.0%)
			218 (65.1%)			29 (8.7%)	
		Total (n=718)	285 (39.7%)	214 (29.8%)	159 (22.2%)	39 (5.4%)	21 (2.9%)
			499 (69.5%)			60 (8.3%)	
Consumer	SPC	Ireland (n=310)	199 (64.2%)	50 (16.1%)	50 (16.1%)	8 (2.6%)	3 (1.0%)
			249 (80.3%)			11 (3.6%)	

		UK (n=300)	174 (58.0%)	72 (24.0%)	41 (13.7%)	11 (3.7%)	2 (0.6%)
			246 (82.0%)			13 (4.3%)	
		Total (n=610)	373 (61.1%)	122 (20.0%)	91 (15.0%)	19 (3.1%)	5 (0.8%)
			495 (81.1%)			24 (3.9%)	
	ONC	Ireland (n=383)	257 (67.1%)	77 (20.1%)	42 (11.0%)	6 (1.6%)	1 (0.2%)
			334 (87.2%)			7 (1.8%)	
		UK (n=335)	168 (50.1%)	86 (25.7%)	61 (18.2%)	13 (3.9%)	7 (2.1%)
			254 (75.8%)			20 (6.0%)	
		Total (n=718)	425 (59.2%)	163 (22.7%)	103 (14.3%)	19 (2.6%)	8 (1.2%)
			588 (81.9%)			27 (3.8%)	
Customer	SPC	Ireland (n=310)	215 (69.4%)	48 (15.5%)	42 (13.5%)	3 (1.0%)	2 (0.6%)
			263 (84.9%)			5 (1.6%)	
		UK (n=300)	190 (63.3%)	67 (22.3%)	32 (10.8%)	7 (2.3%)	4 (1.3%)
			257 (85.6%)			11 (3.6%)	

		Total (n=610)	405 (66.4%)	115 (18.9%)	74 (12.1%)	10 (1.6%)	6 (1.0%)	
			520 (85.3%)			16 (2.6%)		
	ONC	Ireland (n=383)	279 (72.8%)	64 (16.7%)	34 (8.9%)	5 (1.3%)	1 (0.3%)	
			343 (89.5%)			6 (1.6%)		
		UK (n=335)	161 (48.1%)	89 (26.5%)	62 (18.5%)	14 (4.2%)	9 (2.7%)	
			250 (74.6%)			23 (6.9%)		
		Total (n=718)	440 (61.3%)	153 (21.3%)	96 (13.4%)	19 (2.6%)	10 (1.4%)	
			593 (82.6%)			29 (4.0%)		
	Service user	SPC	Ireland (n=310)	123 (39.7%)	54 (17.4%)	94 (30.4%)	33 (10.6%)	6 (1.9%)
				177 (57.1%)			39 (12.5%)	
UK (n=300)			122 (40.7%)	69 (23.0%)	81 (27.0%)	19 (6.3%)	9 (3.0%)	
			191 (63.7%)			28 (9.3%)		
Total (n=610)			245 (40.1%)	123 (20.2%)	175 (28.7%)	52 (8.5%)	15 (2.5%)	
			368 (60.3%)			67 (11.0%)		

	ONC	Ireland (n=383)	140 (36.6%)	68 (17.8%)	124 (32.3%)	37 (9.7%)	14 (3.6%)
			208 (54.4%)			51 (13.3%)	
		UK (n=335)	136 (40.6%)	65 (19.4%)	94 (28.1%)	30 (9.0%)	10 (2.9%)
			201 (60.0%)			40 (11.9%)	
		Total (n=718)	276 (38.4%)	133 (18.5%)	218 (30.4%)	67 (9.3%)	24 (3.3%)
			409 (57.0%)			91 (12.7%)	
Oncology patient	SPC	Ireland (n=310)	16 (5.2%)	27 (8.7%)	136 (43.8%)	93 (30.0%)	38 (12.3%)
			43 (13.9%)			131 (42.3%)	
		UK (n=300)	18 (6.0%)	22 (7.3%)	95 (31.7%)	98 (32.7%)	67 (22.3%)
			40 (13.3%)			165 (55.0%)	
		Total (n=610)	34 (5.6%)	49 (8.0%)	231 (37.9%)	191 (31.3%)	105 (17.2%)
			83 (13.6%)			296 (48.5%)	
	ONC	Ireland (n=383)	10 (2.6%)	26 (6.8%)	168 (43.9%)	121 (31.6%)	58 (15.1%)
			36 (9.4%)			179 (46.7%)	

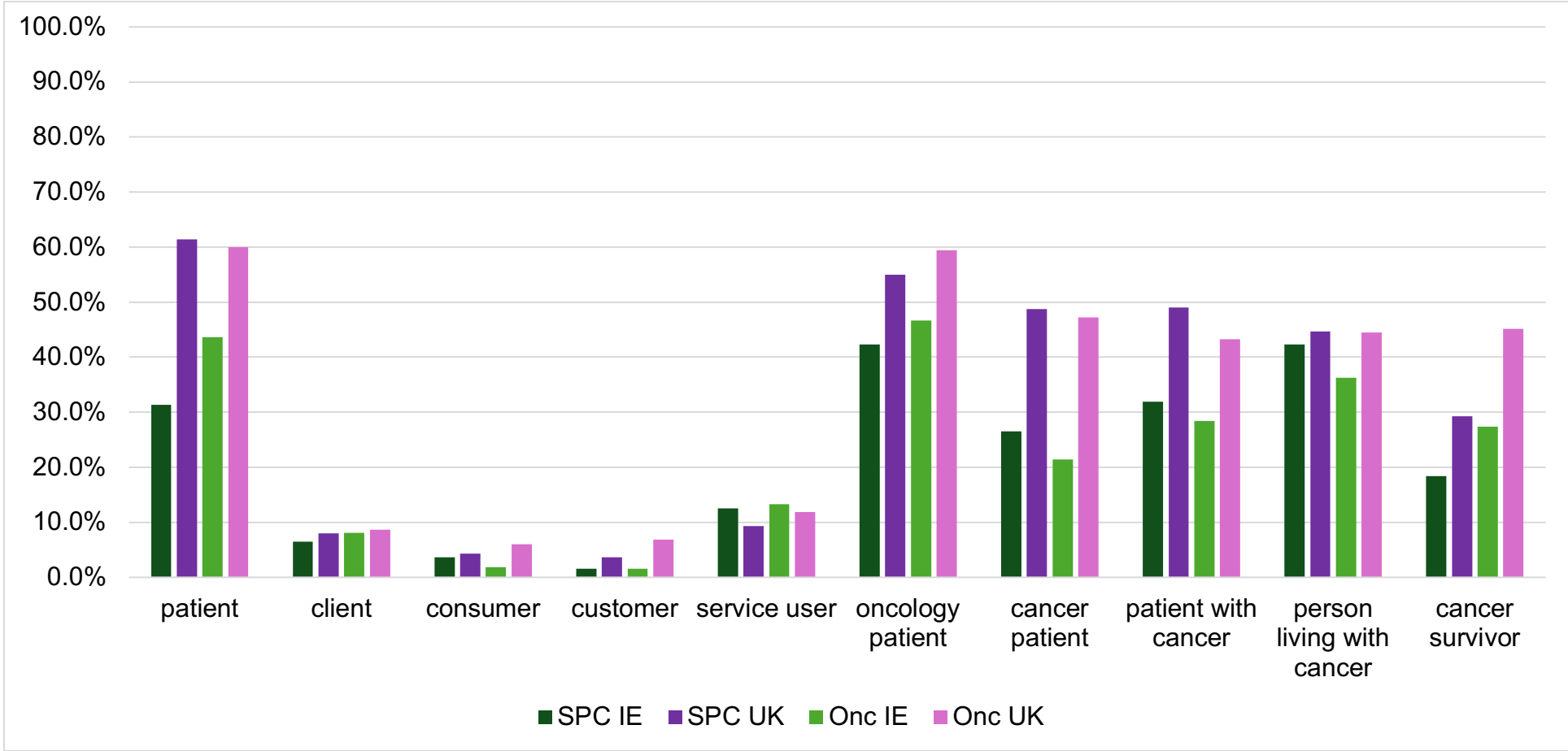
Cancer patient		UK (n=335)	11 (3.3%)	10 (3.0%)	115 (34.3%)	94 (28.1%)	105 (31.3%)	
			21 (6.3%)			199 (59.4%)		
		Total (n=718)	21 (2.9%)	36 (5.0%)	283 (39.4%)	215 (29.9%)	163 (22.7%)	
			57 (7.9%)			378 (52.6%)		
	SPC	Ireland (n=310)	57 (18.4%)	46 (14.8%)	125 (40.3%)	60 (19.4%)	22 (7.1%)	
			103 (33.2%)			82 (26.5%)		
		UK (n=300)	29 (9.7%)	26 (8.6%)	99 (33.0%)	84 (28.0%)	62 (20.7%)	
			55 (18.3%)			146 (48.7%)		
		Total (n=610)	86 (14.1%)	72 (11.8%)	224 (36.7%)	144 (23.6%)	84 (13.8%)	
			158 (25.9%)			228 (37.4%)		
		ONC	Ireland (n=383)	44 (11.5%)	69 (18.0%)	188 (49.1%)	44 (11.4%)	69 (18.0%)
				113 (29.5%)			113 (21.4%)	
			UK (n=335)	15 (4.5%)	32 (9.5%)	130 (38.8%)	78 (23.3%)	80 (23.9%)
				47 (14.0%)			158 (47.2%)	

		Total (n=718)	59 (8.2%)	101 (14.1%)	318 (44.3%)	136 (18.9%)	104 (14.5%)
			160 (22.3%)			240 (33.4%)	
Patient with cancer	SPC	Ireland (n=310)	32 (10.3%)	52 (16.8%)	127 (41.0%)	69 (22.3%)	30 (9.6%)
			84 (27.1%)			99 (31.9%)	
		UK (n=300)	21 (7.0%)	42 (14.0%)	90 (30.0%)	86 (28.7%)	61 (20.3%)
			63 (21.0%)			147 (49.0%)	
		Total (n=610)	53 (8.7%)	94 (15.4%)	217 (35.6%)	155 (25.4%)	91 (14.9%)
			147 (24.1%)			246 (40.3%)	
	ONC	Ireland (n=383)	34 (8.9%)	62 (16.2%)	178 (46.5%)	87 (22.7%)	22 (5.7%)
			96 (25.1%)			109 (28.4%)	
		UK (n=335)	17 (5.1%)	42 (12.5%)	131 (39.1%)	73 (21.8%)	72 (21.5%)
			59 (17.6%)			145 (43.3%)	
Total (n=718)		51 (7.1%)	104 (14.5%)	309 (43.0%)	160 (22.3%)	94 (13.1%)	
		155 (21.6%)			254 (35.4%)		

Person living with cancer	SPC	Ireland (n=310)	45 (14.5%)	29 (9.4%)	105 (33.8%)	80 (25.8%)	51 (16.5%)
			74 (23.9%)			131 (42.3%)	
		UK (n=300)	28 (9.3%)	31 (10.3%)	107 (35.7%)	71 (23.7%)	63 (21.0%)
			59 (19.6%)			134 (44.7%)	
		Total (n=610)	73 (12.0%)	60 (9.8%)	212 (34.8%)	151 (24.8%)	114 (18.6%)
			133 (21.8%)			265 (43.4%)	
	ONC	Ireland (n=383)	60 (15.7%)	42 (11.0%)	142 (37.0%)	78 (20.4%)	61 (15.9%)
			102 (26.7%)			139 (36.3%)	
		UK (n=335)	17 (5.1%)	44 (13.1%)	125 (37.3%)	84 (25.1%)	65 (19.4%)
			61 (18.2%)			149 (44.5%)	
		Total (n=718)	77 (10.7%)	86 (12.0%)	267 (37.2%)	162 (22.6%)	126 (17.5%)
			163 (22.7%)			288 (40.1%)	

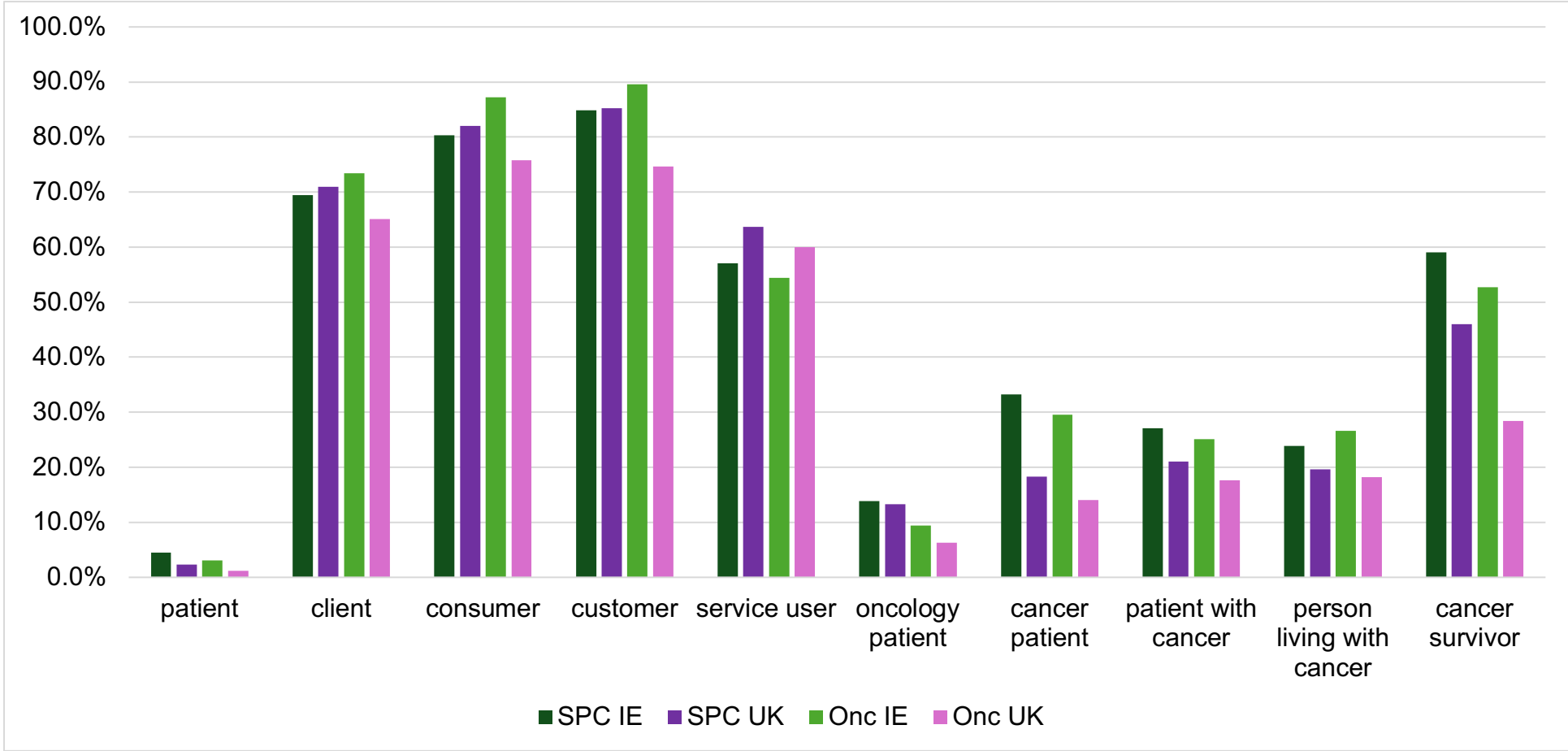
Key: SD = Strongly dislike; MD = Moderately dislike; N = Neutral; ML = Moderately like; SL = Strongly like; CS = cancer survivor; SPC = participants with cancer known to specialist palliative care services; Onc = participants with cancer known to oncology services on anticancer treatment.

Figure 10: Cluster bar graph showing percentages of participants that like being described by different terms used in healthcare according to subgroup.



Key: SPC = participants with cancer known to specialist palliative care services; Onc = participants with cancer known to oncology services on anticancer treatment; IE = Ireland; UK = United Kingdom.

Figure 11: Cluster bar graph showing percentages of participants that dislike being described by different terms used in healthcare according to subgroup.



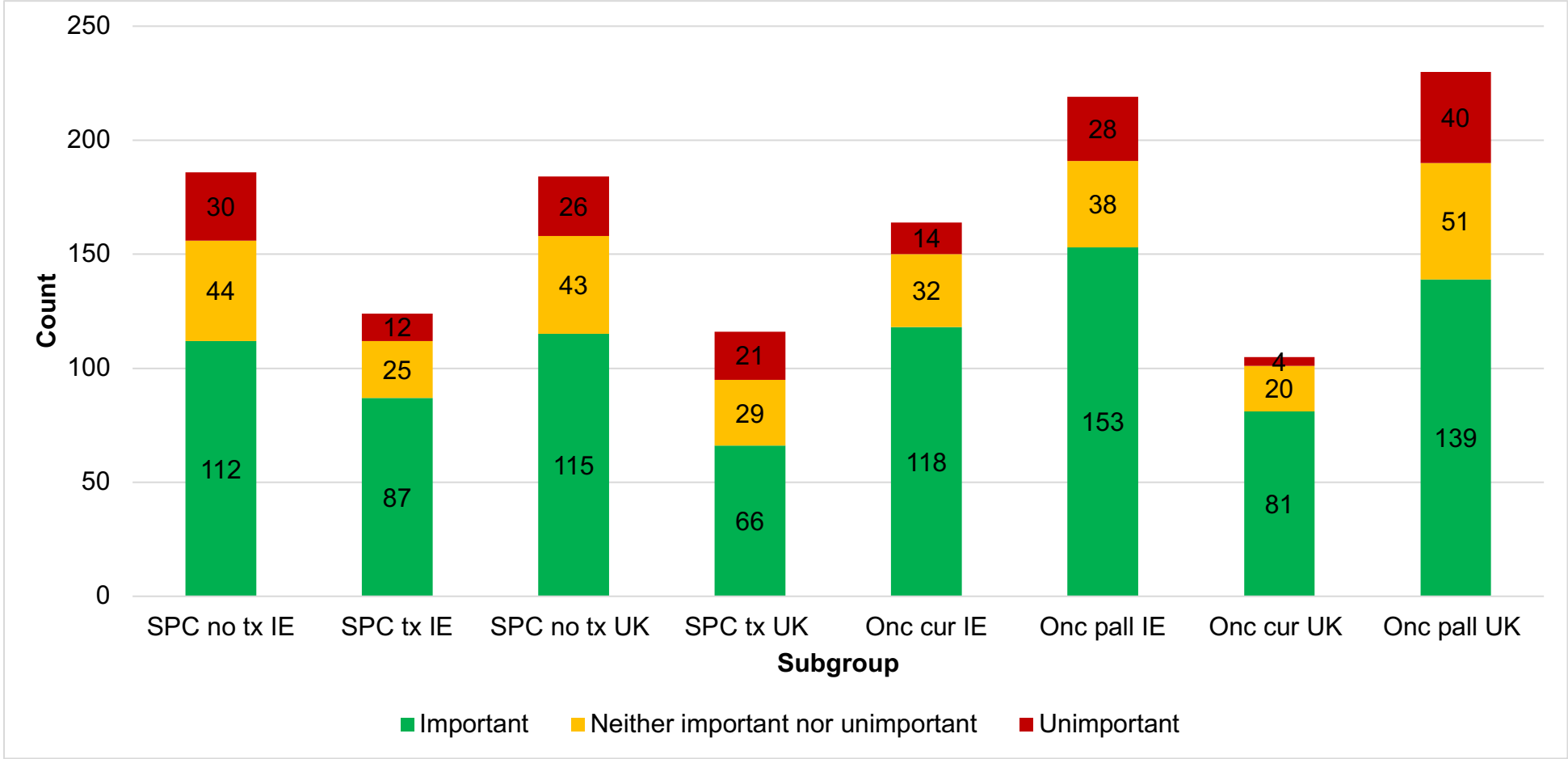
Key: SPC = participants with cancer known to specialist palliative care services; Onc = participants with cancer known to oncology services on anticancer treatment; IE = Ireland; UK = United Kingdom.

Table 22: Level of importance participants attribute to the choice of term used to describe people using healthcare services.

		Very unimportant	Slightly unimportant	Neither important nor unimportant	Slightly important	Very important
SPC	Ireland (n=310)	28 (9.0%)	14 (4.5%)	69 (22.3%)	60 (19.4%)	139 (44.8%)
		42 (13.5%)			199 (64.2%)	
	UK (n=300)	21 (7.0%)	26 (8.6%)	72 (24.0%)	83 (27.7%)	98 (32.7%)
		93 (31.6%)			181 (60.4%)	
	Total (n=610)	49 (8.0%)	40 (6.6%)	141 (23.1%)	143 (23.4%)	237 (38.9%)
		89 (14.6%)			380 (62.3%)	
ONC	Ireland (n=383)	26 (6.8%)	16 (4.2%)	70 (18.2%)	114 (29.8%)	157 (41.0%)
		42 (11.0%)			271 (70.8%)	
	UK (n=335)	18 (5.4%)	26 (7.8%)	71 (21.2%)	113 (33.7%)	107 (31.9%)
		44 (13.2%)			220 (65.6%)	
	Total (n=718)	44 (6.2%)	42 (5.8%)	141 (19.6%)	227 (31.6%)	264 (36.8%)
		86 (12.0%)			491 (68.4%)	

Key: SPC =participants with cancer known to specialist palliative care services; Onc=participants with cancer known to oncology services on anticancer treatment.

Figure 12: Stacked bar graph showing what participants think about the importance of choice of term used to describe people using healthcare services.



Key: SPC = participants with cancer known to specialist palliative care services; Onc = participants with cancer known to oncology services on anticancer treatment; no tx = not on treatment; tx = on treatment; cur = curative-intent treatment; pall = palliative-intent treatment; IE = Ireland; UK = United Kingdom.

5.5.4.2 Relationships among variables

5.5.4.2.1 Manipulation of variables

Variables were divided into categorical outcomes in a similar way to previous comparable studies (249, 253, 257, 277). Some were collapsed if they contained limited numbers, which would have led to violation of the sample size assumption for both the Chi-square test and logistic regression (351, 437). Age was divided into two categorical variables: <65 and ≥65 years, aligning with the definition of older person provided by the National Institutes of Health (NIH) (447). All participants selected male or female as their gender, so the category “other” was removed. Relationship status was recategorised into two groups between those who had a current partner (married / similar relationship), and those who did not (single / divorced or separated / widowed). Educational attainment was divided into low, medium and high levels as per the ISCED, where levels 0-2 equate to low education, levels 3-4 medium education, and levels 5-8 high education (398). Given the limited ethnic diversity within all groups, ethnicity was recategorised into two groups based on the most common ethnicity, and other ethnicities (Ireland: White Irish and other; UK: White English / Welsh / Scottish / Northern Irish / British, and other). ECOG was divided into 0-1 and 2-4, similar to previous studies (448). Some cancer diagnoses were recategorised and combined into “other” where representation was smaller to allow the assumptions required for statistical analysis (351). These were: endocrine, haematological, head and neck, neurological, sarcoma, skin, unknown primary, and other. Regarding anticancer treatment, SPC participants were divided into those not on treatment and those on treatment (only 1.1% (n=7) SPC participants were on curative-intent treatment). Onc participants (all on treatment) were divided according to curative or palliative intent. Anticancer treatment types were analysed separately, since participants may have been receiving more than one type, and specific types have previously demonstrated a significant association (especially chemotherapy) (253, 258, 271, 275, 277). Analysis was not carried out for treatment types where numbers were insufficient.

5.5.4.2.2 Bivariate analyses

Appendix 8, Supplementary Tables S7a-c show relationships between participant and clinical / cancer-related characteristics and dislike of the term cancer survivor using the Chi-square test of independence. Fisher's exact test was used to generate outcomes for radiotherapy for SPC Ireland, hormone therapy for Onc UK, and surgery for all groups, since assumptions were violated due to small numbers within those categories. Numbers of participants undergoing surgery were too small across all groups for valid results to be generated.

5.5.4.2.2.1 All participants

Overall, there were significant associations between dislike of being described as a cancer survivor and the SPC group (χ^2 (1, n=1328) = 16.351; $p < 0.001$; Cramer's $V = 0.112$), Ireland as the country of residence (χ^2 (1, n=1328) = 46.632; $p < 0.001$; Cramer's $V = 0.189$), higher educational attainment (χ^2 (2, n=1328) = 17.607; $p < 0.001$; Cramer's $V = 0.115$; medium (adj. residual -4.0) and high (adj. residual 3.4) groups contributing to significance), White Irish ethnicity (χ^2 (2, n=1328) = 48.184; $p < 0.001$; Cramer's $V = 0.190$; White Irish (adj. residual 6.9) and "other" ethnicity (adj. residual -5.9) contributing to significance), ECOG PS 2-4 (χ^2 (1, n=1328) = 11.595; $p < 0.001$; Cramer's $V = 0.095$), not being on anticancer treatment (χ^2 (2, n=1328) = 8.039; $p = 0.018$; Cramer's $V = 0.078$; curative-intent treatment (adj. residual -2.5) and no treatment (adj. residual 2.1) contributing to significance), "other" cancer type category (see section 5.5.4.2.1 Manipulation of variables for description) (χ^2 (2, n=1328) = 12.116; $p = 0.033$; Cramer's $V = 0.096$; "other" only category contributing to significance (adj. residual -3.1)).

5.5.4.2.2.2 SPC group

Overall, there were significant associations between dislike of being described as a cancer survivor and Ireland as the country of residence (χ^2 (1, n=610) = 9.870; $p = 0.002$; Cramer's $V = 0.130$), higher educational attainment (χ^2 (2, n=610) = 16.267; $p < 0.001$; Cramer's $V = 0.163$; medium (adj. residual -2.7) and high (adj. residual 3.9) groups contributing to significance), White Irish ethnicity (χ^2 (2, n=610) = 8.151 ; $p = 0.017$; Cramer's $V = 0.115$; White Irish (adj. residual 2.8) and

White English / Welsh / Scottish / Northern Irish / British (adj. residual -2.7) groups contributing to significance), and ECOG PS 2-4 (χ^2 (1, n=609) = 7.302; $p=0.007$; Cramer's V = 0.113).

In subgroup analysis, within the Ireland group there were significant associations between dislike of the term and being in a relationship (χ^2 (1, n=310) = 4.423; $p=0.035$; Cramer's V = 0.126), and ECOG PS 2-4 (χ^2 (1, n=309) = 4.445; $p=0.035$; Cramer's V = 0.128). Within the UK group, there were significant associations between dislike of the term and younger age (χ^2 (1, n=310) = 4.009; $p=0.045$; Cramer's V = 0.123), and higher educational attainment (χ^2 (1, n=310) = 13.843; $p<0.001$; Cramer's V = 0.214; medium (adj. residual -2.3) and high (adj. residual 3.7) groups contributing to significance). All effect sizes were small.

5.5.4.2.2.3 Onc group

Overall, there were significant associations between dislike of being described as a cancer survivor and Ireland as the country of residence (χ^2 (1, n=718) = 42.805; $p<0.001$; Cramer's V = 0.247), higher educational attainment (χ^2 (2, n=718) = 8.978; $p=0.011$; Cramer's V = 0.111; medium group contributing to significance (adj. residual -3.0)), and White Irish ethnicity (χ^2 (2, n=718) = 47.931; $p<0.001$; Cramer's V = 0.257; White Irish (adj. residual 6.9), and White English / Welsh / Scottish / Northern Irish / British (adj. residual -5.8) groups contributing to significance).

In subgroup analysis, within the Ireland group there was a significant association between dislike of the term and White Irish ethnicity (χ^2 (1, n=383) = 4.013; $p=0.045$; Cramer's V = 0.111). Within the UK group, there was a significant association between dislike of the term and higher educational attainment (χ^2 (2, n=335) = 10.732; $p=0.005$; Cramer's V = 0.174; low (adj. residual -2.2) and high (adj. residual 2.9) groups contributing to significance). All effect sizes were small.

5.5.4.2.3 Multicollinearity assessment

Association between independent variables was initially assessed to identify strong statistically significant correlations (Cramer's V >0.5) (434). Complete results can be found in Appendix 8, Supplementary Tables S8a-g. In all data

analysis (n=1328), the only variables that were highly correlated were country and ethnicity ($p<0.001$, Cramer's V = 0.959), SPC / Onc group status and treatment status ($p<0.001$, Cramer's V = 0.717), and treatment status and chemotherapy ($p<0.001$, Cramer's V = 0.587). Consequently, in developing the all-data model, country was retained and ethnicity was removed (particularly since ethnic diversity was low), and group status (SPC or Onc) was included instead of treatment status because both groups had respondents on palliative-intent treatment. Specific anticancer treatment types were also removed given the proportion of participants in the overall group not on any anticancer treatment.

In the SPC group, the only variables that were highly correlated were country and ethnicity ($p<0.001$, Cramer's V = 0.965), and treatment status and chemotherapy ($p<0.001$, Cramer's V = 0.605). In the Ireland SPC subgroup, there were high correlations between cancer type and hormone therapy ($p<0.001$, Cramer's V = 0.507), and treatment status and chemotherapy ($p<0.001$, Cramer's V = 0.606). In the UK SPC subgroup, there were high correlations between treatment status and chemotherapy ($p<0.001$, Cramer's V = 0.603). Analogous to the all-data model, ethnicity was removed from SPC analysis and country used instead. Additionally, specific anticancer treatment types were removed from all SPC group analyses due to small numbers, and there was more interest in comparing those on treatment to those not on treatment.

In the Onc group, the only variables that were highly correlated were region and ethnicity ($p<0.001$, Cramer's V = 0.955). There were no high correlations between independent variables in the Ireland or UK Onc subgroups. As before, ethnicity was removed from Onc group analysis and country retained.

When the models were developed (see section 5.5.4.2.4 Logistic regression) and predictor design matrices examined, all VIF results were below five and condition indices below 30, confirming acceptable measures of multicollinearity (442) (Appendix 8 Supplementary Table S9 and supporting information).

5.5.4.2.4 Logistic regression

Direct binary logistic regression was undertaken to determine the impact of certain predictor variables on the odds of an individual disliking the term cancer survivor being applied to them. As previously outlined, the dependent categorical variable

was dislike of being described as a cancer survivor within these models, and personal and clinical / cancer-related characteristics were the independent (predictor) variables.

Two models were developed and analysed. Model A related to personal characteristics and contained five independent variables (age, gender, relationship status, educational attainment, and country for the overall and SPC / Onc groups, or ethnicity for the country models). Model B related to clinical / cancer-related characteristics. Model B for SPC groups contained three independent variables (ECOG PS, anticancer treatment status and cancer type). Model B for all-data analysis also included SPC / Onc group status, and Model B for the Onc groups also contained variables relating to specific anticancer treatments (current chemotherapy, hormone therapy, immunotherapy, targeted therapy, radiotherapy / radiation therapy). Results are provided in Table 23 (including reference groups, odds ratios (OR) with 95% confidence intervals (CI), and *p-values*).

The observed groups and predicted probabilities plots showed effective predicted probabilities for the persons that disliked being described as a cancer survivor. No outliers were detected in the casewise lists of any of the models.

5.5.4.2.4.1 Analysis of all participants

Model A (personal characteristics)

Model A was statistically significant, χ^2 (6, n=1328) = 60.917, $p < 0.001$, and classified 59.9% participants correctly, that is, when the hypotheses (as described in section 5.4.7.4.1 Independent variables) were applied within the model, it predicted the correct binary outcome (dislike / other) regarding perception towards cancer survivor for 59.9% observations in the dataset. Two independent variables were statistically significant, controlling for other variables: Ireland ($p < 0.001$, OR 2.134 (95% CI 1.690-2.694) and high educational attainment (OR 1.422 (95% CI 1.071-1.889), $p = 0.015$). Living in Ireland had the strongest association (OR 2.134). The Hosmer and Lemeshow test showed a good fit, χ^2 (8, n=1328) = 8.217, $p = 0.413$.

Model B (clinical / cancer-related characteristics)

Model B was statistically significant, χ^2 (7, n=1328) = 30.339, $p < 0.001$, and classified 57.9% participants correctly. Three of the independent variables were statistically significant, controlling for other variables: SPC group (OR 1.388 (95% CI 1.081-1.782), $p = 0.010$) and higher ECOG status (OR 1.289 (95% CI 1.008-1.649), $p = 0.043$) were associated with disliking the term, and having a cancer diagnosis within the “other” category (OR 0.581 (95% CI 0.409-0.827), $p = 0.003$) was negatively associated with disliking the term. The Hosmer and Lemeshow test also showed a good fit, χ^2 (8, n=1328) = 3.336, $p = 0.912$.

5.5.4.2.4.2 Subgroup analyses

5.5.4.2.4.2.1 Analysis of SPC groups

Model A (personal characteristics)

- SPC group

Model A was statistically significant, χ^2 (6, n=610) = 30.840, $p < 0.001$, and classified 61.0% participants correctly. Two independent variables were statistically significant, controlling for other variables: Ireland (OR 1.729 (95% CI 1.225-2.440, $p = 0.002$) and high educational attainment (OR 1.882 (95% CI 1.252-2.830), $p = 0.002$). The strongest predictor within the model was high educational attainment (OR 1.882). The Hosmer and Lemeshow test also showed a good fit, χ^2 (8, n=610) = 5.870, $p = 0.662$.

- SPC Ireland subgroup

Model A was not statistically significant, χ^2 (6, n=310) = 12.101, $p = 0.060$, and classified 58.7% participants correctly. Two of the independent variables were statistically significant, controlling for other variables: male gender (OR 1.607 (95% CI 1.004-2.572), $p = 0.048$), and relationship status (OR 0.584 (95% CI 0.369-0.955), $p = 0.032$), where not having a partner was negatively associated with disliking the term. The Hosmer and Lemeshow test showed a good fit, χ^2 (8, n=310) = 5.029, $p = 0.754$.

- SPC UK subgroup

Model A was statistically significant, $\chi^2 (6, n=300) = 17.665, p=0.007$, and classified 61.3% participants correctly. High educational attainment (OR 2.319 (95% CI 1.181-4.552) $p=0.015$) was the only statistically significant independent variable, controlling for other variables. The Hosmer and Lemeshow test also showed a good fit, $\chi^2 (8, n=300) = 3.339, p=0.911$.

Model B (clinical / cancer-related characteristics)

- SPC group

Model B was statistically significant, $\chi^2 (7, n=610) = 16.874, p=0.018$, and classified 58.8% participants correctly. Two of the independent variables were statistically significant, controlling for other variables: higher ECOG status (OR 1.881 (95% CI 1.266-2.796), $p=0.002$) was associated with disliking the term, and having a cancer diagnosis within the “other” category (OR 0.477 (95% CI 0.254-0.895), $p=0.021$) was negatively associated with disliking the term. The Hosmer and Lemeshow test also showed a good fit, $\chi^2 (8, n=610) = 4.207, p=0.838$.

- SPC Ireland subgroup

Model B was not statistically significant, $\chi^2 (7, n=310) = 8.890, p=0.261$, and classified 60.8% participants correctly. Only ECOG status (OR 2.208 (95% CI 1.202-4.057), $p=0.011$) was statistically significant, controlling for other variables. The Hosmer and Lemeshow test, however, showed a good fit, $\chi^2 (7, n=310) = 2.945, p=0.890$.

- SPC UK subgroup

Model B was not statistically significant, $\chi^2 (7, n=300) = 9.498, p=0.219$, and classified 57.7% participants correctly. Having a cancer diagnosis within the “other” category (OR 0.357 (95% CI 0.141-0.903), $p=0.030$) was the only statistically significant independent variable, and was negatively associated with disliking the term. The Hosmer and Lemeshow test showed a good fit, $\chi^2 (8, n=300) = 6.553, p=0.586$.

5.5.4.2.4.2.2 Analysis of Onc groups

Model A (personal characteristics)

- Onc group

Model A was statistically significant, $\chi^2 (6, n=718) = 50.903, p<0.001$, and classified 63.5% participants correctly. Country (Ireland) (OR 2.792 (95% CI 2.005-3.887), $p<0.001$) was the only statistically significant independent variable, controlling for other variables. The Hosmer and Lemeshow test showed a good fit, $\chi^2 (8, n=718) = 9.195, p=0.326$.

- Onc Ireland subgroup

Model A was not statistically significant, $\chi^2 (6, n=383) = 8.692, p=0.192$, and classified 54.8% participants correctly. No independent variables were statistically significant, controlling for other variables. The Hosmer and Lemeshow test showed a good fit, $\chi^2 (8, n=383) = 7.229, p=0.405$.

- Onc UK subgroup

Model A was statistically significant, $\chi^2 (6, n=335) = 13.759, p=0.032$, and classified 71.6% participants correctly. High educational attainment (OR 4.102 (95% CI 1.497-11.241), $p<0.001$) was the only statistically significant independent variable, controlling for other variables. The Hosmer and Lemeshow test also showed a good fit, $\chi^2 (8, n=335) = 4.860, p=0.772$.

Model B (clinical / cancer-related characteristics)

- Onc group

Model B was not statistically significant, $\chi^2 (12, n=718) = 13.812, p=0.313$, and classified 58.4% participants correctly. Not taking hormone therapy (OR 2.141 (95% CI 1.039-4.412), $p=0.039$) was the only statistically significant independent variable, controlling for other variables. The Hosmer and Lemeshow test also showed a good fit, $\chi^2 (8, n=718) = 3.043, p=0.932$.

- Onc Ireland subgroup

Model B was not statistically significant, $\chi^2 (12, n=383) = 9.830, p=0.631$, and classified 56.7% participants correctly. No independent variables were statistically

significant, controlling for other variables. The Hosmer and Lemeshow test also showed a good fit, $\chi^2 (8, n=383) = 7.083, p=0.528$

- Onc UK subgroup

Model B was statistically significant, $\chi^2 (12, n=335) = 17.584, p=0.129$, and classified 72.7% participants correctly. Not taking hormone therapy (OR 4.796 (95% CI 1.295-17.759), $p=0.019$) was the only statistically significant independent variable, controlling for other variables. The Hosmer and Lemeshow test also showed a good fit, $\chi^2 (8, n=335) = 7.872, p=0.446$.

Table 23: Odds ratios from logistic regression models assessing personal and clinical / cancer-related characteristics associated with dislike of being described as a cancer survivor.

	All participants		SPC						Onc					
			Ireland		UK		Total		Ireland		UK		Total	
	OR (95% CI)	<i>p</i> <i>value</i>	OR (95% CI)	<i>p</i> <i>value</i>	OR (95% CI)	<i>p</i> <i>value</i>	OR (95% CI)	<i>p</i> <i>value</i>	OR (95% CI)	<i>p</i> <i>value</i>	OR (95% CI)	<i>p</i> <i>value</i>	OR (95% CI)	<i>p</i> <i>value</i>
<i>Age (years)</i>														
≥65 (ref)														
<65	0.957 (0.761, 1.203)	0.708	1.020 (0.621, 1.674)	0.938	1.471 (0.883, 2.453)	0.139	1.262 (0.890, 1.788)	0.192	0.835 (0.531, 1.313)	0.435	0.970 (0.593, 1.586)	0.903	0.871 (0.627, 1.211)	0.412
<i>Gender</i>														
Female (ref)														

Male	1.102 (0.883, 1.375)	0.393	1.607 (1.004, 2.572)	0.048	0.919 (0.568, 1.487)	0.731	1.253 (0.901, 1.744)	0.180	0.954 (0.626, 1.454)	0.825	0.902 (0.551, 1.477)	0.683	0.982 (0.716, 1.347)	0.910
<i>Relationship status</i>														
Married / similar (ref)														
No partner	1.105 (0.874, 1.398)	0.404	0.594 (0.369, 0.955)	0.032	1.213 (0.739, 1.992)	0.444	0.845 (0.603, 1.186)	0.331	1.426 (0.904, 2.251)	0.127	1.115 (0.641, 1.939)	0.700	1.293 (0.917, 1.824)	0.143
<i>Educational attainment</i>														
Low (ref)														
Medium	0.922 (0.674, 1.261)	0.611	1.701 (0.558, 2.636)	0.838	0.988 (0.514, 1.898)	0.971	0.988 (0.639, 1.529)	0.958	0.789 (0.434, 1.432)	0.436	2.111 (0.756, 5.892)	0.154	0.850 (0.536, 1.349)	0.491

High	1.422 (1.071, 1.889)	0.015	1.551 (0.913, 2.636)	0.105	2.319 (1.181, 4.552)	0.015	1.882 (1.252, 2.830)	0.002	0.902 (0.548, 1.486)	0.686	4.102 (1.497,1 1.241)	0.006	1.206 (0.799, 1.821)	0.373
<i>Region</i>														
UK (ref)														
Ireland	2.134 (1.690, 2.694)	<0.001					1.729 (1.225, 2.440)	0.002					2.792 (1.005, 3.887)	<0.001
<i>Ethnicity</i>														
White Irish (ref)														
White British / similar* (ref)														

Other			1.281 (0.480, 3.4240	0.621	0.604 (0.238, 1.537)	0.290			0.544 (0.278, 1.066)	0.076	0.438 (0.156, 1.231)	0.117		
Group status														
Onc (ref)														
SPC	1.388 (1.081, 1.782)	0.010												
ECOG PS														
ECOG 0-1 (ref)														
ECOG 2-4	1.289 (1.008, 1.649)	0.043	2.208 (1.202, 4.057)	0.011	1.427 (0.832, 2.446)	0.197	1.881 (1.266, 2.796)	0.002	1.427 (0.889, 2.291)	0.140	0.719 (0.409, 1.262)	0.250	1.052 (0.752, 1.572)	0.767

<i>Cancer type</i>														
Breast (ref)														
GI	0.741 (0.524, 1.048)	0.090	0.706 (0.314, 1.584)	0.398	0.577 90.233, 1.427)	0.234	0.642 (0.353, 1.168)	0.147	1.051 (0.566, 1.950)	0.875	1.261 (0.427, 3.720)	0.675	1.018 (0.626, 1.654)	0.943
Lung	0.787 (0.517, 1.198)	0.265	0.665 (0.290, 1.521)	0.333	0.756 (0.288, 1.960)	0.569	0.704 (0.353, 1.314)	0.271	1.409 (0.490, 4.053)	0.525	1.089 (0.285, 4.163)	0.901	1.066 (0.513, 2.214)	0.864
Urol	0.670 (0.435, 1.031)	0.069	0.559 (0.194, 1.605)	0.280	0.768 (0.301, 1.960)	0.581	0.617 (0.314, 1.213)	0.161	1.513 (0.608, 3.763)	0.373	0.447 (0.121, 1.649)	0.227	0.737 (0.388, 1.399)	0.350
GYN	0.867 (0.544, 1.379)	0.546	0.743 (0.277, 1.992)	0.555	0.735 (0.249, 2.169)	0.577	0.727 (0.352, 1.501)	0.388	1.231 (0.481, 3.152)	0.665	1.533 (0.444, 5.294)	0.499	1.202 (0.620, 2.332)	0.586
Other	0.581 (0.409, 0.827)	0.003	0.779 (0.316, 1.921)	0.588	0.357 (0.141, 0.903)	0.030	0.477 (0.254, 0.895)	0.021	1.257 (0.645, 2.452)	0.502	0.826 (0.278, 2.453)	0.731	0.826 (0.509, 1.340)	0.438

<i>Anticancer treatment (tx) status</i>									
On tx (ref)									
Not on tx		0.704 (0.421, 1.176)	0.180	0.898 (0.530, 1.522)	0.690	0.757 (0.582, 1.084)	0.128		
Curative (ref)									
Pallia- tive								1.414 (0.887, 2.253)	0.145 1.272 (0.709, 2.281) 0.420 1.189 (0.847, 1.669) 0.316
<i>Anticancer treatment type</i>									
CT (ref)									
Not on CT								1.710 (0.842, 3.470)	0.137 1.411 (0.635, 3.136) 0.397 1.331 (0.824, 2.152) 0.243
HT (ref)									

Not on HT			1.947 (0.743, 5.102)	0.175	4.796 (1.295, 17.759)	0.019	2.141 (1.039, 4.412)	0.039
IT (ref)								
Not on IT			1.088 (0.541, 2.191)	0.812	0.767 (0.338, 1.740)	0.526	1.003 (0.612, 1.644)	0.990
TT (ref)								
Not on TT			1.072 (0.625, 1.841)	0.800	1.720 (0.693, 4.266)	0.242	1.454 (0.932, 2.269)	0.099
RT (ref)								
Not on RT			1.599 (0.546, 4.682)	0.391	1.033 (0.441, 2.418)	0.940	0.888 (0.487, 1.619)	0.698

Key: SPC = participants with cancer known to specialist palliative care services; Onc = participants with cancer known to oncology services on anticancer treatment; ECOG PS = Eastern Cooperative Oncology Group Performance Status; OR = odds ratio; CI = confidence interval; GI = gastrointestinal; Urol = urological; GYN = gynaecological; tx = treatment; CT = chemotherapy; HT = hormone therapy; IT = immunotherapy; TT = targeted therapy; RT = radiotherapy / radiation therapy; *White English / Welsh / Scottish / Northern Irish / British; bold p value in shaded cell = significant (p<0.05).

5.6 Discussion

5.6.1 Interpretations

This discussion predominantly explores the responses of participants in this study about being described as a cancer survivor, alongside their perspective on the NCI's definition of this term (17), the groups of people they think it should be used to describe, and personal and clinical factors relating to disliking the terminology. Additionally, their preferences about other common terms used to describe people known to healthcare services are discussed, as well as their views on the importance of the words used to describe people with cancer.

5.6.1.1 Study response

The study response rate in Ireland (69.6%) was comparable to typical patient surveys in healthcare (approximately 70%) (449), although it was not as high as other studies that also mainly used in-person recruitment (449), or even similar studies assessing opinions on the cancer survivor term (249, 277). This probably reflects the challenges of recruitment to the particular groups in POST (see section 5.6.3 Strengths and limitations).

5.6.1.2 Participant characteristics

The samples appropriately reflected the intended groups. Participants were varied in gender, relationship status and educational attainment, but limited in ethnic diversity (although the majorities of white ethnicities likely reflect the major ethnic backgrounds of people within these regional areas (393, 394)). Despite heterogeneity in cancer type, the predominance of gastrointestinal, lung and breast cancers also aligns with these cancer types currently being the most common cancers worldwide (450), so this is unsurprising given the convenience sampling approach. As expected, participants in the SPC group had a worse ECOG status than participants in the Onc group, reflecting their reduced functional ability, and indeed most were no longer receiving anticancer treatment (60.7%). Consequently, it is likely appropriate to generalise that within this study the Onc group reflected people earlier in the cancer journey, and the SPC group reflected people with a shorter prognosis.

5.6.1.3 Attitudes towards cancer survivor

5.6.1.3.1 Being described as a cancer survivor

Crucially, this is the first study of its type to determine the perspectives of people mainly with incurable cancer about cancer survivor terminology. The scoping review in Chapter 3 showed that previous studies suggested that individuals still on treatment (249, 252), individuals with advanced disease (256), and individuals who had experienced recurrence (250) were less likely to identify with cancer survivor terminology. Results from the POST study have reinforced these findings, as more participants in each group disliked the term being applied to them (SPC: 52.6%; Onc: 41.3%) compared to the proportion that liked the application (SPC: 23.8%; Onc: 35.7%). However, aversion to the term was much greater in the SPC group (28.8% difference), compared to the smaller difference between the like and dislike categories in the Onc group (5.6%), as demonstrated in the Mann-Whitney U test ($U = 253265.5$, $p < 0.001$). Although this trend towards dislike had been previously hypothesised (91, 252), the terminology has still been widely applied to these groups. These results support the suggestion that such application needs to be reconsidered.

Although there was no control group of people with no evidence of disease in this survey, its participants show greater disdain towards cancer survivor terminology than previous studies where participants typically had no evidence of disease / completed treatment, corresponding with the hypotheses. Jagielski et al. found that 78% of 629 people with a history of breast cancer favoured the term (277), Park et al. showed that 83% of 168 people mostly with a history of breast or prostate cancer endorsed the term (91), and in Wee et al.'s survey, 75% of 417 people who had completed treatment for colorectal cancer related to the term (249). Wee et al. was also the only similar previous study which specifically assessed the perspectives of individuals on anticancer treatment (122 people with colorectal cancer), and only 46.7% related to the term. Likewise, the POST study shows lower endorsement, and to a greater extent, with only 35.7% participants in the Onc group liking the term being applied to them. Moreover, it is relatively unsurprising that an even smaller proportion of people in the SPC group liked being described by the term (23.8%). This study is the first to provide clear evidence of these outcomes.

However, it should be noted that results can vary according to the measurement technique, such as dichotomous responses compared to various rating scales, or the phrasing used in the question (290). The order of questions can also influence participant responses (451), likely with an unknown impact. Indeed, the lack of standardisation in the approach to identifying if people endorse the term cancer survivor was highlighted in Chapter 3. Furthermore, these results only reflect participant preferences regarding the words being used to describe them, and do not ultimately equate to an individual's identity.

5.6.1.3.2 Cancer survivor definition

A unique aspect, and strength, of this study was its analysis of the cancer survivor construct in different ways. As explored in Chapters 1 and 3, the definition of cancer survivor has been debated, yet the primarily American perspectives are widely applied (mostly reflecting the attitudes of people with no evidence of disease). In the SPC group, 43.8% disliked the definition and 27.0% liked it, aligning with the hypothesis that this group would dislike the NCI's definition (17) (although majorities were not reached). Similar to results for individual application, the distinction was less sizeable in the Onc group, where 39.7% disliked the definition and 35.2% favoured it.

Moreover, the proportions of the groups disliking the definition (SPC 43.8%; Onc 39.7%) were slightly smaller than the proportions disliking individual application (SPC 52.6%; Onc 41.3%). This likely reflects differences in attitudes towards terms / concepts being applied in general settings, and using terms within a personal context.

Expert groups ranked agreement with the NCI definition (17) in the PRiSM study (Chapter 4), and similar proportions of the expert groups explicitly disagreed with the definition (44% of the specialist palliative care expert group, and 31% of the oncology expert group), corresponding to the proportions of participants disliking the definition in the POST study (SPC 43.8%; Onc 39.7%). However, the expert groups had less neutrality and higher proportions agreed with the definition (44% of the specialist palliative care expert group and 57% of the oncology expert group) than the proportions of participants that liked the definition in the current study (SPC: 27.0%; Onc 35.2%). This is an important distinction, revealing that the

perception of the appropriateness of cancer survivor terminology may be more positive amongst experts (particularly healthcare professionals) than amongst people with cancer themselves.

5.6.1.3.3 Describing people as cancer survivors

In establishing their own criteria to be described as cancer survivors, participants in the SPC and Onc groups overwhelmingly selected people post-treatment with no evidence of disease. What is striking within these results is that the largest majority in both groups selected a timeline of 5 years (SPC 65.7%; Onc 66.0%), likely aligning with awareness of historical 5-year survival statistics in cancer care (227). Although a minority within healthcare still use this definition (158), it is considerably outdated within the concepts now surrounding cancer survivorship terminology, as explored in the introduction of this thesis.

Another important identification is the alignment of these results with expert opinion from the PRiSM study (Chapter 4). Similarly, both specialist palliative care and oncology expert groups largely agreed that the same groups (individuals who have completed anticancer treatment and have no evidence of disease) should be defined as cancer survivors, with the highest majorities agreeing with the 5-year timeline as well (specialist palliative care expert group 90%; oncology expert group 95%). Such agreement of outcomes between studies adds credibility to results.

Moreover, only minorities of POST participants selected that any individual with a cancer diagnosis should be called a cancer survivor (SPC 19.8%; Onc 19.1%), criteria that would align with the current all-encompassing NCI definition (17). It may even be argued that this item was more likely to be selected since participants tend to choose answers at the top in tick all that apply responses (387, 414), and so the small proportional selection is even more meaningful. Irrespective of this, these differed from the proportions that liked the NCI's definition (SPC 27.0%; Onc 35.2%), which may be explained by the different wording of the questions (290) or their order (451). However, essentially these add credibility to each other by demonstrating that only minorities of both groups support the broad application of the cancer survivor term to people from the point of diagnosis. Furthermore, the majorities of both expert groups in the PRiSM project also

disagreed with the universal application of cancer survivor to all individuals with cancer (specialist palliative care expert group 82%; oncology expert group 79%).

Another informative outcome was that minorities of each group thought the term should not be used at all (SPC 21.6%; 19.5%). Correspondingly, in the PRiSM study 16% of the specialist palliative care expert group and 14% of the oncology expert group agreed that the term should not be used. The probable enduring nature of cancer survivorship terminology (271, 275) was acknowledged in Chapter 3, and equally it may be inferred that most participants in this study accepted its use for certain groups with appropriate consideration and clarity. However, it may also be argued that the fact that approximately a fifth of participants would prefer that this common term was not used at all must be considered.

These results add greater depth of understanding to findings from previous studies that also assessed the endorsement of cancer survivor terminology by people with a history of cancer. People with active cancer (on treatment or with advanced disease) have been underrepresented, and crucially, this is the first time people with cancer have been asked about the NCI's definition (17). The unique aspects of this study add weight to its results and accompanying implications towards the cancer survivor terminology argument.

5.6.1.3.4 Association with characteristics

Comparable to preceding studies, preferences regarding cancer survivor terminology were found to be multifaceted (explored in Chapter 3). A number of personal and clinical / cancer-related characteristics were associated with dislike of being described as a cancer survivor. However, the inconsistencies between group results within this study, and with previous studies (outlined below) ultimately demonstrate that perception towards cancer survivor is individual, contextual and unpredictable, and above all that results from one area should not be generalised to another.

5.6.1.3.4.1 Model A: personal characteristics

Model A was statistically significant overall and for both the SPC and Onc groups, but only for the UK subgroups, revealing that certain personal characteristics were associated with disliking cancer survivor.

One unexpected result was the statistical significance of country in both the SPC and Onc groups. Indeed, it was the factor with strongest association within Model A. It was anticipated that the two English-speaking European areas would generally dislike the terminology (given its North American origins), but such a difference between the geographically neighbouring areas was curious. This highlights the influence of regional culture on the development of perceptions towards identity (452), and moreover, demonstrates that applying terminology across different regional areas may be problematic, even if acceptable within one of those areas.

Higher educational attainment was significantly associated with dislike of cancer survivor, analogous to earlier studies, which found that cancer survivor endorsement is associated with lower educational attainment (256, 257, 296). Educational status tends to align with socioeconomic status (396, 397), so this association may be extrapolated. This factor was significant in the all-data model and in the SPC group, and remained in subgroup analysis for the SPC UK group. Although identified as significant in bivariate analyses in the Onc group, it only remained significant after accounting for other variables in the Onc UK group. The association is therefore not consistent across groups, even within this study.

Male gender and having a partner were related to disliking the term cancer survivor, but only in the SPC Ireland group. Male gender was an expected association (256), although previous studies more commonly identified having a partner with endorsement of the term (250). Similarly, although White Irish ethnicity in the Onc Ireland group, and age <65 years in the SPC UK group, were associated with dislike of the term in bivariate analyses, these were not maintained after accounting for other variables, despite age in particular being previously identified as an association (249, 250, 252, 293). Otherwise, gender, age, and relationship status were not significantly associated with disliking cancer survivor, unlike results from previous research.

5.6.1.3.4.2 Model B: clinical / cancer-related characteristics

Model B was significant overall and for the SPC group, revealing that certain clinical characteristics were associated with disliking cancer survivor. However, this did not hold for SPC subgroups or the Onc group overall (notably, different factors were included in certain subgroups).

Importantly, there was a significant difference in results between the SPC group and the Onc group. People with cancer known to SPCS generally have advanced or metastatic cancer, and difficult-to-manage cancer-related symptoms (206), and are usually considered to have a limited prognosis, compared to people in the Onc group who may have an uncertain prognosis. Although more people in both groups disliked the term compared to the numbers who liked the term, the findings reported here suggest that people with the perception of having a more limited prognosis dislike the term even more (unsurprisingly).

In the all-data model and within the SPC group (and SPC Ireland subgroup), having a higher ECOG performance status was associated with dislike of cancer survivor. Functional capacity may be associated with perception of prognosis, which was previously found to be linked to cancer survivor perspectives (277). However, the inclusion of ECOG status was unique to this study and has importantly proven that an individual's practical capabilities, energy and activities can influence their perception towards terminology.

Given the association of the breast cancer community and cancer survivor advocacy (90), it was anticipated that cancer types other than breast cancer would be associated with disliking the term. However, the only group with a significant association was the other category in the overall analysis and in the SPC group (maintained in the SPC UK group). This association was also negative, that is, that individuals with these cancer types were less likely to dislike the term. This group encompassed a variety of cancer types smaller in number in the study: endocrine, haematological, head and neck, neurological, sarcoma, skin, unknown primary, and other. It may be suggested that people with these less common (but not uncommon) cancer types may see even more value in endorsing a term that could help them feel part of a wider community, influencing perception positively towards cancer survivor.

Contrary to the hypothesis, there was no significant difference between curative and palliative treatment intent in the Onc group, even though it may be assumed that people undergoing curative intent treatment should have the perception of a better prognosis. Therefore, even though people on anticancer treatment may have a different perception of prognosis according to whether the intent is curative or palliative, this did not appear to influence present opinion. Interestingly, in the PRiSM study the specialist palliative care expert group disagreed that people on anticancer treatment (whether curative or palliative) should be referred to as cancer survivors, whereas the oncology expert group only reached consensus for people on palliative-intent treatment (not curative). Collectively, these expert perceptions and results from the POST study suggest that people still on treatment likely should not be described as cancer survivors, irrespective of treatment intent.

Furthermore, despite previous associations between chemotherapy and endorsement of the term (271, 275, 277), no significant association was detected in this study for chemotherapy, immunotherapy, targeted therapy, or radiation therapy. It may be argued, however, that since these therapies were ongoing at the time of the study for participants, results may have been different if they had been completed. The only characteristic showing significant association was not taking hormone therapy in the Onc group, and Onc UK subgroup. People taking hormone therapy likely had breast, gynaecological or prostate cancer, potentially for a prolonged time, so it could be inferred that people on more aggressive regimens may perceive the term more negatively.

Contrary to expectations, this study did not find a significant difference between treatment status within the SPC group. This is important because of the general agreement amongst participants in both the PRiSM and POST studies that people with advanced / progressive disease and no further anticancer treatment options should not be described as cancer survivors. Crucially, participants in the SPC group had similar perspectives whether on anticancer treatment (largely palliative intent) or not.

5.6.1.3.4.3 Uncontrolled confounding factors

These are other relevant characteristics which were not assessed in this study, and may have influenced participants' views. Specific factors previously identified as associated with cancer survivor endorsement include greater time since diagnosis (251), number of cancer diagnoses (252), and more cancer-related symptoms (258). Cancer-related identity has also been found to be intertwined with some aspects of psychological functioning (257). Previous studies have identified consequences of cancer survivor endorsement to include mental wellbeing (90, 250, 257, 259, 277), higher health-related quality of life (249), and engagement in coping strategies (90, 258). Such factors were not assessed in the POST study as expanding the questionnaire would have increased participant burden.

Similarly, engagement in cancer-related activities (90, 257), and online support groups (253) have been found to be related to supporting cancer survivor terminology, aligning with the idea that the social environment informs identity (84). However, these were not assessed in this study, and indeed may have been less relevant to this group of participants with reduced function and less energy for social initiatives. The potential beneficial associations derived from previous studies cannot therefore be generally applied to this group.

5.6.1.5 Choice of alternative terms

Previous studies have shown that people affected by cancer can find a number of terms appropriate (248, 250, 257), and that affiliations with different terms are associated with different factors (257). Given the apparent dislike of cancer survivor amongst the study groups, it can be suggested from the additional information about likes and dislikes towards other terms that some of these may be more acceptable to describe people with cancer in healthcare settings.

The highest proportion of both the SPC and Onc groups selected moderately like / strongly like for oncology patient (SPC 48.5%; Onc 52.6%, see Figure 10), although there were slight differences in the regional subgroups. Interestingly, no previous study has assessed the perceptions of people with a history of cancer towards this term. Indeed, it may have been considered medical jargon that is not universally understood. However, it largely implies treatment, and also specifically

avoids the word cancer, which some may find repulsive (see Chapter 6, section 6.4.3 Themes). Results for oncology patient also showed correspondingly low proportions who disliked the term (13.6% SPC; 7.9% Onc). Despite the general positivity towards it, some people on treatment may see little difference between the word oncology and cancer, and some people known to SPCS may no longer attend oncology, or feel a sense of affiliation. Nevertheless, according to these data we can infer that oncology patient may be more acceptable for the groups in the POST study than cancer survivor.

However, the term patient was disliked the least by the participants (3.5% SPC; 2.2% Onc) (see Figure 11). Despite previous criticism of patient (378, 381), the familiar term has endured and appears least offensive in the current study. Considering the settings of the POST study, people attending or staying in cancer centres or hospices may be more accepting of this term that is associated with treatment / medical care (381). When the word cancer was added, the number of people disliking the term increased. Even using the phrase patient with cancer, instead of cancer patient (307), proved to have little influence in this study, with comparable likes and dislikes reported for each. Moreover, person living with cancer, the modern term promoting individual agency (381), was disliked by over a fifth of each group (SPC 21.8%; Onc 22.7%), comparable even to results for cancer patient (SPC 25.9%; Onc 22.3%). However, it should be noted that the different proportions of the groups who like / dislike the terms do not necessarily equate to rank order of preference, since such variation in question style will influence results (290).

A notable finding is that there was only one significant difference between the group's opinions regarding terms used to describe them (after correction for multiple comparisons), and this was cancer survivor. This underpins the very problem with this terminology, as no other term in this questionnaire is proven to be as divisive or controversial. However, although the responses towards different terms lends to the idea that some of these may be preferred to cancer survivor, equally they demonstrate that no one term or label will be acceptable to everyone. Previous studies have referred to the difficulty finding a term for people with advanced / metastatic cancer given the diversity of experiences within this diagnosis (285). Certainly, proportions of people still disliked each term. The focus should be on finding those words / phrases that are least offensive and confusing.

5.6.1.6 Importance of the choice of term

Furthermore, the majority of individuals in this study deemed words to be important, with 65.6% overall rating the issue as very or slightly important (SPC 60.4%; Onc 68.4%). The importance of language in healthcare has previously been recognised (90, 247), however, a greater proportion of participants in the POST study reported the choice of term to be important than in comparable studies (249). The POST study represented people with a current cancer diagnosis, and the importance they attribute to this issue is notable, particularly since this group have not been included in previous research regarding cancer survivor terminology. These results reinforce the need for sensitivity around terms used to describe people with cancer across settings, and indeed the importance of including people with different types and experiences of cancer in the discussion.

5.6.2 *Reliability and validity*

5.6.2.1 Reliability

As explained in the previous chapter, reliability (consistency of the measure) may be considered as inter-rater reliability, intra-rater (test-retest) reliability, or internal consistency (364). Inter-rater reliability was less relevant as the study did not rely on researcher observation; the self-reported questionnaire (self-administered or supported by the researcher) ensured consistency in the process and interpretation of results. However, the study sample size was not reached (see section 5.6.3 Strengths and limitations), increasing the risk of false negative or false positive results. Test-retest reliability was also not applicable in this study as identities and opinions are likely to change over time (453).

Using three key questions around the same construct about cancer survivor (who respondents thought it should describe (nine items), and their opinion in relation to the NCI's definition (17), and their own situation) enabled a more complete understanding of participant thoughts. This approach also reduced measurement error in relation to the concept (391), decreased further by the large sample size (414). Internal consistency (correlation between questionnaire items) is typically measured using Cronbach's α (454)) with ≥ 0.70 deemed acceptable (455). Cronbach's α was 0.737 for these 11 items, showing acceptable reliability,

particularly since the measurement includes questions that use both Likert-scale and binary outcomes.

5.6.2.2 Validity

Validity (accuracy of a study in determining its outcome) was also explained in the preceding chapter, and includes both external validity (how well results represent similar individuals who did not participate) and internal validity (how well results represent the true findings of the participants, encompassing face validity, content validity, construct validity and criterion validity) (364, 391, 456).

The paper approach, although perhaps slower and more costly, prevented bias that would be introduced using an electronic method, such as access or ability (affecting external validity).

Face validity (subjective assessment of the suitability of the questionnaire format / appearance for the target participants) was considered during questionnaire design (see section 5.4.2.3 Questionnaire design), and was enhanced by PPI feedback, which led to some formatting changes to aid clarity and ensured the questionnaire was suitable and meaningful for the target population (see section 5.4.2.3.5 Questionnaire revision).

The study also had appropriate content validity, which is the extent to which the questionnaire items represent the construct it seeks to measure (391). The study primarily sought to determine the views of people with cancer about the term cancer survivor, and including three different quantitative questions and an optional free text response enabled the same construct to be analysed in different ways. Content validity was also improved by expert review of the questionnaire prior to implementation (391, 392, 457), ensuring items effectively represented the measured construct (392), as well as augmenting clarity, ease of completion and questionnaire satisfaction (391).

These ideas also relate to construct validity, the extent to which the tool measures what it is supposed to, typically pertaining to measures not directly assessed by the tool (related or unrelated) (391, 456). Formal determination of construct validity would have involved administering another questionnaire (such as that from a previous study) alongside the POST questionnaire to assess alignment. However,

this study was not aiming to establish a validated questionnaire that could be used in the future, but instead to add to the current body of evidence by determining the perspectives of underrepresented groups in the least burdensome way for those individuals. Similarly, criterion validity was not determined for the whole questionnaire (extent to which one measure predicts an outcome for another (391, 456)). Furthermore, no gold standard question exists to ascertain endorsement of the cancer survivor identity, given the variety of approaches previously used (see Chapter 3).

Finally, the study outputs align with results from the PRiSM project (Chapter 4), noted throughout the discussion. This adds substantial credibility to findings and consequent implications, establishing agreement between European SPC and oncology experts, and people with active cancer (known to SPCS, and on anticancer treatment), about the meaning and use of cancer survivor terminology; appropriate for people post-treatment with no evidence of disease, and less appropriate for people with cancer on anticancer treatment or with no further anticancer treatment options.

5.6.3 Strengths and limitations

This study contributes important information to the ongoing nomenclature debate regarding people with a history of cancer. Its unique inclusion of participants known to SPCS and people on anticancer treatment, details of certain personal and cancer-related characteristics, and large sample size are of particular value. The specific inclusion of ECOG PS was especially important, not previously assessed as a factor associated with identity, and identified as significant within most groups. The heterogeneity in sample characteristics is also a strength, especially regarding cancer type, a notable limitation of previous research (see Chapter 3). Furthermore, including different groups on anticancer treatment (curative and palliative intent), and known to SPCS (largely not on anticancer treatment, suggesting no further anticancer treatment options) provides greater insight and clarity regarding the views of people within these previously under-researched phases.

The study design also had particular strengths. The survey design sought to minimise measurement error through its systematic and evidence-based approach

(reducing error arising from poor questionnaire design (407)). In particular, the simplest structure with the minimum numbers of questions required for the construct was chosen, especially considering the target population (391). The mixed methods approach was also effective. Previous qualitative studies seeking to understand the cancer survivor identity have shown that associated ideas are complex and changing (92, 453), and so the addition of free text responses to fixed-choice questions will have enabled greater understanding of the perceptions of these groups towards the term, and even alternatives (see Chapter 6).

However, the study has limitations. There are numerous potential sources of survey error, including coverage, sampling, and measurement (75) (see section 5.4 Methods). Response bias is likely a particular issue in this study design. Certainly, convenience sampling has limited generalisability to specialist palliative care and oncology populations (420). Moreover, the non-random approach to convenience sampling (depending on factors such as researcher availability or clinic / ward accessibility) may have created unknown biases (458). Similarly, nonresponse was managed by only including records with completed outcomes for the analysis, which can introduce unknown biases. Furthermore, since the population is unknown, and given the study design, the true survey response rate is also ultimately unknown.

A major limitation is that the target sample sizes for the SPC group in Ireland and both UK groups were not reached, despite seven research sites being established in Ireland and 21 in the UK over two years (not all sites recruited). General barriers impacting all groups included the timeline, access to participants, and the ability of collaborators outside of the primary research team to contribute. Moreover, there are well-recognised barriers to research in SPC specifically (459), and recruitment is a common problem (460). Gatekeeping, where people involved in the research process prevent the participation of potentially eligible patients, may have been a particular issue in recruitment to the SPC group, where attitudes are ultimately shaped by gatekeepers' personal feelings instead of objective individual patient assessment (461). Medical and nursing staff, allied healthcare professionals and managers can be concerned about burdening the patient, feel limited by logistics (such as lack of time), as well as attitudes towards research (including doubt about the importance of the proposed study) (461). Furthermore, researchers themselves can feel disruptive in approaching people to participate, or can

become fatigued by the difficulties of recruitment and anticipate high refusal rates (461). Importantly, the POST study is continuing to recruit so that the pre-determined sample size is achieved.

The lack of a control group of individuals with no evidence of disease may also be seen as a limitation. Although the reasons have already been discussed (see section 5.4.3.2 Participants), direct comparison with such a group would have enhanced understanding of results. Finally, despite careful selection of personal and clinical characteristics to be included in the study, there are other potential confounding factors not assessed which may have influenced responses (see section 5.6.1.3.4.3 Uncontrolled confounding factors).

5.6.4 Generalisability

The study has restricted generalisability. Illness theory proposes that illness identity is a dynamic, changing process impacted by experiences over time (453). The cross-sectional study design does not allow for assessment of changing perceptions. Additionally, association in this study does not equate to causality, although reciprocity is likely appropriate to apply to the associations identified (for example, in some groups worse ECOG PS was associated with dislike of the term, so it can be assumed that better ECOG PS was associated with feeling neutral or liking the term).

The sampling approach is perhaps the main limitation to study generalisability. Results from convenience sampling, a form of non-probability sampling, may only be generalised to the group that was conveniently accessible (420, 458). This relates to the particular hospitals, hospices and community systems where the participants were located. In this regard, the study likely had internal validity but deficient external validity since the results cannot be generalised to groups with characteristics differing from the sample (458), as the sample's relationship to the population is ultimately unknown (462). Nevertheless, it has been found that convenience samples provide evidence that can be comparable to that derived from population-based samples (462), and this is the first study of this sample type.

Indeed, certain participant demographics were somewhat limited in heterogeneity. Most participants recruited to previous studies had a history of breast cancer (see

Chapter 3) and similarly most participants in the Onc Ireland group had breast cancer (31.6%). This is perhaps unsurprising with convenience sampling, since breast cancer is the most common cancer in Europe (463). Additionally, although sampled across regions, areas were still limited to Ireland and the UK (particularly England). Even within these, diversity in race / ethnicity was lacking, which prevented robust analysis of this variable. Moreover, the study was only undertaken in the English language, and individuals from other countries likely have different opinions given their varied cultural and ethnic backgrounds (247, 250, 276, 300). The influence of language, region / country, culture, race and ethnicity therefore requires further research. The limitation of recruitment from under-represented groups within the target populations (ethnic minorities, non-binary / other gender) could be addressed by collaboration with certain patient advocacy organisations, and likely conducting smaller studies of alternative styles.

There may also be associations that have not been identified. For example, Dalton et al. found that a majority (78%) of a sample of 70 men with breast cancer liked the term cancer survivor, whereas Deber et al. found that only 0.5% of a sample of men with prostate cancer liked the term. Accordingly, particular subgroups may have unique associations that were not tested for in this analysis, or representation may have been too small for statistical significance.

5.6.5 Implications of study

These results have important implications for service development / models, education of healthcare professionals and students, and future research. At present, cancer survivor terminology is applied in various ways, so this study could better inform this application, as well as ongoing research and development within cancer survivorship care.

5.6.5.1 People who have or had cancer

This study has provided greater understanding of the perceptions of people who have or had cancer about the healthcare terms used to describe them, with some influential terms like cancer survivor proving to be less acceptable than previous studies have demonstrated. Additionally, the study highlights the need to engage people with lived experience in discussions on the application of terminology,

particularly ensuring the whole body of people encompassed by a term are represented. Endorsement of various terminologies has many potential underlying factors, and given the diversity of people who have or had cancer, their cultures, settings and experiences, one universally acceptable term likely does not exist.

There is also relevance for patient advocacy groups and similar organisations. Given the opinions demonstrated in this survey towards the choice of term used to describe people with cancer, participation could be impacted if an alienating term is used (although this has not yet been formally determined) (251). Many include survivorship terminology in their names and literature, but there has already been departure from such use, like the National Coalition for Cancer Survivorship renaming itself Cancer Nation in 2025 (75). Results of this study corroborate the need for these actions to continue.

5.6.5.2 Clinical services and care provision

These results also have important implications for identifying and applying appropriate and sensitive language when describing people who have or had cancer across healthcare settings. The need to reconsider the application of cancer survivorship terminology is highlighted, as demonstrated by the majority of people in the SPC group, and the largest proportion of people in the Onc group disliking the term being applied to them. Furthermore, the variety of responses about who should be called a cancer survivor show that greater clarity of application is needed, allowing services to be provided for the right people in the right way.

Promoting individualised preference regarding the choice of term should be considered within person-centred care. An individual's identity can have important behavioural / psychological consequences, and the two are likely reciprocal (257). As such this can impact an individual's interaction with clinical services, so the high proportion of people who do not like the term cancer survivor may not engage with required services affiliated with the term.

Indeed, the relevance of a service should be easily understood, promoting its accessibility for those individuals. A particularly relevant component of clinical care is survivorship care plans (SCPs), and indeed the impact this nomenclature has on patient engagement is unknown (251). Although typically created post-treatment,

establishing care plans called SCPs for people with stable disease needs to be carefully considered. Moreover, the need to develop culturally appropriate survivorship programmes has also been identified, given the different experiences across settings and cultures (286), promoting professional-patient relationships, and ultimately person-centred care.

5.6.5.3 Research and education

These perspectives of people with cancer should also be regarded when conducting research that includes / refers to these groups. This has particular implications when using the term cancer survivors in trials and literature, influencing recruitment and clarity in results interpretation. The POST study has also demonstrated the need for ongoing research in understanding perceptions across groups of greater diversity of personal and cancer-related characteristics (see section 5.6.4 Generalisability).

This study also highlights areas for public and professional education, predominantly surrounding the preferences of people with cancer regarding the terms used to describe them amongst healthcare professionals, and / or education around the meaning of the term cancer survivors when applied in healthcare settings and academia.

5.6.5.4 Guidelines and policy

Survivorship terminology is widely used in standards and practice recommendations (6), and indeed there are international calls for these to influence research, practice and policy. Although there is extensive evidence of the need for this type of care for people with advanced or metastatic cancer, results of the POST survey corroborate the notion that survivorship is likely not the most appropriate terminology to describe this. The language chosen going forward in this area should recognise opinions demonstrated in this study.

5.7 Conclusion

In this unique survey-based study in Ireland and the UK, more people with cancer known to SPCS, and more people with cancer on anticancer treatment (both curative and palliative intent), disliked being described by the term cancer survivor compared to the proportions that liked the description. In the overall analysis of personal and clinical / cancer-related characteristics, factors significantly associated with disliking the term included residence in Ireland, high educational attainment, being known to SPCS, and higher ECOG PS. Less common cancer types were negatively associated with disliking the term. Regarding alternative terminologies, the highest proportion of both the SPC and Onc groups liked being described as an oncology patient. Crucially, the majority of participants thought the choice of term used to describe people using healthcare services was important.

The trend towards dislike of the cancer survivor term, the significant difference between the SPC and Onc group opinions towards the term, and the lack of significant associations with many potentially relevant personal and clinical characteristics, reinforce that careful consideration is required when describing people who have or had cancer with certain terms or labels, and perhaps overall the need to ask individuals their preference. In particular, and corresponding with the PRiSM study, the findings reported here suggest that application of cancer survivor to people with active cancer should be reconsidered across clinical and academic settings.

Chapter 6: “How can you call me a cancer survivor if I’m not going to survive?” Content analysis of free text responses in the Palliative care and Oncology Survey on Terminology (POST) on how people with cancer perceive the term “cancer survivor”.

6.1 Abstract

Introduction

Cancer survivorship terminology is commonly applied to people with advanced or metastatic cancer in clinical and academic settings. Interpretation and endorsement of the term “cancer survivor” is variable amongst people with a history of cancer, but the perceptions of people with active cancer have been previously under-represented. The aim of this part of the Palliative care and Oncology Survey on Terminology (POST) was to understand the perceptions of people with cancer known to SPCS, and people with cancer on anticancer treatment in Ireland and the UK about the term cancer survivor.

Methods

Individuals with cancer on anticancer treatment and known to SPC and oncology services were recruited from cancer centres and SPCS across Ireland and the UK, and completed a study-specific questionnaire. Inductive content analysis was used to identify themes from optional free text responses about the term “cancer survivor”.

Results

1328 participants completed the study, and 766 (57.7%) provided comments about the term “cancer survivor”. The majority of comments were negative (n=547; 71.5%). Participant perceptions were summarised into five themes: there is uncertainty around “cancer survivor” (“cancer survivor” can be unclear; it can create misperceptions; its need is questionable); there are challenges applying “cancer survivor” universally (the term’s use should be an individual’s choice; labels are not always appropriate; the term is inappropriate for people who still have cancer); “cancer survivor” may be used to describe certain groups (referring

to an event that is over; dependent on certain conditions); “cancer survivor” often evokes negative feelings, but can also be viewed positively; and different wording may be preferable (alternative terminology is available; alternative options are limited).

Conclusion

People with cancer known to SPC and oncology services provided overwhelmingly negative comments about cancer survivor terminology and demonstrated a range of interpretations of the meaning. The potential confusion, alienation and offence this term can cause highlights the need to reconsider its use in clinical and academic settings.

6.2 Introduction

6.2.1 Problem formulation

There is much variation in interpretation of the term “cancer survivor”. Previous studies have shown that individuals with a history of cancer apply different meanings to the term, such as people who are alive, people who no longer have evidence of disease, or people who have undergone a battle (see Chapter 3). An individual’s understanding of the meaning of a term is likely to influence their endorsement (281), which is consequently also variable. A qualitative systematic review categorised the attitudes of people with a history of cancer as embracing (accept and identify with the term), constructive (create their own definition to identify with it), ambiguous (uncertain), resisting (dislike and disregard the term), and non-salient (indifferent) (90). A consequent study that explored the views of people with a history of colorectal cancer (including those on treatment) summarised ideas into similar themes of aversion, discomfort, indifference, reluctance, and acceptance (249).

However, as demonstrated in Chapter 3, these perspectives, although diverse, largely represent people who no longer have evidence of disease. Given that the NCI defines cancer survivors as any individual from the point of diagnosis (17), the breadth of people included in this identity are not currently represented.

Additionally, individual perception and identity is changeable (92, 453), relevant when considering people’s perceptions within the different phases of treatment or disease. There is a particular lack of evidence and understanding about the terminology in relation to the emerging population of people living longer with advanced / metastatic cancer (285), despite its frequent application to them (6). Importantly, one small qualitative study of people with advanced lung cancer on treatment showed that they generally viewed survivor and other battle terms negatively (285).

Results from the previous chapter demonstrate the general lack of endorsement of cancer survivor terminology by people with cancer known to SPCS and those on anticancer treatment. The underlying reasons should be identified, including interpretations of the term cancer survivor, enhancing comprehension of these results.

6.2.2 Purpose

The aim of this part of the Palliative care and Oncology Survey on Terminology (POST) is to understand the perceptions of people with cancer known to SPCS, and people with cancer on anticancer treatment (that is, people with active cancer), in Ireland and the UK, and about the term “cancer survivor”.

6.3 Methods

The study is reported according to Standards for Reporting Qualitative Research (464).

6.3.1 Qualitative approach and research paradigm

Qualitative research encompasses different approaches, including narrative research (exploring the life of an individual), phenomenology (studying human experiences), grounded theory (developing theory from real-world data), ethnography (describing people and their culture), and case study (in-depth understanding of complex real-life issues) (465). This study used a qualitative descriptive design, which aims to generate a focused yet comprehensive summary of results by describing an experience, perception or event through low-inference data analysis (446). Typical characteristics include pragmatism, flexibility, naturalistic inquiry (seeking to understand real experiences within individuals' natural environments), purposeful sampling (intentional selection of desired characteristics for maximum variation), content analysis (see below), and clear presentation of organised, accurate results (466). This approach was appropriate for the study's aim to understand the perceptions of people with cancer about the term cancer survivor on a descriptive level, effectively and comprehensively summarising ideas using participants' language and reflecting their original intention (446, 466, 467). It is deemed to be less theoretical than other approaches, informed by existing knowledge and linked to previous work as well as the researchers' clinical expertise (468), enabling greater flexibility in design to meet outcomes (446), particularly for clinically relevant issues (467). This approach is also commonly used in mixed methods surveys, making it ideal for the POST study; it can complement and explain quantitative results whilst highlighting the subjective nature of participants' experiences, enhancing meaning (469), and

indeed capturing data not represented quantitatively (467). Furthermore, other qualitative approaches, such as phenomenology, would seek to generate more detailed understanding and underlying theory, which is not the aim of this research, and would use alternative data collection methods (such as interviews).

A research paradigm is a set of beliefs that inform research inquiry (470), based on different philosophical assumptions regarding axiology (values and ethics), ontology (nature of reality), epistemology (nature of knowledge) and methodology (research design) (470). Positivism (assuming that a single objective reality can be obtained through measurement) and constructivism (assuming there are multiple subjective realities at individual levels) are two main paradigms (471). The previous chapter adopted a post-positivist approach, common in medical research, which asserts that objective realities can only be known imperfectly as knowledge is subject to human error (471). Categorical survey responses are typical data sources for this paradigm. However, the open-ended free text responses in the POST study also allowed participants to share their subjective interpretations. Qualitative descriptive analysis aligns with a constructivist research paradigm and the view that reality is perceived differently according to individuals' unique contexts (467). This approach was taken to complement findings of the former chapter, which identified that more individuals with cancer disliked being described as a cancer survivor compared to the number that liked the description, to explore the numerous underlying reasons.

6.3.2 Researcher characteristics and reflexivity

Researcher reflexivity refers to the characteristics and roles of the researchers (464). Reflecting on potential biases is essential for research integrity (472), especially in qualitative descriptive analysis which depends on researcher sensibilities (466). One researcher (AT) was responsible for the background literature reviews and study design (supervised by AD), and undertook the majority of data collection, processing and management in Ireland, and overall quantitative analysis. AT was therefore very familiar with the study background and data, possibly enabling presuppositions in dual data collection and analysis. However, although AT undertook data collection, the written questionnaire format likely minimised her influence on participant responses (since respondents completed free-text responses themselves, or AT transcribed responses verbatim). This

restricted bias-inducing interaction between the researcher and respondents (473), whilst promoting researcher understanding of the context of participant comments.

The second researcher involved in analysis (CG) was not involved in study design or conduct, so was distanced from the data with fewer initial assumptions. Both researchers had some qualitative research experience and were palliative medicine physicians. The latter may be advantageous for the study sample (people with cancer known to SPCS or on anticancer treatment), as the researchers were familiar with the study population. However, this may also have contributed to preconceived ideas about participants' attitudes. Finally, the researchers had personal views about cancer survivorship terminology and needed to separate these from the data.

6.3.3 Context, sampling strategy, data collection and processing, ethical issues

The POST study was a multicentre cross-sectional survey in Ireland and the UK between September 2023 and October 2025. Purposeful sampling is typical for a qualitative descriptive study (466, 467). Given the large recruitment target, convenience sampling was applied, nevertheless, the diversity of sites and clinics selected enhanced variation and supported rigour (472). Sample size was determined by the POST study's quantitative objectives, whereas it is normally determined by informational need in qualitative studies (343). However, given the large target number, it was assumed that data saturation (when no new additional information can be obtained and further coding is impracticable (474)) would be achieved within this. Moreover, data richness and data thickness are deemed primary quality markers of qualitative research (475). Data richness is determined by the depth of conceptual interpretation, relating to its transferability and data transformation (the degree of meaning derived from participants' perspectives and how current understanding is developed by the findings); data thickness refers to contextual description (476). Data richness would be increased by the diversity of participants and the analytical approach (discussed below), and appreciation of participants' contexts would also increase data thickness (476).

The questionnaire design, recruitment and consent process, ethics review board approvals, confidentiality and data security issues, and data processing are outlined in the previous chapter. Providing an open response to the final question,

“Do you have any other comments about the term, “cancer survivor”?” was optional. Questionnaire free text responses are common data sources in qualitative descriptive studies (446).

6.3.4 Data analysis

Content analysis was used to interpret the free-text responses, a systematic and transparent process to describe and quantify phenomena (342, 343, 477), enabling understanding of the text, and providing valid inferences and new insight (477). Practical guidance was used to inform the process, including preparation, organisation and reporting (343, 477, 478). Content analysis is the most common approach in qualitative descriptive studies since it requires low-inference interpretation, enabling researchers to stay close to the data itself (466). Indeed, it was appropriate since the intended outcome was to generate understanding and clarify concepts, not to establish theory (466, 479).

Furthermore, content analysis was useful for this study since it has both qualitative aspects (data presented as words / themes, enabling interpretation) and quantitative aspects (facts reported according to frequency) (478). Within qualitative descriptive studies, providing corresponding descriptive statistics of concepts enhances the depth of description (466), increasing understanding about their size of influence (478), particularly when combined with quantitative results in mixed methods studies (Chapter 5). This contrasts to thematic analysis, where over-arching ideas and how they interact are inferred, but the frequency has no consequence (480). Although time-consuming, the method is flexible and can be applied to any textual data (477, 478), so it is especially helpful for large data quantities requiring some interpretation, as generated by the POST study (473). Previous studies have also utilised content analysis to understand open-ended survey questions (478).

Core steps in content analysis include selecting the unit of analysis, creating categories (compressing texts into smaller numbers of related groups with similar meaning, that are mutually exclusive (473)), and establishing themes (linking meaning within and across categories to form overall concepts supporting underlying explanation (473, 481)). There are no recommendations for the size of analysis units or number of data subjects, merely that they should be sufficient for

the research question (478). All data were therefore analysed, and units of analysis (phrases within free-text responses) were divided into groups according to treatment status, and whether known to SPCS, and analysed accordingly.

Content analysis can be inductive (particular phenomena are observed and combined into larger statements), and / or deductive (movement from the general to specific based on previous theories / models) (473, 477). An inductive approach is recommended when there are no previous similar studies, or the evidence is fragmented, whereas the deductive approach is appropriate to test earlier theories in new situations (477). Wee et al. (249) formerly sought to determine the perspectives of a group of people with colorectal cancer towards the term cancer survivor, some of whom were on treatment, and identified five themes (aversion, discomfort, indifference, reluctance, and acceptance (249)), so a deductive approach was considered (477). However, such directed content analysis is inherently limited since using previous findings to predict outcomes is strongly influential (479). This may be especially problematic when predetermined categories are vague, and these previous themes did exhibit some obscurity (479). Additionally, researchers are more likely to find supportive than non-supportive evidence, and it can limit identification of differences within the new context, impacting neutrality and trustworthiness (479). Former studies also involved convenience sampling, which limits generalisability, supporting the preference for study replication (462).

Conventional (inductive) content analysis was therefore chosen to create new insights and categorisations from the data itself, and ultimately richer understanding of the phenomenon (479). Within this, analysis can be manifest (surface structure, using words close to the original text) or latent (deep structure, inferring the underlying meaning) (478). Both were applied; manifest analysis is appropriate for initial keywords, but most studies use latent analysis to generate themes, deducing meaning from participant comments (482).

Qualitative comments were transposed to NVivo version 12.7.0. Two researchers (AT and CG) undertook each stage independently before collaboratively reviewing findings and resolving disagreement by consensus. In the preparation phase, coding rules were agreed: phrases were used as the unit of analysis; all statements would be coded; and the frequency of concepts would be counted (342, 343, 477). The researchers familiarised themselves with the data content.

Participant responses were identified as positive (supported / praised the term), negative (disliked / rejected the term or its definition) or neutral (no opinion about the term, or mixed views). Keywords were extracted from each unit to guide preliminary coding in the organisation phase. The researchers kept memos during the process and followed an analysis schedule (consisting of meaning units, keywords, codes, subcategories, categories, and themes, representing consecutively higher levels) (478). In open coding, meaning units were labelled with codes based on the keywords and maintained with a coding list, and the process was repeated and adjusted (477, 478). Content analysis ultimately uses a data reduction process, that is, limiting analysis to the data associated with the research question (473), ensuring that results closely represent the participants' statements. The researchers therefore agreed to exclude certain irrelevant data (478). Consecutively broader subcategories, categories and themes were identified and refined (477, 478), named and defined according to content (477, 479). Exemplars for each were identified to support reporting (479). The process was carried out for the first 1000 participants recruited to the study and then iteratively with responses from the final 328 participants. No new codes were derived in this latter part (data saturation) (474). Analysis was concluded when the researchers determined that reasonable explanation was achieved (478), and data richness was satisfactory (476).

6.3.5 Techniques to enhance trustworthiness

As outlined in Chapter 4 (section 4.10.9.3), trustworthiness refers to credibility, dependability, confirmability and transferability (336, 372). Triangulation (using multiple methods / data sources to develop comprehensive understanding (483)) was employed by collecting and combining data across groups and regions, enhancing credibility. This could be further supported by other data collection methods (such as interviews). Using multiple researchers to undertake analysis also increased credibility, with a third colleague (AD) sense-checking results, without coding the data formally (472, 478).

The analytical approach has been detailed (477). Maintaining analysis schedules and memos reduced the margin for error, enhancing dependability, although human error and biases are always possible (478). Researcher reflexivity (self-reflection about their role) is important in confirmability, so the researchers kept

memos to consider and understand their biases during the process (472, 477, 484). Additionally, use of manifest analysis to generate initial keywords and preliminary codes increased researcher ability to maintain objectivity (478). Transferability is supported by providing information about participant demographics, as well as clarifying the analytical process (481), although ultimately restricted by any limitations within these (see section 6.5.5 Strengths and limitations).

6.4 Results

6.4.1 Units of study

The study was completed by 610 participants known to SPCS, and 718 participants known to oncology on anticancer treatment (1328 altogether). The demographics of study participants can be found in Chapter 5, Table 18. Most participants provided a response to the qualitative question (n=766, 57.7%). Table 24 shows the breakdown according to treatment status and regional subgroups, and Table 25 shows the proportion of comments which were positive, negative and neutral.

Table 24: Proportion of participants that provided comments according to subgroup.

Participant group	Treatment subgroup	Regional subgroup (number of participants)	Comments n (%)
SPC	Not on treatment	IE (n = 186)	125 (67.2%)
		UK (n =184)	80 (43.5%)
		Total (n = 370)	205 (55.4%)
	On treatment	IE (n = 124)	91 (73.4%)
		UK (n = 116)	70 (60.3%)
		Total (n = 240)	161 (67.1%)
	Overall	IE (n = 310)	216 (69.7%)
		UK (n = 300)	150 (50.0%)
		Total (n = 610)	366 (60.0%)

ONC	Curative	IE (n = 164)	113 (68.9%)
		UK (n = 105)	39 (37.1%)
		Total (n = 269)	152 (56.5%)
	Palliative	IE (n = 219)	141 (64.4%)
		UK (n = 230)	107 (46.5%)
		Total (n = 449)	248 (55.2%)
	Overall	IE (n = 383)	254 (66.3%)
		UK (n = 335)	146 (43.6%)
		Overall (n = 718)	400 (55.7%)
Total (n = 1328)		766 (57.7%)	

Key: SPC = participants with cancer known to specialist palliative care services; ONC = participants with cancer on anticancer treatment; IE = Ireland; UK = United Kingdom.

6.4.2 Types of comment

In the previous chapter, when participants were asked to select a fixed-choice response to being described as a “cancer survivor”, 618 disliked the description, 309 were neutral and 401 liked the application. Within these response categories, 463 participants who disliked the description provided a free text comment (60.4% of all comments), 123 who responded neutrally (16.1%) and 180 who favoured this use (23.5%).

Table 25: Types of comments within each subgroup.

Group (number of comments)	Positive n (%)	Neutral n (%)	Negative n (%)	Not coded n (%)
SPC – not on treatment (n = 205)	24 (11.7%)	22 (10.7%)	156 (76.1%)	3 (1.5%)
SPC – on treatment (n = 161)	14 (8.7%)	23 (14.3%)	118 (73.3%)	6 (3.7%)
SPC – overall (n = 366)	38 (10.4%)	45 (12.3%)	274 (74.9%)	9 (2.4%)

ONC – curative intent (n = 152)	23 (15.1%)	27 (17.8%)	100 (65.8%)	2 (1.3%)
ONC – palliative intent (n = 248)	41 (16.5%)	31 (12.5%)	173 (69.8%)	3 (1.2%)
ONC – overall (n = 400)	64 (16.0%)	58 (14.5%)	273 (68.3%)	5 (1.2%)
Total (n = 766)	102 (13.3%)	103 (13.4%)	547 (71.5%)	14 (1.8%)

Key: SPC = participants with cancer known to specialist palliative care services;
ONC = participants with cancer on anticancer treatment

6.4.3 Themes

Content analysis of participant responses revealed five themes: 1) there is uncertainty around “cancer survivor”; 2) there are challenges applying “cancer survivor” universally; 3) “cancer survivor” may be used to describe certain groups; 4) “cancer survivor” often evokes negative feelings, but can also be viewed positively; and 5) different wording may be preferable. Table 26 provides a summary alongside the frequency of codes across the groups. In Appendix 9, links to empirical data are demonstrated through representative quotes according to anticancer treatment status, intent, and involvement with SPCS within each sub-category.

Table 26: Themes, categories, subcategories and codes, and frequencies according to subgroups.

Theme	Category	Sub-category	Code	Frequency (number)				
				SPC no tx (n = 205)	SPC on tx (n = 161)	Onc cur (n = 152)	Onc pall (n = 248)	Total (n = 766)
There is uncertainty around “cancer survivor”	“Cancer survivor” can be unclear	Lacks clarity	Confusing	7	10	4	11	32
		Uncertainty surrounding cancer	Limbo	6	2	4	5	17
		More education is needed	Education	1	2	1	0	4
	“Cancer survivor” can lead to assumptions	False impression	Misleading	7	4	9	7	27
		Cancer can recur	Come back	6	7	4	9	26
		The cancer experience is never really over	Never free	9	6	9	10	34
		Implies responsibility	Choice over situation	7	5	4	11	27
			Choice over outcome	1	3	4	7	15

	The need for a term is questionable	A term is unnecessary	Leave it behind	2	2	0	7	11
			Irrelevant	2	3	1	4	10
			Unlike other diseases	2	6	3	4	15
		Indifference towards the term	Indifference	11	6	2	8	27
Challenges with applying “cancer survivor” universally	Use of the term should be an individual’s choice	Individuality	Personal preference	14	12	9	10	45
			Personal experience	5	0	5	9	19
			Change over time	3	3	5	2	13
	Labels are not always appropriate	Dislike of being labelled	Label	7	8	8	9	32
		Dislike of being defined by cancer	Define	2	7	7	6	22
	The term is inappropriate for people who still have cancer	People who still have cancer have not survived it	Still have cancer	12	9	5	5	31
		Some people with cancer will die from cancer	Death	15	7	4	4	30

		It is not appropriate for people with a limited prognosis	Terminal	4	10	0	4	18
			Palliative	2	1	0	1	4
“Cancer survivor” may be used to describe certain groups	An event that is over	A “cancer survivor” should be cancer free	Cancer free	27	17	13	28	85
			Treatment completed	6	5	12	7	30
			Time related	5	2	3	5	15
		The cancer experience has been overcome	Gone through it	1	2	5	2	10
			Battle won	0	2	2	4	8
			Certain outcome	1	0	3	4	8
	Certain circumstances	It depends on certain conditions	Setting	0	0	2	5	7
			Cancer type	2	3	1	2	8
			Anticancer treatment	2	1	0	4	7
			Personal threat	0	2	3	4	9
			Quality of life	3	1	1	2	7
			Timeline from diagnosis	3	0	2	8	13
			Particular groups	1	0	0	2	3
“Cancer survivor”	“Cancer survivor” can	Negative emotional responses	Distress	2	4	4	2	12
			Insulting	4	4	2	1	11

often evokes negative feelings, but can also be viewed positively	evoke negative feelings		Victimising	4	0	2	3	9
			Resentment	0	2	0	1	3
		“Cancer survivor” is disagreeable	Ridiculous	8	2	1	11	22
			Too dramatic	2	3	3	2	10
			Too broad	2	4	1	7	14
			Unhelpful “battle” terms	7	3	9	12	31
			Dislike / avoidance of the words	12	8	3	12	35
	“Cancer survivor” can evoke positive feelings	Positive emotional responses	Positive	4	5	13	13	35
			Hopeful	6	7	6	10	29
			Proud	1	3	0	2	6
			Strong	2	0	0	2	4
			Grateful	2	0	0	0	2
		“Cancer survivor” is agreeable	Inclusive	11	4	8	12	35
			Still alive	1	1	1	6	9
			Fighting the battle	3	2	1	6	12
Different wording	Alternative terminology	Accurate descriptions	Factual	4	1	4	9	18

may be preferable		Other terms are proposed	Alternative wording	5	10	15	6	36
			“Living with cancer”	9	16	5	17	47
			“Surviving”	1	4	3	3	11
	Limited alternatives	Limited options	What else	2	0	5	4	11

Key: SPC no tx = participants with cancer known to specialist palliative care services not on treatment; SPC on tx = participants with cancer known to specialist palliative care services on treatment; ONC cur = participants with cancer on anticancer treatment with curative intent; ONC pall = participants with cancer on anticancer treatment with palliative intent.

6.4.3.1 Summary of themes

Theme 1: There is uncertainty around “cancer survivor”

“Cancer survivor” can be unclear

Many participants across the groups expressed confusion surrounding the term, particularly the lack of clarity regarding who could claim the identity, and if a change in status (such as recurrence) could affect that claim.

“I like things that are clear cut - that's just like putting a plaster over the issue”

(Specialist palliative care group, not on treatment)

Similarly, some participants across groups felt there is too much uncertainty around the cancer itself, with many feeling in limbo, without enough assurance about the outcome to adopt the term.

“No way! That's wrong. I'm on treatment, going along the road and waiting for all those tests to tell me if the treatment is working or not.”

(Oncology group, curative-intent treatment)

Consequently, most of the groups alluded to the notion that more education is needed, either regarding the meaning and application of cancer survivor terminology, or indeed the cancer itself.

“It doesn't have to be that scary. More needs to be explained... I just think there should be more education about cancer.”

(Oncology group, curative-intent treatment)

“Cancer survivor” can lead to assumptions

Given this confusion, people across all groups focused on the fact that using “cancer survivor” could lead to misplaced assumptions. Many felt the term was misleading, giving false impressions about the reality or hope of a situation, perhaps by suggesting cure where it was not possible.

"I'm never going to be free of cancer so I won't ever be a survivor. There's no point in painting a picture that's wrong or misleading."

(Specialist palliative care group, not on treatment)

Others felt even if people had no evidence of disease, the risk of cancer recurrence would always exist, and the cancer survivor identity suggested greater certainty than could be grasped. Indeed, some people shared examples of experiencing recurrence personally, or people close to them, leading them to feel they could never claim the status.

"No one can guarantee a 100% survival from cancer nor that it won't come back despite all the treatments and drugs. I have secondary breast cancer which is incurable despite the treatments first time round."

(Specialist palliative care group, palliative-intent treatment)

Similarly, others proposed that even if people had no evidence of disease, the risk of consequential ongoing physical, psychological and / or social struggles, meant they would never really be "free" of cancer.

"I don't think you ever really survive cancer, do you? Even if it isn't physically there, it will still always be in your mind."

(Specialist palliative care group, not on treatment)

Accordingly, others suggested that "cancer survivor" implied responsibility or choice over their current situation, or even over the outcome as one of success or failure, depending on how hard they had fought.

"It implies failure in those who are unable to be cured and strength in those who achieve cure. To attribute responsibility to a patient for their outcome, which is beyond their control, is unhelpful."

(Oncology group, palliative-intent treatment)

The need for a term is questionable

There was also uncertainty about the need for a term at all. Some people across all groups saw it as irrelevant to their current situations. Some people on palliative intent treatment or known to SPCS also felt that if people had the opportunity to be cancer free, then they should leave it behind rather than adopt a cancer-related identity.

“My overriding feeling is that it is important to feel as much as possible like a normal person, not to be reminded that you have cancer by the words used.”

(Specialist palliative care group, palliative-intent treatment)

People across all groups identified that using this term for people with a history of cancer gave cancer a different status from other diseases that wasn't required.

“You don't call someone with any other disease a survivor of that, do you?”

(Specialist palliative care group, palliative-intent treatment)

Some people across all groups demonstrated apathy / indifference towards the term and its use:

“Does it matter? If you have survived then what is wrong with the term? This really is a “first world” question! Who cares!”

(Oncology group, palliative-intent treatment)

“It's a bit silly to be worried about that in life when you're dying of cancer.”

(Oncology group, palliative-intent treatment)

Theme 2: Challenges with applying “cancer survivor” universally

Use of the term should be an individual's choice

It was frequently perceived that use of the term should be an individual's choice, based on either personal preference or personal experience. It was also widely considered that such individual opinion was likely to change over time.

"As we are all individual, it would seem only right that everyone was asked their own preference."

(Oncology group, palliative-intent treatment)

"Your opinion on this can change during your experience, can even change day to day!"

(Oncology group, curative-intent treatment)

Labels are not always appropriate

Others across groups took issue with "cancer survivor" as a label, with many disliking labelling in general, and others specifically disliking being defined by a cancer-related term.

"Labelling people is the problem - it doesn't help. You have to be very careful with words, particularly with cancer...Some get through it, but a lot of people don't get through it. There are so many cancers and so many different ways it affects people, so we can't all be labelled the same."

(Specialist palliative care group, palliative-intent treatment)

"Not sure cancer is a badge I want to wear at any time - now or later."

(Oncology group, curative-intent treatment)

The term is inappropriate for people who still have cancer

Many suggested that the term is not appropriate for people with active cancer, since they have not survived it yet, and particularly unsuitable for people who risked dying from cancer. People on a palliative pathway alluded to particular words including "terminal" and "palliative" which they did not feel could co-describe people also described as "cancer survivors".

"How can you be called a survivor if you're not going to survive?"

(Oncology group, palliative-intent treatment)

Theme 3: “Cancer survivor” may be used to describe certain groups

An event that is over

Those who found the terminology acceptable generally preferred a restricted application instead of broadly referring to any individual from the point of a cancer diagnosis as a cancer survivor. Some individuals from all groups equated it to a completed event: reaching the point of no evidence of disease, treatment completion, or after a certain amount of time (typically 5 years).

“‘Cancer survivor’ should be restricted to someone who has survived cancer and is cancer free for a pre-determined period.”

(Oncology group, palliative-intent treatment)

Others were less factual in their application, and applied it to people where the cancer experience had been overcome, in terms of something people had “gone through”, or indeed a battle that had been won. Moreover, people from most groups specified it was only when that outcome was certain (i.e. cure) that it was appropriate.

“It suggests you’ve gone through the trench and come out the other side of the battle...you may or may not come out the other side.”

(Oncology group, curative-intent treatment)

Certain circumstances

Some people attributed the term to certain circumstances / conditions, such as particular cancer types, or an acceptable quality of life. People on a palliative pathway specified certain types of anticancer treatment, especially chemotherapy, and some people on anticancer treatment proposed the term depended on a personal threat to life, or was only appropriate in certain settings / locations. Some individuals had very alternative applications of the term, describing particular groups.

"Living with cancer means you have a bit of quality. No point in being alive if you don't have quality of life - then you can't be a survivor. So it all depends on the individual."

(Oncology group, palliative-intent treatment)

"A cancer survivor should have been through at least 1 round of radiotherapy or chemotherapy. Less about the cancer and more about the treatment."

(Specialist palliative care group, not on treatment)

Theme 4: "Cancer survivor" often evokes negative feelings, but can also be viewed positively

"Cancer survivor" can evoke negative feelings

"Cancer survivor" was an emotive term for many participants. A number described negative responses, including distress / upset, and feeling personally insulted. Others equated survivor with victim terminology. The groups on palliative-intent treatment (within both the oncology and specialist palliative care groups) also suggested the term could make them resentful of people who had curable cancers.

"This term makes me feel sad and fearful. It's like you should be dead, but managed to survive, this time. But death is somewhere around you, waiting."

(Oncology group, curative-intent treatment)

"It is like adding insult to injury to call someone a cancer survivor when the person is currently struggling with the debilitating effects of the illness and treatments. Much worse if all treatments have failed and the person is now on terminal stage of the illness."

(Specialist palliative care group, not on treatment)

"I'm not sure though if I have a dislike of the term, or rather envy of people who have achieved cancer survivor status, and have no evidence of disease and are actually free."

(Specialist palliative care group, palliative-intent treatment)

Respondents across all groups also found “cancer survivor” to be disagreeable in various ways. Some described its application to any individual from the point of diagnosis as ridiculous, and others as too broad. Additionally, some people across all groups found battle / fighting terminology unhelpful, too dramatic, or specifically disliked the word “survivor”, or even the word “cancer” being associated with them.

“Where are these people coming from? Are they stupid?”

(Specialist palliative care group, not on treatment)

“This all-encompassing attitude is over-stepping.”

(Oncology group, curative-intent treatment)

“Cancer survivor” can evoke positive feelings

Positive reactions were also described. People across all groups identified that “cancer survivor” could be positive and hopeful. People on palliative-intent treatment and known to SPCS said they would be “proud” to be known as a cancer survivor, and that it would represent strength. People known to SPCS not on treatment were the only group to specifically equate the term with gratitude.

“I am extremely grateful thus far to be able to use the term 'survivor'.”

(Specialist palliative care group, not on treatment)

A number appreciated the inclusive, all-encompassing nature of the description. Others found it acceptable for people who are still alive, and some endorsed the language of a metaphorical battle.

“I think anyone diagnosed is a cancer survivor. Even if they can't receive any more treatment they have survived the battle even if not cancer free. I feel you are a survivor from the day you get told. A true battle.”

(Oncology group, curative-intent treatment)

Theme 5: Different wording may be preferable

Alternative terminology

A common theme across all groups was consideration of alternative options. Using factual, accurate descriptions instead was particularly popular. The terms “living with cancer” or “surviving” were identified as being preferable to “cancer survivor”, and less frequent suggestions included person-first language, “cancer patient”, “patient”, “cancer thriver”, “warrior” / “fighter”, or rescinding all terms and simply using people’s names.

“You have cancer and that’s it. Keep it factual.”

(Specialist palliative care group, not on treatment)

“Being treated for cancer that has extended their life (including quality) is surviving cancer or better still living with cancer.”

(Oncology group, palliative-intent treatment)

Limited alternatives

However, some people from most groups acknowledged that although “cancer survivor” wasn’t ideal, there are limited alternative options, and were unsure what could be used in its place.

“I don’t like the term personally, but I know some term has to be used. It’s hard to find the right one though.”

(Oncology group, palliative-intent treatment)

6.5 Discussion

This part of the POST study sought to understand the perceptions of people with active cancer about the term cancer survivor, and showed that people known to SPCS or undergoing treatment for cancer have largely negative views about cancer survivorship terminology. Overall, 71.5% of comments were negative, reinforcing quantitative findings from Chapter 5. Furthermore, even when the terminology was found to be acceptable, participants mostly preferred application to people with no evidence of disease (instead of any individual who has or had

cancer), aligning with corresponding expert opinion from the PRiSM project (Chapter 4). These important results reinforce the need to reconsider application of cancer survivor terminology to people with active cancer.

6.5.1 Alignment with previous studies

The study illustrates similar findings to previous research. Cheung and Delfabbro's (90) review summarised the attitudes of people with a history of cancer towards "cancer survivor" into five categories, reinforced by subsequent studies (Chapter 3). The stances of rejection (90), acceptance (90), uncertainty (90), and indifference (90, 261, 266, 268, 294) appear universal in the POST study. Corresponding reasons for these perspectives were likewise identified, including accepting the term by viewing its description as suitable (267), rejecting the term by considering it to be inappropriate / offensive (252, 262, 263, 280, 281), particularly for people with incurable disease (281), or by rejecting labels altogether (252, 264, 279, 280, 295, 296).

Negative perceptions were particularly dominant. Prior studies also displayed substantial negativity: Berry et al.'s (252) cross-sectional survey of people with a history of breast cancer identified mostly negative comments (59.83%) compared to positive (29.35%); Wee et al. (249) surveyed people with a history of colorectal cancer, whose negative comments related to aversion (24.9%), discomfort (5.0%), and reluctance (26.9%). In these studies, the majority of participants had completed treatment but some (<25%) were still on treatment. The POST study (71.5% negative comments) therefore affirms and expands upon the unfavourable connotations surrounding cancer survivorship terminology, particularly amongst people with active cancer.

Unsurprisingly, another emergent idea was the variable interpretation of the meaning of "cancer survivor". Chapter 3 summarised results from previous studies, where the most common definitions were someone who was alive or someone who was cured (and had completed treatment). The POST study uniquely offers the perspective of people mostly with incurable disease, and their association of the term with a cancer-free status was particularly common, relatedly considering the term to be misleading when applied to people with a palliative diagnosis. Association with a specific timeframe was again demonstrated

(252, 254, 256, 258, 260, 264, 271-273, 278, 291, 294, 298), including the traditional concept of being 5 years cancer-free (252, 254, 256, 258, 260, 271, 272, 278, 294); other dependent factors included the type of anticancer treatment (92, 249, 262, 268, 298), or quality of life (285). Some participants alluded to the cultural / regional relevance of the term, particularly within the USA, and especially the breast cancer community (90, 258). Only a minority considered the inclusivity of an all-encompassing term from the point of diagnosis acceptable, resembling the minority who liked being described by the term. Uncertainty, both regarding cancer survivor terminology and cancer itself, was a frequent finding, reflecting the ambiguity similarly demonstrated in the literature (15).

These findings give rise to important considerations. Despite the existence of cancer survivor terminology for decades, the meaning ascribed by people with a history of cancer remains disparate from the most common definition used in healthcare services and academia. As one participant outlined, "If there is a new definition...then there should be a clear structured campaign for the public to highlight this change in meaning, so as to avoid confusion." This demonstrates the insufficiency of current public education, and indeed the perpetual confusion that arises around this terminology.

The concept that individuals may accept the term by constructing their own definition (90) was also apparent, and likewise that an individual's understanding of its meaning influenced their endorsement (281). Importantly, this illustrates that most people see a role for the term, but not for every person who has or had cancer, and often not individually. This adds credibility to the corresponding consensus statements from the PRiSM project, which concluded that "cancer survivor" should only be applied to people with no evidence of disease. Interestingly, this is contrary to the foundational ideas of the cancer survivor identity, which sought to unite people with cancer or a history of cancer through an empowering term (75). By constructing an alternative definition, individuals with active cancer endorse the term for others but reject it for themselves, and may be more positive towards the term as a result, in light of the many potential negative reactions (distress, insult) described.

Furthermore, the opportunity for free-text responses allowed individuals to declare that their current perception could change, as previous studies also noted (92, 453), with the process leading to its acceptance or rejection multifaceted and non-

uniform, and often through comparison with others, rather than at a pre-defined point (90).

6.5.2 Importance of choice of term

As outlined in the previous chapter, 65.6% POST participants considered the choice of term to be important. Qualitative responses provided insight into underlying reasons, including the risk of emotive reaction, or application being confusing, inappropriate or disagreeable. Although indifference was recorded, it was less common than negative comments.

Interestingly, results also questioned the need for a term at all, with some taking issue with labelling in general, being defined by cancer and others simply seeing it as unnecessary. These concepts also support a pragmatic categorisation of people who have or had cancer, such as that developed in the PRiSM project, where factual descriptions were identified as preferable in directing care provision. Results therefore have important implications for identifying and applying appropriate and sensitive language within healthcare.

6.5.3 Differences from previous studies

Certain ideas had differing prominence from other studies. POST participants did not emphasise participation in the cancer survivor community, highlighted in previous studies as a factor in the term's endorsement (90, 252, 265, 282, 296). It might be assumed since the majority of participants did not like the identity, they would not feel camaraderie with its social community. Within the era of greater numbers of people living longer with cancer, the demographics and perspectives of people who have or had cancer are changing, and the appropriateness of terminology used within the public domain should be reconsidered.

Former studies have repeatedly likened cancer survivorship terminology to battle terminology (249, 254, 260, 262, 265, 266, 268, 269, 273, 274, 278). Interestingly, this alignment was less dominant in POST, especially "winning the fight" (252, 256, 272, 275, 294, 296), and indeed the link was often criticised when identified, particularly the implication that people had choice / responsibility over their

situation or outcome. This is perhaps even more isolating and emotive than the idea of chance, described in previous studies (254, 260, 272, 274, 278, 298).

6.5.4 Development of previous understanding

This study generated certain ideas that refine and enrich previous research (479). The threat of death was more apparent amongst POST participants, with death / similar words mentioned 30 times, and “terminal” 18 times. Previous studies associated “cancer survivor” with people who were not going to die from cancer (249, 260, 265), whereas POST participants also stated that the term is inappropriate for people who will die from cancer, likely reflecting that most participants had incurable disease.

Moreover, results provided greater detail about the types of negative reaction cancer survivor terminology can evoke (249). Participants suggested the term could be insulting, distressing, victimising or generally disagreeable, or could foster resentment towards others who had a different experience. Furthermore, directly positive remarks were comparatively less common, despite being widely represented in previous studies (249, 258, 268, 271, 282, 294, 298). This detail is significant given the current lack of understanding about the consequences of applying cancer survivor terminology (247). Such reactions could influence engagement with services or treatment (251, 268, 271), and even cause psychological harm (252).

There was also particular disdain for the word “cancer” itself, reinforcing the historical fear of cancer and its association with poor outcomes. Such ideas may reflect the age of participants (median 65 years); research has identified that middle-aged and older adults often associate cancer with death, despite improved outcomes (485). This has wider implications for using any cancer-related term, particularly when other diseases, even with comparable morbidity, are not used to describe people in similar ways. A small number highlighted the need for education surrounding the meaning of cancer survivor terminology, but the ongoing fear around cancer itself shows that broader education is indicated. Nevertheless, it may be argued that such anxieties are appropriate for people with advanced / metastatic cancer, and healthcare professionals need to continue to be sensitive around all cancer-related terms for these individuals.

6.5.5 *Strengths and limitations*

The mixed methods approach in the POST study provided a comprehensive insight into the perceptions of people with cancer towards the term “cancer survivor”, with qualitative outputs promoting greater understanding of the quantitative responses.

6.5.5.1 Reliability, validity, trustworthiness, and data richness and thickness issues

Although there is no consensus about how the quality of content analysis should be judged (478), reliability, validity, trustworthiness, and data richness and thickness are typically considered in qualitative research.

6.5.5.1.1 Reliability

In content analysis, reliability (consistency of a measurement (364), or agreement between coders (343)) is determined by stability (extent to which the same data are generated repeatedly from the same phenomena), replicability (degree to which independently obtained data from the same phenomena determined by different coders agree), accuracy (extent to which the coding instruction produces data relative to a standard) and decisiveness of majorities (degree to which individual judgements deviate from the majority (343)). Two researchers improved replicability / inter-rater reliability (342), repetition of steps in the process enhanced stability, and risk of ambiguity in researcher interpretation was minimised by the researchers tightly adhering to the question (477). Content analysis itself supports authenticity / accuracy since the process is data driven (472), aided further by its clear description (clear coding rules, data checking) (477). Indeed, the creation of a coding list minimised cognitive load, promoting stability and accuracy (478), and using a data analysis software programme (NVivo) facilitated order and management, potentially even promoting new levels of analysis (486). However, content analysis lacks specific guidance and criteria, limiting the method's replicability (478). Researchers also interpret data individually, so results ultimately depend on researcher skills and biases. More researchers contributing to data analysis would have increased reliability (481).

6.5.5.1.2 Validity

Validity (accuracy of the study in determining its outcome (364)) in content analysis reflects the extent the inferences about the context correlate with independently obtained evidence (343). This is typically achieved retrospectively, given the novel nature of research questions, and hence assessment of validity is limited (343). However, comparison / demonstration of alignment with previous evidence as described in the discussion adds value (478). Internal validity can be assessed as face validity, determined by agreement between researchers (477), and although this would be greater if more researchers were involved (477), at least two are recommended (481), as in this study. Adherence to the study outcome was also important to validity, and a small amount of data unrelated to the aim (1.8% responses) was removed from analysis after researcher agreement (477). Conventional (inductive) content analysis was also advantageous as an approach in minimising the impact of preconceived theories and categories on researcher interpretation, grounding results in the actual data (479). Additionally, the aim was broad but specific, and the large volume of respondents allowed for participant misinterpretation of the question, or other misrepresentation (478).

6.5.5.1.3 Trustworthiness

Measures to enhance trustworthiness (credibility, dependability, confirmability and transferability) have been highlighted previously (section 6.3.5 Techniques to enhance trustworthiness). Additionally, credibility (how well categories / themes reflect the data (481)) is linked to validity (discussed above) and is further increased through appropriate anonymised citation to demonstrate categories (487). However, quantification of ideas through content analysis must be interpreted cautiously, since not all respondents will have referred to their particular opinions on separate ideas (478).

Dependability is linked to reliability (also discussed above). However, the absence of member checking is a limitation to trustworthiness (going back to respondents and confirming that results align with their intentions (478)). This would have been impractical for this study, given the study size and limited retention of participant details.

6.5.5.1.4 Data richness and thickness

The data richness is appropriate for the qualitative descriptive approach, and the discussion demonstrates alignment with and development of previous literature. It was particularly enhanced by the iterative approach to analysis, since including responses from the final 328 participants did not generate any new codes, proving adequate interpretive depth. Although data richness could have been superior if different methodologies were applied, this would not have enhanced the relevant study outcomes. Data thickness was strengthened by reporting the data collection methods and participant demographics, uniquely including ECOG status which may help to explain some findings, and particularly since analysis was divided according to group and treatment status. Consideration of researcher reflexivity also promoted both aspects.

6.5.5.2 Limitations

This study has other limitations. Although the simple data collection method was chosen to minimise participant burden, interviews / focus groups would have enabled a different analytical process and likely richer data and insight (476, 478). Indeed, qualitative descriptive approaches are themselves criticised as they lack guidelines, clarity of process and underlying theory (468). However, any inconsistency was minimised by the clear description of methods (467) and critical approach, increasing design rigour (472). Convenience sampling is inherently limiting in terms of generalisability (420, 458), although minimised by the heterogeneity of the sample across personal and cancer-related demographics, as well as recruitment across regions and sites (467). Finally, the data was biased towards negative responses, as the majority of comments were from participants who disliked being described as a “cancer survivor” (although it may be argued this distribution appropriately reflects the most common categorical response within this group). Ultimately, additional research should validate and improve upon these outcomes.

6.5.6 Implications of study

The study gives voice to people with active cancer on the issue of survivorship terminology, who have previously been under-represented. It has meaningful implications across clinical and academic areas.

6.5.6.1 Clinical services and care provision

What stands out from the study are the negative perceptions towards cancer survivor terminology, which should draw attention to its present use. It has previously been noted that words like “survivor” should be used cautiously, depending on the meaning cancer has or had in someone’s life (488), so this study adds to the proposal that alternative wording may ultimately be better.

Nevertheless, participants themselves recognised this as challenging, but one popular suggestion was using factual language, which the PRiSM study also highlighted (Chapter 4). Moreover, as several candidates suggested, people ultimately favour being addressed by their name.

6.5.6.2 Research and education

Results demonstrate the need for broad representation of people’s views when a term is used to describe them, and the problems generalising opinions, particularly given the unique appearance of categories within particular subgroups. Notably, the words “terminal” and “palliative” were used in all groups except curative-intent treatment, likely reflecting the awareness of those groups about the differences between them and people on curative-intent pathways. Similarly, it was also only these palliative groups who suggested the term should be avoided if people had the opportunity to leave it behind, given how they could not do the same.

Interestingly, the idea of gratitude being attributed to the term only occurred amongst people no longer on treatment, and pride / strength only amongst people on a palliative pathway. Ongoing engagement with diverse groups is required as the debate around survivorship terminology develops, influencing its use in research and education. Finally, the study highlights the need for superior public education about cancer itself, given the fear that remains associated with the word “cancer” (see section 6.5.4 Development of previous understanding).

6.6 Conclusion

This study confirms that although people with active cancer demonstrate a range of perspectives towards cancer survivor terminology, most are negative. Given the confusion, alienation and offence the term can cause, its application in clinical and academic settings should be re-evaluated to align with the wishes of people who have cancer themselves.

Chapter 7: The proposed model of care: PRiSM: Specialist Palliative Care's Role in Cancer Survivorship Model.

7.1 Abstract

Background

Many factors contribute to the need for health service development, but changes in the complexities and outcomes of people who have or had cancer have led to a particular disparity between their needs and healthcare services, necessitating reform. Developing a new model of care is one strategy to reduce this malalignment. Former chapters have provided evidence to support the role of SPCS for people living beyond cancer with no evidence of disease, but this group is not included in the current SPC model of care. This chapter aims to propose a new conceptual model of care for SPCS for people who have or had cancer.

Methods

The Agency for Clinical Innovation describes the phases in developing a model of care as project initiation, diagnostic, solution design, implementation and sustainability. This chapter discusses the three initial phases, and outlines the next steps.

Results

In project initiation, the needs of people who have or had cancer were identified as a European priority, and the role of SPCS was considered as part of the solution in the diagnostic stage. In solution design, development of a model of care for the role of SPCS for people who have or had cancer is discussed. It incorporates consensus statements from an electronic Delphi study (PRiSM project) and aligns core functions of SPCS with different groups within a new classification. Key aspects include collaboration / integration, flexibility, training / education, and resource allocation. The next steps to guide implementation include developing the evidence, promoting endorsement, and change management strategies. Digital healthcare and the public health approach are also considered, and strategies for evaluation and sustainability are suggested.

Conclusion

A new model of SPCS for people who have or had cancer is proposed. This model is based on transferable and generalisable expert consensus statements, within which population and organisation-specific interventions can be applied. Higher-level research is required to identify if the model can improve support for groups of people who have or had cancer in effective and efficient ways.

7.2 Introduction

Health services relate to “the promotion, maintenance and restoration of health...both personal and population-based” (489, p.1). Many factors contribute to the need for health service development, including changing disease and population trajectories and needs, medical and technological advancements, resource availability / allocation, policy / structures, and adjustments in societal expectations (12). Planning, implementing and evaluating such changes are huge undertakings that require major reform.

The WHO Innovative Care for Chronic Conditions (ICCC) report (2002) (490) provides a framework for healthcare system change relating to the prevention and management of chronic conditions, which are “health problems that persist across time and require some degree of health care management” (490, p.6). The framework is relevant to SPCS, which typically utilise chronic care concepts (491). The report highlights that the changing prevalence, needs and impact of chronic conditions has created gaps within current systems and models, presenting a framework for improvement and redesign relating to patient, organisation, community and policy levels (490). Its strategies to reorient systems to become more integrated and people-centred include: empowering and engaging people and communities; strengthening governance and accountability; reforming models of care; coordinating services within and across sectors; and creating enabling environments (489). Models of care therefore play a fundamental role in systemic change, and can reflect and inform policy, funding and resource allocation, education, and service delivery. Importantly, developing a new model of care can reduce malalignment between evidence and care delivery, ultimately improving health services (11, 492, 493).

As defined in Chapter 1, a model of care describes the delivery of healthcare services (rather than the practices within them) for individuals with certain conditions / needs, and may focus on a specific disease, service or part of a system (11). Models enable visualisation of abstract ideas and how they interact, and can foster common goals between teams and systems (493). Conceptual models particularly describe the responsibilities and interactions of teams (14), and can be used to inform clinical models across settings where skills, training and capacity differ (14). Optimal models of care should be patient-centred, flexible, equitable, innovative and promote patient safety, quality, integration, and

efficiency, aligning with robust outcome measures and evaluation processes (11, 493). Models informed by clinical experience may be particularly strong (11).

Developing a new care model is complex. Models should be developed collaboratively by people with lived experience, healthcare professionals, professional organisations, policy makers, and funders, and use the best available evidence, linking to local / national strategies (11, 493). There are different approaches to reorienting models of care, such as redefining service priorities based on a group's changing needs, or incorporating new technologies (489). Although different guides exist to direct the process, commonalities are planning, development, implementation, evaluation and sustainability assessment (493). The Agency for Clinical Innovation (11) describes one practical process.

7.2.1 Specialist palliative care models

It has been highlighted throughout this thesis that people “living with, through and beyond cancer” (102, p.1) are becoming more diverse, along with their problems (Chapter 2, Table 1 (44)), and that historical SPC models have correspondingly evolved, alongside the changing healthcare systems supporting them (494). Chapter 1 explored the drift from the traditional SPC model where services supported people towards the end of life, to the current model where services are relevant from the point of diagnosis (Chapter 2, Figure 3) (24, 39). However, consequent chapters have also provided evidence supporting a role of SPCS for people living beyond cancer with no evidence of disease (a group not included in that current model (39)). A new evidence-based conceptual model may enable greater flexibility, reproducibility, and impact.

A major issue with the increasing applicability of SPCS is that it would be impossible for everyone who could benefit from referral to be reviewed. Huge resource expansion would be needed, and the process likely extremely inefficient. The suggestion of “timely palliative care” (44, p.363) attempts to alleviate this, where needs-based referral is determined by systematic screening and standardised criteria, aligning referrals with available resources, and enabling the right patient to be referred at the right time to the right service (44, 495). Indeed, a cluster-randomised controlled trial of the impact of early palliative care in people with advanced cancer showed that individuals with greater symptom severity

benefited more from SPC intervention than those with milder baseline symptoms (496). Additionally, a stepped care model (involving reviews at key points / triggers) was found to be non-inferior to scheduled care regarding quality-of-life outcomes, supporting a more patient-centred, less resource-intense approach (497). Timely palliative care can contribute to various beneficial patient outcomes, and enable a positive systemic cycle of timely referrals (44). These pragmatic concepts need to be carried forward into the potential expansion of SPCS for all groups of people who have or had cancer.

7.3 Aim

The aim of this chapter is to propose a conceptual model of care for SPCS for people who have or had cancer that integrates the outputs from the preceding chapters (particularly PRiSM, Chapter 4) using the phases proposed by the Agency for Clinical Innovation (11).

7.4 Methods

The Agency for Clinical Innovation (11) describes the phases in developing a model of care as project initiation, diagnostic, solution design, implementation and sustainability. This chapter discusses how findings from previous chapters contribute to the three initial phases, and outlines the next steps.

7.5 Model development

7.5.1 Phases

7.5.1.1 Project initiation

The first phase is identifying a priority area of need (11). The requirement to reconsider the current SPC model has been outlined (see section 7.2 Introduction). Furthermore, the current approach lacks alignment with European priorities to support the unmet needs of people who have or had cancer across holistic domains (78). The ECCF endorsement of the project (Rising Star Grant 2023) confirmed international support to develop the evidence, further demonstrated through high European expert engagement in the PRiSM project e-Delphi process (Chapter 4) (Figure 13).

Figure 13: PRiSM project icon.



7.5.1.2 Diagnostic

The diagnostic stage involves defining the problem and understanding an approach to the solution (11). Much work has been undertaken regarding the unmet needs of people with a history of cancer (114-116). Assessment of current evidence and identification / prioritisation of relevant issues have been described in the literature reviews (Chapters 2 and 3), supported by real-world expert opinion in the PRiSM project (Chapter 4). The latter highlighted that SPCS could and should have a role in supporting people who have or had cancer, and facilitated progress by identifying educational targets and barriers. The POST study (Chapters 5 and 6) also advanced understanding about the terminology to use within the model.

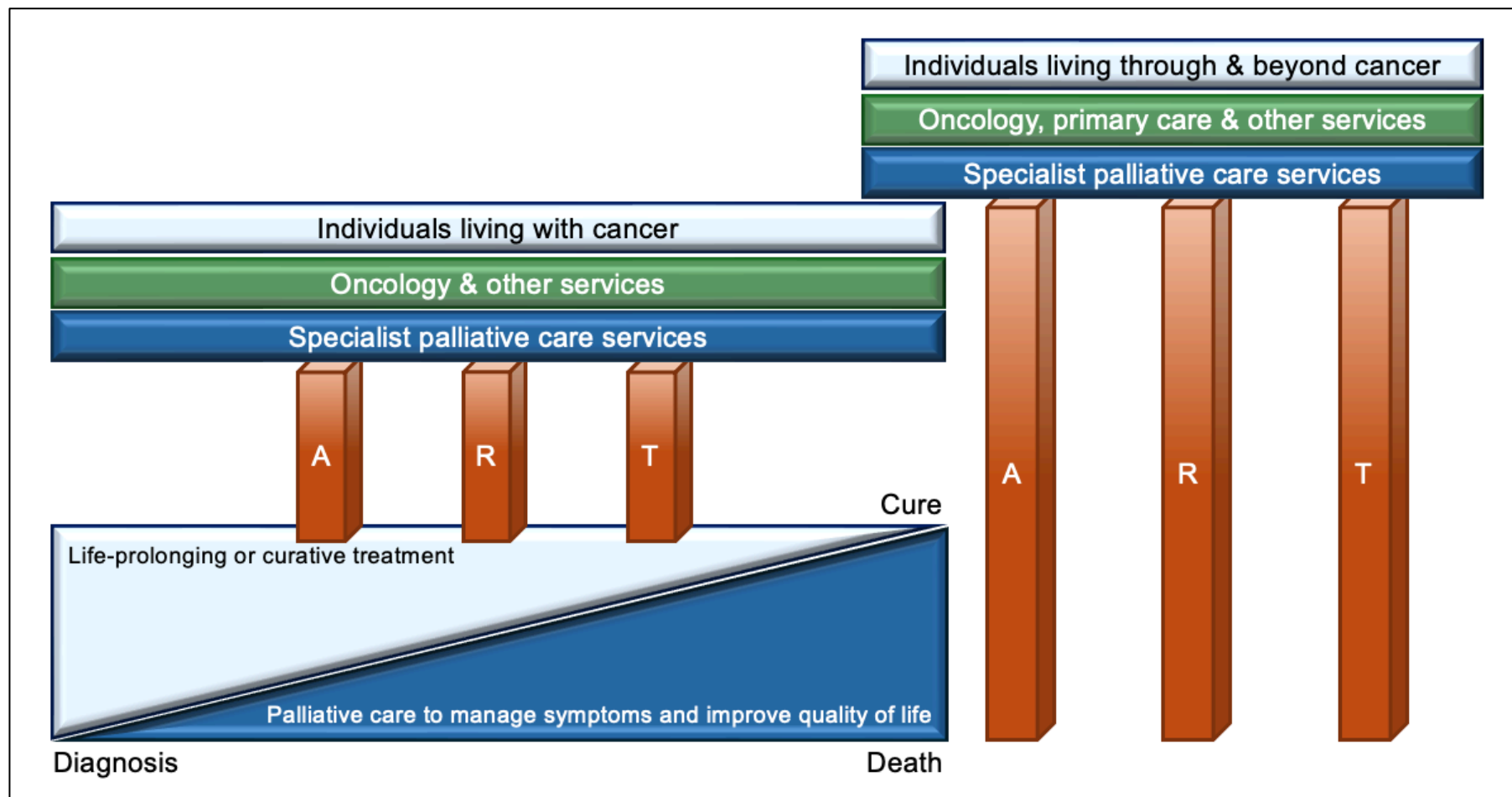
7.5.1.3 Solution design (model development)

Designing a model of care involves determining the scope of practice / role of relevant services, including the components of care and training required (492). The PRiSM project (Chapter 4) identified the core functions of SPCS, alignment with two groups of people with a history of cancer where the evidence was unclear (people with stable disease, and people with no evidence of disease), and the areas requiring more education / training. The current SPC model of care (Chapter 2, Figure 3) (39) could be adapted, as demonstrated in Figure 14. This adapted model reinforces the ongoing relevance of SPCS for people living with cancer, but also includes potential SPC support for people living through or beyond cancer. However, the adapted model does not address many of the issues raised in the

PRiSM project, and indeed, the necessary enablers must exist for its workability (i.e. acceptability, resources and training).

Greater detail is provided in Figures 15-17. Figures 15 and 16 align SPC functions with different groups of people who have or had cancer in tabular summaries, derived from the PRiSM project. Figure 15 summarises outcomes for the three main groups directly assessed in the PRiSM project (core functions as applicable to people with progressive disease; statements for people with stable locally advanced or metastatic disease; statements for people with no evidence of disease), whilst Figure 16 is an interpretation of these results to align standardised core functions across the groups in the new consensus classification of people who have or had cancer (generated in PRiSM). Figure 17 combines these to offer a new pyramidal SPC model of care, visually demonstrating the fluidity of care provision according to enabling factors (i.e. acceptability, resources and training). The model assumes compatibility with the preferred definitions of palliative care (20) and SPC (23) from the PRiSM project, particularly the multidisciplinary holistic approach (20, 498). Key aspects include core functions of SPCS, groups of people who have or had cancer, distribution of core functions across groups, collaboration and integration, flexibility, training and education, and resources.

Figure 14: Adapted model of SPC in oncology to include individuals living with cancer and individuals living through and beyond cancer (adapted from Kaasa et al. (39)).



Key: ART bricks = enablers (A = acceptability; R = resources; T = training).

Figure 15: Tabular summary of the role of SPCS for people who have or had cancer using direct PRiSM statements.

Living with cancer		Living through cancer	Living beyond cancer
Progressive disease (core SPC)	Stable locally advanced / metastatic disease	No evidence of disease	
Management of pain	Surveillance of physical symptoms / problems	Management of pain	
Management of other physical symptoms	Surveillance of psychological distress	Management of other physical symptoms / problems	
Management of psychological problems	Management of pain	Management of psychological distress	
Emotional support (patient / family)	Management of other physical symptoms / problems		
Advance care planning	Management of psychological distress		
Coordination of care	Support for cultural, spiritual and religious needs		
End-of-life care	Supporting caregivers		
Bereavement care	Advance care planning		
Research & education	Care coordination between specialists and primary care providers		
Spiritual support	Rehabilitation		
Social assistance	Supporting occupational issues / return to work		
Rehabilitation			



All specialist palliative care services
Resources / continuous professional development
Some specialist palliative care services

Key: Green = component of care reached consensus in both SPC and oncology expert groups; amber = component of care reached majority in both expert groups.

Figure 16: Tabular summary of the proposed role of SPCS for people who have or had cancer using consensus-based categories from the PRiSM project.

Interspecialty collaboration

Living with cancer					Living through cancer	Living beyond cancer
Individuals with cancer not on anticancer treatment with advanced / progressive disease and no further anticancer treatment options	Individuals with cancer on anticancer treatment with "palliative" / non-curative intent (primary or other)	Individuals with cancer not on anticancer treatment on "watch and wait" / active monitoring	Individuals with cancer on anticancer treatment with "curative intent" (primary or other)	Individuals with cancer before the start of primary anticancer treatment	Individuals with a history of cancer who have completed anticancer treatment and have no evidence of disease, on active oncology follow-up (some risk of recurrence)	Individuals with a history of cancer who have completed anticancer treatment and have no evidence of disease, not on active oncology follow-up (low risk of recurrence)
Management of pain	Management of pain	Management of pain	Management of pain	Management of pain	Management of pain	Management of pain
Management of other physical symptoms	Management of other physical symptoms	Management of other physical symptoms	Management of other physical symptoms	Management of other physical symptoms	Management of other physical symptoms	Management of other physical symptoms
Management of psychological problems	Management of psychological problems	Management of psychological problems	Management of psychological problems	Management of psychological problems	Management of psychological problems	Management of psychological problems
Emotional support (patient / family)	Emotional support (patient / family)	Emotional support (patient / family)	Emotional support (patient / family)	Emotional support (patient / family)	Research & education	Research & education
Spiritual support	Spiritual support	Spiritual support	Spiritual support	Spiritual support		
Social assistance	Social assistance	Social assistance	Social assistance	Social assistance		
Advance care planning	Advance care planning	Advance care planning	Research & education	Research & education		
Coordination of care	Coordination of care	Coordination of care				
End-of-life care	Occupational support	Occupational support				
Bereavement care	Rehabilitation	Rehabilitation				
Research & education	Research & education	Research & education				
Rehabilitation						

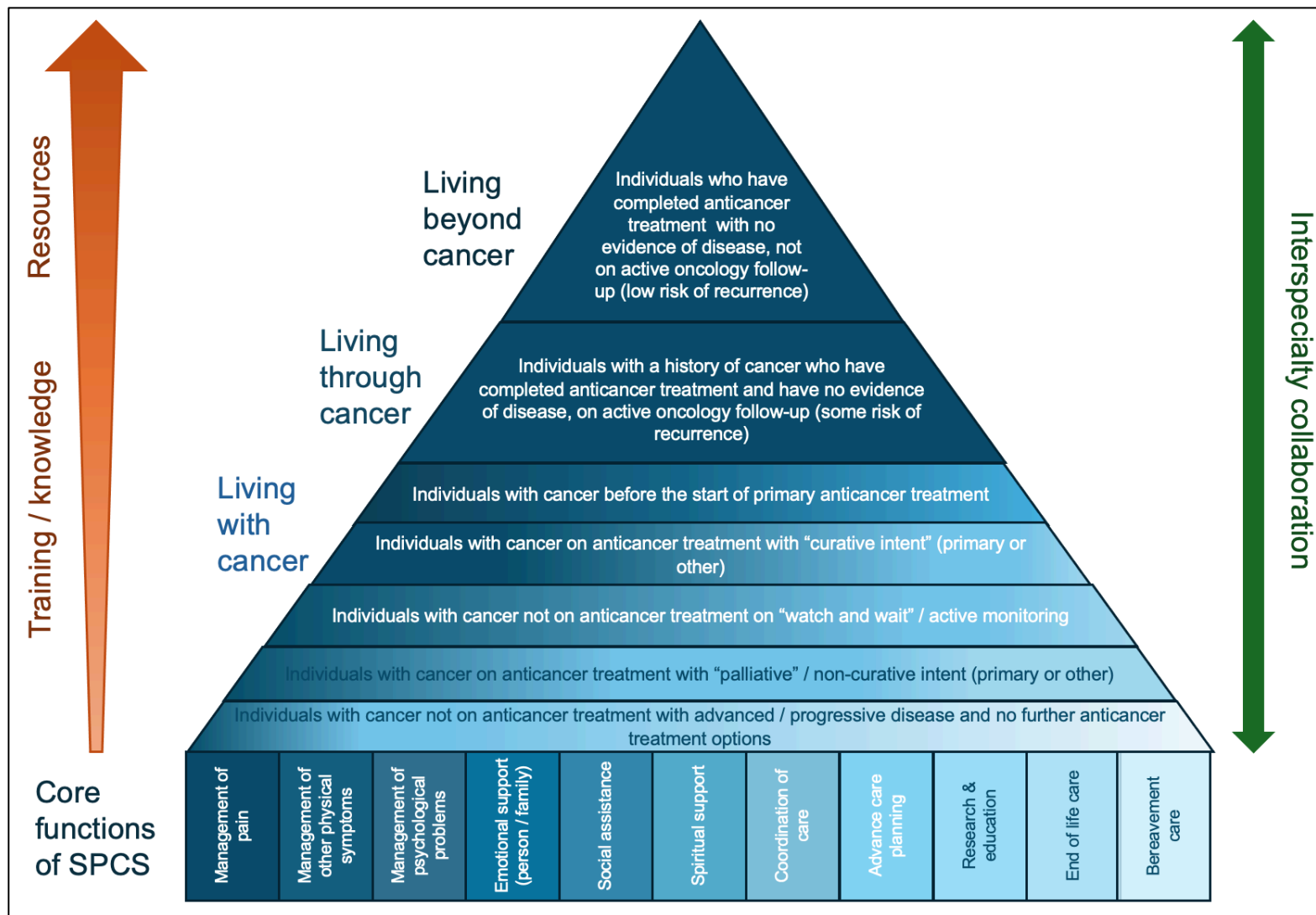
All specialist palliative care services

Resources / training / knowledge

Some specialist palliative care services

Key: Green = core function of SPCS that *should* be provided for these groups if ART enablers allow (ART: A = acceptability; R = resources; T = training); amber = core function of SPCS that *could* be provided by SPCS if ART enablers allow.

Figure 17: Pyramidal model of care for the role of SPCS for people who have or had cancer.



7.5.2 Key aspects

7.5.2.1 Core functions

The core functions are those generated in the PRiSM project. Further detail can be gleaned by complementary consensus statements (Chapter 4), such as description of the type of pain (e.g. acute and chronic cancer-related and cancer treatment-related pain). In the model, these are distributed according to relevance to different groups of people who have or had cancer; some are relevant to all groups (such as pain management), whereas others are only relevant to certain groups (such as end of life care for people with progressive disease).

7.5.2.2 Groups of people who have or had cancer

A novel aspect of the proposed model (Figure 17) is its categorisation of people who have or had cancer using groups determined to be useful by experts in the PRiSM project. It combines the classification of people “living with, through and beyond cancer” (102, p.1) with a new pragmatic classification of individuals with cancer or a history of cancer, based on cancer and anticancer treatment status (Chapter 4, Box 10: Categorisations of people who have or had cancer). Notably, cancer survivorship terminology is not applied in the model in reference to the groups or the care provided, aligning with the preferences of both the PRiSM project experts (Chapter 4) and POST study participants (Chapters 5 and 6).

7.5.2.3 Distribution of core functions across groups

The most appropriate role of SPCS differs for each group. The model aligns SPC core functions variably with each group, integrating its role for people with progressive disease (traditional palliative care), the more recently established role for people on anticancer treatment (“early palliative care” (10, p.7)), and the newly identified role of SPCS for other groups (people with stable disease; people with no evidence of disease). The model therefore provides a complementary rather than competing framework with previous models (demonstrated by Figure 14).

In Figures 15 and 16 (summaries of PRiSM project results), SPC core functions appear as tabular lists under groups, with the relevant number reducing as the categories move through living with, through and beyond cancer. In the proposed pyramidal model (Figure 17), the core functions appear along the bottom of the

pyramid and their relevance to the groups reflects Figure 16, but the alignment is less prescriptive, displayed through a colour gradient. All SPCS will provide all core functions for the group(s) towards the bottom of the pyramid, but only few SPCS will have the training, skills, and resources required to support people in the groups nearer the top.

7.5.2.4 Collaboration / integration

In the PRiSM project, the experts asserted that groups of people who have or had cancer should be supported by multiprofessional teams. Moreover, they determined that SPCS should contribute to the teams, but not in the same way. For example, SPC was identified as a core / extended team member in the MDT for people with stable advanced / metastatic disease, but no consensus was reached about the extent of SPC team involvement for people with no evidence of disease, simply that they should be involved. The only definite clinical component of care across all groups in the model is pain management, and the PRiSM experts had correspondingly highlighted the need for collaboration (specifying chronic pain teams and, where relevant, addiction services). Such fluidity of roles across groups requires collaboration and integration with other specialties, where each understands the extent of one another's responsibilities relative to each group.

Consequently, interspecialty collaboration is an important facet of the model. Alignment of processes and information across health programmes, providers and sectors requires coordination (489), which may be facilitated by clear referral systems, improved care transition and promotion of multidisciplinary working. Indeed, interdisciplinary teams are likely more effective, with different team members having changing relevance across time (44). Indeed, the previous focus on medical and nursing models has been criticised for disregarding the necessary social and environmental aspects of care (494). Furthermore, the model delineates expert opinion that it is appropriate for SPCS to coordinate the care for people towards the end of life, perhaps for people with stable disease, but not for people with no evidence of disease.

7.5.2.5 Flexibility

An essential aspect of the model is flexibility, allowing for the variations in needs and resources. Although population-specific interventions and models are needed to address a specific group's diverse needs within limited resources (62), the influence of local factors on regional care models has previously reduced transferability (494). The conceptual model proposed here provides clarity about the components of care for SPCS, but is not prescriptive about timing, longevity or delivery, therefore supporting local refinement according to resources. Additionally, individuals post-treatment have been found to have fluctuant preferences about care delivery, so flexibility is desirable to promote patient engagement (146).

The model acknowledges that not all SPCTs will be able to provide services for all groups. Service extension will require more resources, new / different strategies, and focused training. Only the (minority of) teams able to access / engage in these ventures should provide the suggested extended services. It is important that teams continue to support people with progressive disease and those at the end of life as a priority, and this may be the only group they can support according to capacity and skills.

7.5.2.6 Training / education

The model has been developed through recognition of the potential relevance of SPCS within the changing trajectory and demographics of people who have or had cancer. The evidence base for SPCS, its interventions and the ways in which its services are provided, also continues to change. Continuous professional development is therefore emphasised across the model in relation to all groups of people who have or had cancer, alongside the new knowledge acquisition potentially required for groups not traditionally reviewed by SPCS. Certainly, the model may be revised as evidence, and people who have or had cancer, continue to change.

Disparity between existing curricula and new models of care is a recognised area of contention (12). The need for further education / training was identified as a barrier to SPC service extension to people living beyond cancer in the PRiSM project, and specific SPC training suggestions were provided (Chapter 4).

Intersectoral coordination is also an important part of the model (489). Education of other healthcare professionals is a core SPC function that can extend across groups (Figure 16), supporting other services / teams to provide generalist palliative care (23). This would include systematic screening, basic symptom assessment and management, and identifying the need for specialist referral (44). Upskilling other teams promotes longitudinal and more immediate management of issues, enabling implementation of timely palliative care and improving SPC service efficiency (44). However, the competing educational needs within other specialties, and variety of cultures within other teams, creates disparity between this suggestion and real clinical environments (499). Space needs to be created within modern models of care to enable these needs to be met.

Additionally, general education about the principles, application and appropriateness of palliative care for professionals, patients and the public is required. Misperceptions about the role of SPCS were identified as a barrier in the PRiSM project, namely equating the specialty to end of life care (30, 191). Consistent education and public awareness campaigns are required alongside this model for these to be overcome.

7.5.2.7 Resources

Figures 14-17 all highlight that SPCS are relevant to people towards the end of life, but that more resources are required to support other non-traditional groups, especially people living beyond cancer. Only smaller numbers of SPCTs (with the appropriate training and resources) will be able to support the latter.

7.6 Beyond model design: next steps

There are many steps that can help guide implementation and sustainability, including developing the evidence, strategic endorsement and change management (11).

7.6.1 Developing the evidence

7.6.1.1 Bridging the academic / clinical gap

This thesis assesses issues primarily within an academic context, especially those relating to terminology. An essential next step would be to understand actual current clinical practice, particularly regarding clinical application of cancer-related terminologies. Indeed, effective implementation starts with investigation of many levels (individual, organisational, community and policy), since the context must be fully understood to determine the clinical relevance of such academic outputs (500).

7.6.1.2 Expert panel review

The recommendations for the Conducting and REporting of DElphi Studies (CREDES) (310) state that a dissemination plan should include endorsement by professional associations / authorities to aid implementation. As a step towards this, the model generated from the PRiSM project requires endorsement / refinement from a multidisciplinary expert panel.

PPI is essential to this process (493). People who have completed anticancer treatment have fluctuant preferences about their care delivery, depending on personal concerns, perception of need, and experience of care transition (146). Although people with lived experience / advocates took part in the PRiSM project, further inclusion will promote shared vision, enabling healthcare professionals and structures to develop services aligning with the needs and expectations of those who will use them (492).

7.6.1.3 Future research

Healthcare change and supportive initiatives should be driven by the best available evidence. The model provides a conceptual starting point, but further evidence is required to determine the details of care delivery across groups. For example, each category of people who have or had cancer should have specific referral criteria for SPCS (recommendations exist for outpatient referral for people with advanced cancer (49), but not other groups). Indeed, a needs-based approach for people living beyond cancer, similar to referrals for early palliative care, would likely be appropriate (44). Triggers for referrals to / collaboration with

other relevant services should also be identified, and requirements around transitions between groups also need consideration, as identified by post-treatment individuals themselves (146). Moreover, interventions orientated towards each group and their issues require much greater evidence.

Ultimately, evaluation of the proposed model in feasibility studies and definitive RCTs is needed to determine acceptability, effectiveness and efficiency. Such studies should be pragmatic, apply the model to real-life settings, and use appropriate outcomes (500). Indeed, implementation science will latterly be relevant (concerned with the factors influencing the uptake of evidence into practice) (501).

To add to the complexity, the term model of care is inconsistently applied in palliative care literature. SPC model reporting varies widely, with services often only described by the setting or target group (494). Various checklists have been developed to improve their description and comparison (498, 502), with one study identifying 20 criteria to define and differentiate SPC model components (see Box 15) (498). However, these criteria are UK-specific, and European and international application is limited. Ultimately, there is a lack of recommendations to guide implementation and evaluation of a new model of care.

Box 15: Criteria to define and differentiate SPC model components (UK) (498).

Setting
Type of care (direct or advisory)
Service size
Primary diagnoses
Disciplines involved
Mode of care (in-person or remote)
Interventions provided
Out-of-hours services
Educational provision
Use of outcome measures
Bereavement follow-up

Referral and discharge processes
Purpose of care
Funding (498)

7.6.2 Promoting endorsement

7.6.2.1 Cultural

Pre-existing assumptions about services / models remain a major challenge in implementing change (492). Indeed, stakeholders need to be aware of the need for change, associated urgency and evidence-base, and strategies must be in place to communicate and engage them in the vision (12, 490). This includes those in leadership positions, who have the ability to direct and inspire organisational vision (503). However, education and monitoring are not enough to change behaviour (504), and so implementation strategies are necessary to influence both individuals and their surrounding systems (500). Furthermore, services cannot expand without the relevant practical support, skills and resources. Perceived lack in these areas will negatively affect cultural engagement (12).

7.6.2.2 Policy

The reorientation of healthcare services is widely acknowledged to be a long process. Regulatory barriers must be identified, resources need appropriate reallocation, and cultural engagement is essential. Such complex change will only be successful if supported by specific policy (489). It is suggested that the opportunistic time to implement policy is when there is general agreement about the need for that change (505), and agreement has been presented via the results of the PRiSM study.

7.6.3 Implementation

This model provides a classification of people who have or had cancer, and aligns the groups with particular SPC functions. Specifying such roles can help direct resource allocation, and development of relevant capacity and skills. The conceptual model therefore provides an overall structure, but ownership of

implementation belongs to local teams and networks, and importantly, the model's transferability across organisations / regions depends on the support and collaboration of the surrounding systems (506).

Implementation involves supporting the system to bring about the necessary changes at system and behavioural levels, but it is a complex, multifactorial and unpredictable process dependent on the nature of the local network (11). Vitally, successful implementation considers the social / behavioural aspects, as well as the practical. For instance, the PRiSM project identified what experts perceived to be real-world barriers to the extension of SPCS, and their acknowledgement should influence how the service is provided (12). Additionally, change integration typically encounters issues, so change management strategies are required, which include collaborative leadership, clear responsibilities and communication, in an ongoing process beyond initial implementation (12).

7.6.3.1 Change management

Model implementation can be approached through change management theory, project management strategies and / or quality improvement theory. Change management theory involves understanding the nature of change to support stakeholders / organisations in implementation (12, 507). Although several change management strategies exist (508, 509), they generally involve identifying and raising awareness of the need for change, creating a vision, planning for change, implementation, and finally sustainability. Project management involves the application of knowledge, skills, tools and techniques to different activities to meet project outcomes (510, 511), enabling a project to be completed within budget and time constraints (510). Organisational steps typically include gap analysis (economic and resource assessment and strategy) and stakeholder engagement (senior and frontline) (11, 489). Quality improvement deals with specific problems in particular environments, affecting iterative changes towards improvement goals (512, 513). It is recommended at local level to increase success through collaborative stakeholder engagement (489, 493), and pilot trials can highlight benefits and develop strategic relationships (514). Indeed, such cultural change is a key part of this complex process, and it is likely that a combination of strategies is required for successful change management. These also overlap with implementation science to varying degrees (500).

7.6.3.2 Resource allocation

Resource allocation is hugely important in the reorganisation of care delivery (503) and should align with reform priorities (489). However, SPC resources are typically scarce. Workforce issues (shortages and maldistribution) are a major barrier (515), and there are weaknesses within information, financing and educational systems (489). However, it is not simply a matter of more. Novel models of care are generally implemented within resource-limited systems (493). Healthcare spending continues to rise and cannot be sustained within finite resources, so the nature of care provision must change instead (11). Cost analysis of a new care model should therefore consider reorganisation, reallocation and disinvestment (11), helping the model to gain support going forward.

7.6.4 Other considerations

7.6.4.1 Digital healthcare

The evolving world of digital technology likely has an important role in the flexibility and efficiency of a new care model (68, 489). Digital healthcare can support alternative or hybrid in-person / telehealth consultations, or platforms for remote monitoring, symptom management, and self-management (68). Indeed, hybrid models may be preferred by both patients and practitioners (516), with video conferences particularly favoured (517), and quality of outcomes remain reassuringly non-inferior (72). Remote monitoring can detect evolving issues earlier and promote adherence (516). Digital interventions to support symptom management, such as psychotherapy or exercise programmes, can positively impact symptoms and quality of life (516, 518). Digital self-management strategies may supplement direct SPC services, particularly in providing information to promote patient understanding and expectations (519), a considerable unmet need for people with a history of cancer (114). However, self-management likely necessitates its own care model (and related to this, a relevant health promotion model (493)). Self-management may also be more effective if certain groups are targeted (520) and strategies to enhance engagement are applied (520). Although further research into digital health in SPC is required, its promotion aligns with the PRiSM model, within which it should complement (rather than replace) in-person care. Nevertheless, equity of access to digital platforms remains an issue, and

targeted interventions for certain groups (requiring particular additional resources) would be required (516).

7.6.4.2 Public health approach

Public health aims to prevent disease, prolong life and promote health through the organised efforts and informed choices of society, organisations, communities, and individuals (521). A public health approach to palliative care would seek to empower people / society to support suffering as it expands. Only in recent years has the utility of this been considered in supporting people at the end of life (522, 523), enabling palliative care programmes to extend to individuals with relevant needs across settings and systems (524, 525). Although there is limited evidence about the impact on how health services are used, public health palliative care interventions have been found to reduce social isolation, improve wellbeing and increase community caring capacity (525), and international organisations have advocated the public health process, given the fragmentation and disparity of services (489, 490, 526, 527).

The individuals who would benefit from SPC input within the new proposed model differ from those included in historical SPC models of care, necessitating a reformed approach. Within this, health promotion amongst people with stable or no evidence of disease is particularly important. The increasing needs and complexity of patients today impact the resource, economic and access burden facing healthcare (522), and so the public health concept of communities supporting people with illness and those close to them through community strategies, education (public and professional) and advocacy (528) is ideal to reduce the gap between needs and services. Suggested techniques include workshops, self-management programmes, and tailored sessions delivered by professionals (529), but to succeed this would require support from local and national strategies, as well as communities and systemic culture (523).

7.6.5 Evaluation

Evaluation describes “the systematic and objective assessment of the design, implementation and results” (11, p.12). Measures need to be identified to determine if change has led to improvement, as well as the impact on the system

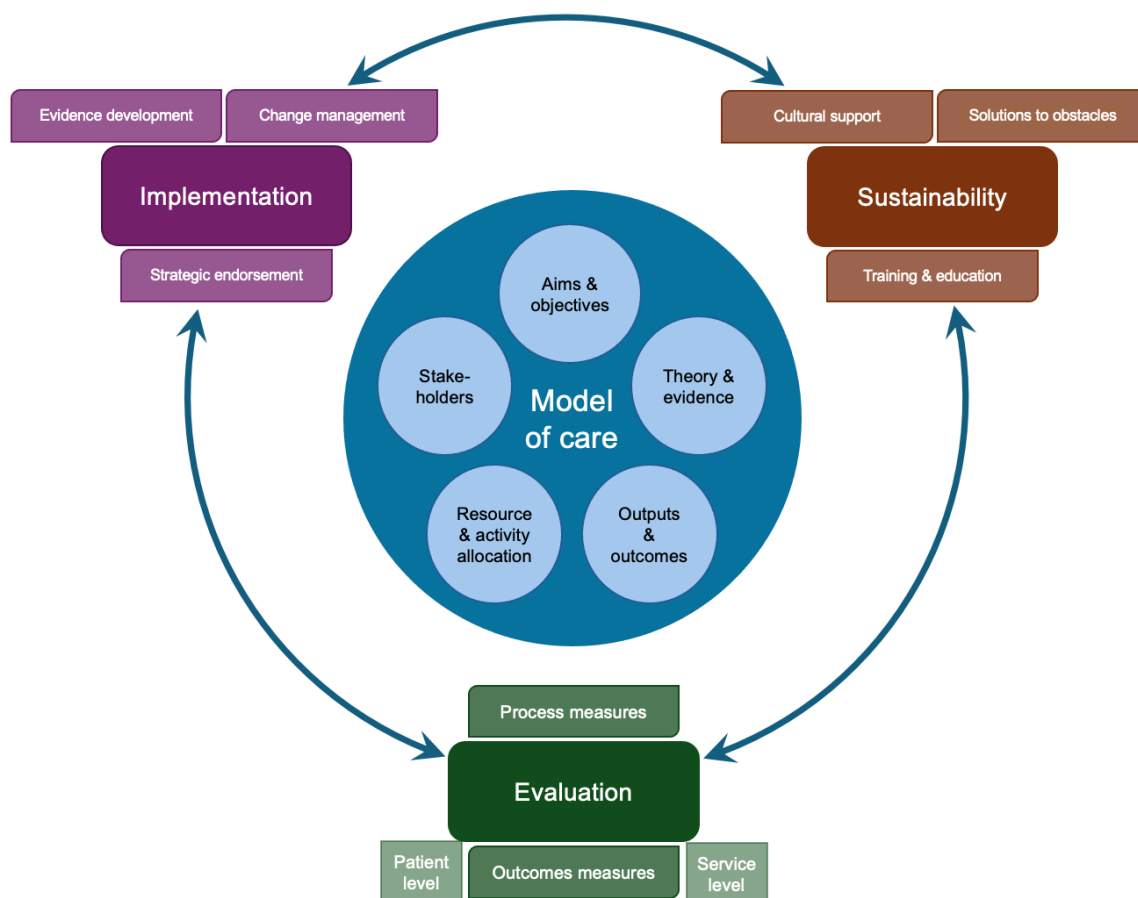
and its stakeholders (493). Effective evaluation should be guided by a framework, using standard measures of process and outcomes, especially given the increasing complexity within healthcare systems (494). To enable this, models should have clear aims and objectives, resource and activity allocation, outputs (immediate results) and outcomes (short, intermediate or long-term changes towards the overall objectives) (11, 12). Outcomes should be relevant to both service and patient levels, and prioritise patient-centred quality indicators, such as quality of life domains (530).

However, indicators will also likely differ according to clinical sites, and an evaluability assessment process has been promoted to identify if the preconditions for effective evaluation exist within organisations before evaluation begins (531). Steps include identifying if the model and its outcomes, stakeholders, and performance indicators can be clearly defined, if its underlying theory and evidence are robust, and if the implementation and evaluation plans are clear (531). Early evaluation can encourage engagement and increase support if results are positive, as well as identify problems earlier to minimise impact (12). Moreover, evaluation should be ongoing throughout implementation and beyond, incorporating both formative and summative aspects (11), ideally supported by quality improvement methodology (513).

7.6.6 Sustainability

Service sustainability is determined by its efficiency, effectiveness and equitability (489). Ongoing evaluation is essential to sustainability, promoting local focus and accountability (11), particularly in understanding and finding solutions to organisational and individual obstacles (12). Sustainability also requires the principles of the new model to be indoctrinated into the culture of the service (12), enabled by an iterative approach to implementation. Furthermore, the personnel involved in delivering the service need the appropriate knowledge and skills, so the model needs to be supported by ongoing continuous professional development and educational opportunities (12). Figure 18 displays how these factors work together towards a model of care.

Figure 18: Next steps in development of the model of care (implementation, evaluation and sustainability).



7.7 Further discussion

7.7.1 Strengths and limitations

This proposed model of care aligns with international strategies to improve the care of people with a history of cancer (78). Importantly, the model aims to promote flexibility and efficiency, major priorities for both patients and healthcare leaders in maximising use of limited resources. Its development has been collaborative across disciplines and specialties, including patient advocates, and the systematic approach (as opposed to reactionary) seeks to provide a strong foundation (493).

However, the proposed model is based solely on expert opinion (albeit consensus). Further research is needed to identify if the model is feasible and beneficial, and how it could facilitate optimal care delivery. Despite the variety of backgrounds and disciplines amongst the participants of the PRiSM project, the

model would be stronger with greater non-clinical professional support, including managerial and policy-maker representation. Identification of evaluation processes and measurable outcomes would also add strength (11).

This model also only deals with the role of SPCS. SPC models need to integrate with other services (particularly oncology and primary care, for these patient groups), and indeed with people with cancer. As systems, services, patients and their needs grow in complexity, models of care must consider their interactions within these changing paradigms (494).

7.7.2 Implications for practice

7.7.2.1 Clinical services and care provision

This model utilises expert consensus opinion about the role of SPCS to better support groups of people who have or had cancer. The aim is for the expanding needs of these individuals to be met in more efficient, effective and appropriate ways, within the limitations of SPC skills and resources.

7.7.2.2 Research and education

The model of care requires expert endorsement and evaluation in feasibility studies and RCTs. Given the identified roles of SPCS within the model, more evidence is required about the mechanisms and interventions within the care delivery itself (see section 7.5.1 Developing the evidence).

The model also highlights the need for education of SPC professionals in certain areas relevant to the suggested expanded responsibilities, continuous professional development of SPC professionals relevant to all groups of people who have or had cancer, interprofessional education of other specialties about palliative care principles, and general public / patient education about the role of SPCS to alleviate misperceptions about it equating to end of life care (see section 7.4.2.5 Training / education).

7.7.2.3 Resources and policy

As previously highlighted, any increase in SPC service provision will require more resources, and changes in how current resources are utilised. Policy changes are

required to ensure that the evidence supporting the change is translated into practice, enabling the support of resource reallocation / access, cultural engagement and change management (see sections 7.5.2.2 Policy; 7.5.3.2 Resource allocation).

7.8 Conclusion

A model of SPCS for people who have or had cancer is proposed. It incorporates the core functions of SPCS, and aligns these with different groups within a new classification. This model is based on transferable and generalisable expert consensus statements, within which population and organisation-specific interventions can be applied. The model requires higher-level research and evaluation to identify if its application can improve SPC support for groups of people who have or had cancer in effective and efficient ways.

Chapter 8: Discussion

8.1 Introduction

This thesis has explored the potential extended role of SPCS for individuals with cancer or a history of cancer, including people living beyond cancer, and suggested a new evidence-based model of care. Additionally, it has explored the perspectives of people with cancer about the terminologies used to describe them, in particular cancer survivor. This final discussion provides a summary of the background, revisits the aims and objectives, considers how each chapter has addressed them, reflects on the overall limitations, explores the implications of this research and suggests future directions.

8.2 Summary of background

Chapter 1 presented the background to the topic, exploring the evolution of both cancer care and SPCS, and the imperative to consider their alignment. In recent years, cancer services and outcomes have changed hugely, and so more people are living longer with, through and beyond cancer (7, 8) due to earlier diagnoses, evolving oncology anticancer treatments, and improved supportive care services (5). However, many of these individuals live with adverse consequences of cancer and its treatment, and have significant unmet needs across physical, psychological, social, informational and educational domains.

SPCS provide holistic care (physical, psychological, social and spiritual) for individuals with health-related suffering and those close to them. Historically, SPCS have cared for people with advanced cancer nearing the end of life. Most individuals on anticancer treatment, and most living beyond cancer (who have completed anticancer treatment and have no evidence of disease), do not have access to SPCS. Furthermore, current SPC models of care are not necessarily applicable to all people following a cancer diagnosis. As mentioned in the literature review in Chapter 2, the traditional SPC model was time-based, with SPCS providing support towards the end of life, and the current model integrates SPCS in various ways from the point of diagnosis and alongside active treatment, particularly in advanced cancer, with its role increasing as prognosis shortens (24, 39). However, people living beyond cancer are not specifically included in this model (39). There is much contention about the role of SPCS for this growing

diverse group, and controversy surrounding the terminology used to describe them.

Terminology has important implications for public and professional understanding and expectations of healthcare services. Cancer survivor terminology is particularly contentious, especially regarding who it should describe. The NCI (17) definition states that, “an individual is considered a cancer survivor from the time of diagnosis through the balance of life. There are many types of survivors, including those living with cancer and those free of cancer”, whereas other organisations like ESMO (76) use functional definitions, only including people who have completed primary curative-intent treatment. Given the breadth of people that could be classed as cancer survivors, a number of categories / phases have been proposed (96-99, 102). Cancer survivorship then refers to the unique physical, psychological, social and economic issues affecting an individual with a history of cancer (80), and encompasses prevention, surveillance, intervention and coordination (18), with many statements and organisations using the term specifically to describe the phase and issues arising post-primary treatment (18). However, this application has drifted, particularly as oncology treatments and outcomes improve, and there is a notable current movement surrounding cancer survivorship for people affected by advanced or metastatic cancer (6). However, the lack of clarity about these terms has led to diverse application in clinical and academic settings, creating ambiguity and confusion. Furthermore, there has also been concern about the interpretation and impact of cancer survivor terminology on those it is used to describe.

There are many different survivorship care models (142), and disagreement amongst professionals, patients and their advocates about the roles of oncologists, GPs and other specialty providers (136). There is little high-quality evidence to guide these decisions, with proposals lacking generalisability across populations / settings, and cancer types and stages (143). Furthermore, healthcare professional education regarding cancer survivorship is limited (167). Importantly, there is a distinct paucity of evidence on the overlapping positions of SPCS and cancer survivorship care. The two share many principles, such as comprehensive assessment, holistic symptom management, promotion of quality of life, collaboration, and flexible, coordinated patient-centred models (154, 169-173), but suggestions about their alignment are largely derived from observations

of local initiatives and expert opinion. Models involving both have been presented, but an evidence-based model is yet to be described.

8.3 Aims and objectives

The overall aim of this thesis was to determine the potential role of SPCS in the different cohorts of people with cancer or a history of cancer to inform a model of care.

The objectives were:

- To explore the evidence for the current / potential role of SPCS in supporting individuals living beyond cancer i.e. people with a history of cancer and no evidence of disease.
- To explore the evidence for the meaning and acceptance of cancer survivorship terminology.
- To determine the views of professional and non-professional SPC and oncology experts on the role of SPCS within cancer survivorship.
- To determine the perceptions of individuals with cancer known to SPC and oncology services regarding the terms used to describe them, in particular cancer survivor.
- To develop an overarching European model of care for SPCS for people with cancer or a history of cancer.

8.4 Chapter summaries

This thesis was composed of seven chapters. Each chapter addressed particular objectives, and included a detailed introduction, methods section, results section, discussion and conclusion.

Chapter 1: Introduction

The introduction explored the background to the terminologies and models of SPC and cancer survivorship, and the rationale behind the exploration of their potential alignment (summarised above).

Chapter 2: The role of specialist palliative care in long-term cancer survivors (individuals “living beyond cancer”): a narrative review of the literature.

- Thesis objective: to explore the evidence for the current / potential role of SPCS in supporting individuals living beyond cancer i.e. people with a history of cancer and no evidence of disease.

A systematic search strategy of four databases was used to inform this comprehensive narrative review, in which palliative care and SPC were defined, current models of SPC were presented, the core activities of SPCS were outlined, and the relevance of SPCTs was determined, including barriers to change. The review demonstrated that there are many synergies between the core activities of SPCS, the essential components of survivorship care, and the unmet needs of individuals living beyond cancer, but there is very little evidence to inform the actual involvement of SPCTs, and potential barriers include limited resources, and lack of appropriate expertise.

Chapter 3: A scoping review on the evidence for the meaning and acceptance of cancer survivor terminology.

- Thesis objective: To explore the evidence for the meaning and acceptance of cancer survivorship terminology.

A systematic search strategy of four databases was used to inform this scoping review which identified evidence-based definitions and classifications of the terms cancer survivor and cancer survivorship, and determined what is known about the perceptions of individuals described as cancer survivors towards these terms, including which individuals have been represented in study samples. The review showed that there is great variation in the meaning and application of cancer survivor terminology, and limited evidence-based categorisation. Professionals typically describe cancer survivors either as individuals from the time of diagnosis onwards, or as individuals post-treatment. People with a history of cancer commonly define cancer survivors as people who are alive, who no longer have cancer, or who have undergone a battle. The review also demonstrated that previous studies on the perception of cancer survivors towards the term do not reflect the views of all groups of individuals with a history of cancer, having largely

recruited white participants from the USA who had completed primary treatment for early-stage breast cancer. Indeed, there has been little research exploring the views of individuals on anticancer treatment and individuals with advanced / progressive cancer towards the term.

Chapter 4: PRiSM project: Specialist Palliative Care's Role in Cancer Survivorship Model: European e-Delphi study on the role of specialist palliative care services in cancer survivorship.

- Thesis objective: To determine the views of professional and non-professional SPC and oncology experts on the role of SPCS within cancer survivorship.

In this e-Delphi study, European SPC and oncology experts formed two separate groups (each with professional experts and patient advocates / people with lived experience). The groups undertook the same Delphi process simultaneously, consisting of three successive online rounds informed by the literature reviews from Chapters 2 and 3. Sections included the definition and core functions of SPCS, application of cancer survivor terminology, categories of individuals with cancer or a history of cancer, and the extended role of SPCS for individuals with cancer or a history of cancer. Consensus (using pre-defined criterion) was reached in both groups that the term cancer survivor should be applied to people post-treatment with no evidence of disease, indicating that application to people with active cancer should be reconsidered. Participants also felt that pragmatic (factual) categories may be useful in providing tailored care for people who have or had cancer. Consensus statements were also generated on the specific role of SPCS in supporting people with stable disease, and in supporting people living beyond cancer, particularly regarding pain management. The study also highlighted key areas of contention within and between the groups, and areas still lacking consensus.

Chapter 5: Palliative care and Oncology Survey on Terminology (POST). What do individuals known to palliative care and oncology services think about the terminology used to describe them?

- Thesis objective: To determine the perceptions of individuals with cancer known to SPC and oncology services regarding the terms used to describe them, in particular cancer survivor.

The POST study was a multicentre, survey-based observational study that sought to determine the perceptions of heterogeneous groups of people with cancer known to SPCS (SPC group) and people with cancer known to oncology on anticancer treatment (Onc group) regarding the terminologies used to describe them, and in particular the term cancer survivor. Participants were recruited from cancer centres, inpatient hospice units and community services in Ireland and the UK, and completed a one-off study-specific questionnaire. The questionnaire was completed by 1328 people with cancer (610 in SPC group; 718 in Onc group). Overall, 618 (46.5%) disliked being described as a cancer survivor, 401 (30.2%) liked the description, and 309 (23.3%) felt neutral. An obvious finding emerging from analysis was the significant difference in opinions between the groups, with participants in the SPC group showing greater propensity to dislike the term. Living in Ireland, higher educational attainment, and higher ECOG status were also associated with disliking the term. The majority of participants selected that people who had completed anticancer treatment with no evidence of disease (irrespective of time since completion) should be called cancer survivors.

A striking observation related to the similarities between these results and expert consensus outputs from Chapter 4, collectively suggesting that application of cancer survivor to people with active cancer should be reconsidered. Furthermore, as a universally agreeable term is likely unachievable, less contentious terms should be adopted, although an individualised person-centred approach should be taken.

Chapter 6: "How can you call me a cancer survivor if I'm not going to survive?"
Content analysis of free text responses in the Palliative care and Oncology Survey on Terminology (POST) on how people with cancer perceive the term "cancer survivor".

- Thesis objective: To determine the perceptions of individuals with cancer known to SPC and oncology services regarding the terms used to describe them, in particular cancer survivor.

This complementary part of the POST study used a qualitative descriptive design and inductive content analysis to identify themes from 766 participant free text responses about the term cancer survivors. The majority of these comments (71.5%) were negative. Participant perceptions were summarised into five themes: there is uncertainty around “cancer survivor”; there are challenges applying “cancer survivor” universally; “cancer survivor” may be used to describe certain groups; “cancer survivor” often evokes negative feelings, but can also be viewed positively; and different wording may be preferable. Importantly, results demonstrated the potential confusion, alienation and offence the term cancer survivor can cause, reinforcing the need to reconsider its use in clinical and academic settings.

Chapter 7: The model of care: PRiSM: Specialist Palliative Care's Role in Cancer Survivorship Model

- Thesis objective: To develop an overarching European model of care for SPCS for people with cancer or a history of cancer.

This chapter explored the development of models of care and SPC models, and proposed a conceptual model of care for SPCS for people who have or had cancer, integrating the outputs from the preceding chapters using the phases proposed by the Agency for Clinical Innovation (11). The model detail is based on the expert consensus statements from the PRiSM project (Chapter 4), which are intentionally transferable and generalisable, enabling local / regional and population-specific interventions to be applied. The model requires further research to identify if its application is feasible, efficient and effective.

8.5 Limitations of the thesis

Each chapter includes evaluation of its distinct strengths and limitations, although there are additional considerations. These include the methodologies incorporated, sample sizes, PPI representation, generalisability of results, and remaining gaps in the area.

The range of methodologies and study designs adopted in this thesis support its overall strength (narrative and scoping reviews, e-Delphi study, and mixed

methods survey-based study). In particular, the literature reviews utilised robust, transparent methodologies to generate results used to inform the subsequent studies (PRiSM and POST). However, these latter studies both employed survey-based methods. Surveys are inherently biased, and encompass numerous potential sources of error, including coverage, sampling, and measurement (75). Response bias is especially problematic, limiting generalisability of results.

Moreover, there are other generalisability issues. In the PRiSM project (e-Delphi study), despite purposive sampling across regions, representation remained skewed towards physician participation. POST study participants lacked ethnic diversity, and its convenience sampling approach potentially limits transferability. Both studies were also limited in geographical representation; the e-Delphi study was a European study, and largely included respondents from western countries, so it has less applicability outside these areas. The POST study was undertaken within Ireland and the UK. It is likely there would be differences in other English-speaking countries, particularly the USA where advocacy for cancer survivor terminology is potentially higher, and further difference again in non-English speaking countries. Indeed, the significant difference in opinion even between Ireland and the UK demonstrates the problem generalising results from one study group to another.

Although sample sizes appear reasonably large (PRISM: n=80 for SPC group; n=49 for ONC group; POST: n=1328), they remained limited. Notably, the POST study did not reach the target of 1532 participants in Ireland and the UK. This fundamentally impacts the significance and interpretation of results by increasing risk of bias. The barriers to research in SPC were explored in Chapter 5 (see section 5.6.3 Strengths and limitations), encompassing research culture (including gatekeeping), capacity, and patient vulnerabilities / burdens (459). Beyond increasing awareness and education, potential areas for improvement include research infrastructure, resources, personnel, and collaboration between research departments and clinical sites (461). It should be noted that the POST study is continuing to recruit to its target sample size.

The thesis successfully included representation from patient advocacy and PPI groups. There were representatives in the PRiSM expert panels (although small in number), and the Voices4Care (PPI group of the AIHPC) reviewed and provided feedback on participant materials to ensure accessibility and clarity in the POST

study. However, despite the importance of the aim and objectives of the thesis being widely acknowledged and advocated (78), the thesis did not specifically include PPI in the original thesis / study designs. Furthermore, the PPI representation included was restricted since it largely encompassed individuals from Ireland affiliated with certain groups.

Gaps also remain within the outcomes. Although 93 consensus statements agreed by both groups were generated in the PRiSM project, many others did not reach consensus and so remain unclear. Additionally, in dealing with the specific role of SPCS, the thesis does not engage with the complementary roles of other teams / specialties in supporting people who have or had cancer. It is beyond its scope to examine the specific roles of services like oncology and primary care, and where the overlap / differences might be, for which further research is required. Similarly, it was not the task of the POST study to directly compare the views of people with cancer with the views of people post-treatment with no evidence of disease. This study is unable to represent views throughout the entire cancer trajectory of people in Ireland and the UK, and any comparison based on previous research studies would be assumptive.

Finally, the model developed is based on consensus statements generated by one group of experts at one point in time. Implementation, evaluation and sustainability assessment require more consideration, and the model requires further development and endorsement by an expert group, and research to assess initial feasibility before definitive studies. Importantly, it is a conceptual model of care, not a clinical one, and so the most effective ways to deliver the care also need to be identified (such as referral criteria, personnel, location, interventions). It is also a model of SPCS for people who have or had cancer; a full discussion of a complete SPC model encompassing non-malignant disease as well lies outside the aim of this thesis, as does a model for cancer survivorship care overall.

8.6 Implications of the thesis

This research has the potential to impact people who have or had cancer, healthcare practitioners, clinical services, research, education and policy relating to cancer survivorship care. Specific suggestions have been explored in Chapters 4-7 for the relevant studies, but there are some general considerations.

8.6.1 People who have or had cancer

The evidence has been developed to better support the quality of life of this heterogeneous group by generating expert consensus opinion on the potential extended role of SPCS to support them, influencing services, education, research, and ultimately clinical care.

These studies have increased understanding about the perceptions of people with cancer about the healthcare terms used to describe them. Most importantly, the need to reconsider the application of cancer survivor terminology to people with advanced or metastatic cancer and people still on anticancer treatment has been highlighted. Similar views towards the terminology emerged from both the PRiSM and POST studies, demonstrating agreement between experts and the survey participants, and adding credibility to its challenge of this notion.

The studies in this thesis also draw attention to the importance of involving people with lived experience in discussions regarding their care, including its surrounding terminology, since the findings in this thesis are notably contrary to current practice.

8.6.2 Clinicians

This research has provided evidence to inform the debates about two contentious issues: the role of SPCS for people who have or had cancer (European expert consensus statements provide initial evidence regarding SPC clinical responsibilities for people with no evidence of disease), and the application of the term cancer survivors (according to European experts and people with cancer in the UK and Ireland).

8.6.3 Services

Findings raise intriguing questions regarding the nature and extent of current SPC service provision, representative of an emerging trend that links people with health-related suffering with SPCS, not just those with life-limiting disease. The consensus achieved in this thesis about the role of SPC for the different groups of people who have or had cancer could direct service development and inform how finite SPC resources are used, and there is potential for further research to build

on the proposed model. Usefully, it has also identified barriers to such service expansion (such as lack of resources, misperceptions about palliative care) that need to be overcome.

Clarifying nomenclature and formalising groups of people with cancer or a history of cancer will also help to direct service provision, especially since results imply that greater clarity is needed. Findings from this thesis should also help to shape the language used to describe people who have or had cancer across healthcare settings, at least regarding cancer survivorship terminology, especially since the way words are used can influence individuals' interactions with services.

8.6.4 Research

This thesis incorporates the first study clarifying European expert opinion on the role of SPCS for people living beyond cancer, within the constraints of SPC skills and resources, providing formative evidence on the topic. The ideal impact is knowledge translation to develop a European expert consensus-based model of care, to be evaluated through feasibility studies and then RCTs. There are also other opportunities for further research resulting from this thesis (see section 8.7 Future directions).

Additionally, the perspectives of people with cancer about the terms used to describe them demonstrated in this thesis should be prioritised when conducting research that includes / refers to these groups. Similarly, the term cancer survivors could be used with greater clarity and consistency in research projects, trial recruitment, and literature.

8.6.5 Education

Some of the emergent issues relate specifically to education. The PRiSM project defined distinct areas for educational development in SPC curricula, relevant to current and suggested extended practice, requiring provision so that training is in tandem with the evidence. Barriers to service extension were also identified, with misperceptions about the role of SPC recurrently identified. The need for ongoing public, patient and professional education about the role and relevance of SPC was ultimately reinforced, and certainly, healthcare professionals and people who

have or had cancer will require explanation and education to understand and accept the suggested service expansion.

The other areas requiring general education relate to the preferences of people with cancer regarding the terms used to describe them, and the meaning of the term cancer survivors. It may be assumed these are relevant to healthcare professionals, as well as people with a history of cancer, and the public generally. Results (particularly from Chapter 6) should help explain why this education is necessary, enabling researchers to find new ways of navigating these issues and better understand the sensitivity required.

8.6.6 Policy

The PRiSM project generated consensus statements which show that European experts agree that SPCS should have certain roles in supporting people with stable cancer, and people living beyond cancer. However, as noted in Chapter 4, these roles would generally require SPC service expansion, which will need increased resources and dedicated funding, for which changes in healthcare policy are required.

In addition, findings from the thesis call attention to the sizable need to reconsider how survivorship terminology is applied in guidelines and policy, particularly in relation to people with advanced or metastatic cancer, and that factual descriptions may be more coherent and acceptable alternatives.

8.7 Future directions

This thesis has contributed appreciably to the discussions about the role of SPCS for people with a history of cancer and no evidence of disease, and about cancer survivor terminology. However, many unanswered questions remain, with some outlined below.

8.7.1 SPCS for people who have or had cancer

What are the most appropriate referral criteria for people with stable disease or with no evidence of disease?

What are the most effective and appropriate strategies for symptom management for people with cancer-related or cancer treatment-related symptoms and stable disease?

What are the most effective and appropriate strategies for pain management for people with cancer-related or cancer treatment-related pain and no evidence of disease?

How can symptomatic interventions be improved according to the underlying pathophysiology, based on cancer type, anticancer treatment, or other contributory factor?

How can the barriers to extending SPCS to people with a history of cancer be overcome?

8.7.2 Terminologies to describe people who have or had cancer

What term do people who have or had cancer most prefer being described by?

How does terminology influence patient engagement with healthcare professionals, services and interventions?

What are the perspectives of people with advanced / metastatic cancer towards the term cancer survivor in other European, and non-European, English-speaking countries?

8.7.3 PRiSM model of care

Which aspects of the model of care would be endorsed by an expert panel, and which would not?

What is the feasibility and acceptability of the model of care?

What are the best ways to implement, evaluate and sustain the model of care?

What is the generalisability of the model of care within and beyond Europe?

What are the optimal recommendations about the personnel delivering care and location of care delivery for the model?

8.7.4 Education

What specific educational and training strategies are effective for SPC practitioners to support people who have or had cancer?

What strategies are most effective in combating the professional, patient and public misperceptions about SPC?

What strategies are required to influence professional, patient and public understanding and interpretation about cancer survivor terminology?

8.7.5 Survivorship care

What are the most appropriate roles for other specialties / services for different groups of people who have or had cancer?

What is the most effective model of survivorship care for different groups of people who have or had cancer?

8.8 Conclusion

There is much contention about the role of SPCS for the growing, diverse group of people who have or had cancer, and surrounding the terminology used to describe them. This thesis has generated European expert opinion about this role of SPCS, confirming that they should be involved in the care of people with stable disease and people living beyond cancer, particularly regarding pain management. The experts also reached consensus that cancer survivor terminology should be applied to people post-treatment with no evidence of disease, which was reinforced by results from a survey-based study that determined the perceptions of people with cancer in Ireland and the UK about the terms used to describe them, supporting reconsideration of the application of cancer survivorship terminology to people with active cancer. A new model of care for the role of SPCS for people who have or had cancer has been proposed, which applies pragmatic factual categorisation of people who have or had cancer, and aligns relevant core functions of SPCS with each group, seeking to better support and alleviate the suffering of this heterogeneous group in appropriate and effective ways. Finally, areas for future research and education have been acknowledged.

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10. Appendices

Appendix 1: Database search strategy for narrative review (Chapter 2)

Search strategy: Medline (Ovid)

1. Cancer survivors MESH term
2. Cancer survivorship key word
3. Cancer survivor key word
4. Living with cancer key word
5. Living beyond cancer key word
6. 1 or 2-5
7. Survivors MESH term
8. Survivorship MESH term
9. Survivor key word
10. 7 or 8-9
11. Neoplasms MESH term
12. Cancer key word
13. 11 or 12
14. 10 and 13
15. 6 or 14
16. Palliative medicine MESH term
17. Palliative care MESH term
18. Hospice care MESH term
19. Terminal care MESH term
20. End of life care key word
21. 16 or 17-20
22. 15 and 21

Search strategy: CINAHL

1. Cancer survivors MESH term
2. Cancer survivorship key word
3. Cancer survivor key word

4. 1 or 2 or 3
5. Survivors MESH term
6. Survivorship MESH term
7. Survivor key word
8. 5 or 6 or 7
9. Neoplasms MESH term
10. Cancer key word
11. 9 or 10
12. 8 and 11
13. 4 or 12
14. Palliative medicine MESH term
15. Palliative care MESH term
16. Hospice care MESH term
17. Terminal care MESH term
18. Supportive care key word
19. Symptom management key word
20. Palliative key word
21. Hospice key word
22. Advance care planning MESH term
23. 14 or 15-22
24. 13 and 23

Search strategy: PsycInfo

1. Cancer survivors or survivors of cancer or cancer survivorship MESH Subject heading
2. Cancer survivor key word
3. 1 or 2
4. Neoplasms or cancer MESH Subject heading
5. Cancer key word
6. 4 or 5
7. Survivors MESH Subject heading

8. Survivorship MESH Subject heading
9. Survivor key word
10. 7 or 8 or 9
11. 6 and 10
12. 3 or 11
13. Palliative medicine MESH Subject heading
14. Hospice care or palliative care or terminal care or end of life care MESH Subject heading
15. Supportive care MESH term
16. Symptom management MESH term
17. Palliative key word
18. Hospice key word
19. Advance care planning key word
20. 13 or 14-19
21. 12 and 20

Search strategy: Embase

1. Cancer survivor Emtree exploded as major focus
2. Cancer survivorship key word
3. Cancer survivors key word
4. 1 or 2 or 3
5. Survivor Emtree exploded as major focus
6. Survivorship Emtree exploded as major focus
7. Survivors key word
8. 5 or 6 or 7
9. Neoplasm Emtree exploded as major focus
10. Cancer key word
11. 9 or 10
12. 8 and 11
13. 4 or 12
14. Palliative therapy Emtree exploded as major focus

15. Hospice care Emtree exploded as major focus
16. Terminal care Emtree exploded as major focus
17. Supportive care key word
18. Symptom management key word
19. Palliative key word
20. Hospice Emtree exploded as major focus
21. Advance care planning Emtree exploded as major focus
22. 14 or 15-21
23. 13 and 22

Appendix 2: Database search strategy for scoping review (Chapter 3)

Search strategy: Medline (Ovid)

1. Cancer survivors MESH term
2. Cancer survivorship key word
3. Cancer survivor key word
4. 1 or 2 or 3
5. Survivors MESH term
6. Survivorship MESH term
7. Survivor key word
8. 5 or 6 or 7
9. Neoplasms MESH term
10. Cancer key word
11. 9 or 10
12. 8 and 11
13. 4 or 12
14. Definition key word
15. Meaning key word
16. Terminology as topic MESH term
17. Systematized Nomenclature of Medicine MESH term
18. Terminology key word
19. Clinical term key word
20. Identity key word
21. Label key word
22. 14 or 15 -21
23. 13 and 22
24. Classification MESH term
25. Categories key word
26. Phases key word
27. Seasons key word
28. Categori*ation key word
29. 24 or 25-28

30. 13 and 29
31. 23 or 30

Search strategy: CINAHL

1. Cancer survivors subject heading
2. Cancer survivors or survivors of cancer or cancer survivorship key word
3. Cancer survivor key word
4. 1 or 2 or 3
5. Survivors subject heading
6. Survivorship subject heading
7. Survivor key word
8. 5 or 6 or 7
9. Neoplasms subject heading
10. Cancer key word
11. 9 or 10
12. 8 and 11
13. 4 or 12
14. Definition or define or meaning or description key word
15. Meaning key word
16. Terminology key word
17. Nomenclature subject heading
18. Snomed subject heading
19. Clinical terminology key word
20. Identity key word
21. Label key word
22. 14 or 15 -21
23. 13 and 22
24. Classification subject heading
25. Categori*ation key word
26. Categories key word

27. Seasons key word
28. Phases key word
29. 24 or 25-28
30. 13 and 29
31. 23 or 30

Search strategy: PsycInfo

1. Cancer survivors or survivors of cancer or cancer survivorship survivor key word
2. Cancer survivor key word
3. 1 or 2
4. Survivors index term
5. Survivorship key word
6. Survivor key word
7. 4 or 5 or 6
8. Neoplasms index term
9. Cancer key word
10. 8 or 9
11. 7 and 10
12. 3 or 11
13. Definition or define or meaning or description key word
14. Terminology index term
15. Self-concept index term
16. Terminology or nomenclature or naming or language key word
17. Clinical terminology key word
18. Identity key word
19. Label key word
20. 13 or 14 -19
21. 12 and 20
22. Taxonomies index term
23. Categori*ation or classification key word

24. Categories key word
25. Phases key word
26. Seasons key word
27. 22 or 23-26
28. 12 and 27
29. 21 or 28

Search strategy: Embase

1. Cancer survivor EMTREE term
2. Cancer survivorship key word
3. Cancer survivors key word
4. 1 or 2 or 3
5. Survivor EMTREE term
6. Survivorship EMTREE term
7. Survivors key word
8. 5 or 6 or 7
9. Malignant neoplasm EMTREE term
10. Cancer key word
11. 9 or 10
12. 8 and 11
13. 4 or 12
14. Definition key word
15. Meaning key word
16. Nomenclature EMTREE term
17. Terminology key word
18. Identity key word
19. Label key word
20. 14 or 15 -21
21. 13 and 22
22. Classification EMTREE term

- 23. Categories key word
- 24. Phases key word
- 25. Seasons key word
- 26. Categorization key word
- 27. 24 or 25-28
- 28. 13 and 29
- 29. 23 or 30

Appendix 3: PRiSM study materials

a) Recruitment email

Subject line: Invitation to participate in **PRiSM project: Specialist Palliative Care's Role in Cancer Survivorship Model**

RE: PRiSM project: Specialist Palliative Care's Role in Cancer Survivorship Model

Developing European consensus recommendations on the role of specialist palliative care in cancer survivorship to inform a model of care

To whom it may concern,

The Academic Department of Palliative Medicine in Dublin, Ireland, would like to invite you to participate in the PRiSM project: Specialist Palliative Care's Role in Cancer Survivorship Model. This is a European e-Delphi study seeking professional and non-professional expert consensus on the role of Specialist Palliative Care for individuals who have cancer or a history of cancer.

This study was awarded the European Cancer Community Foundation Rising Star Grant. The Chief Investigator is Professor Andrew Davies, Professor of Palliative Medicine (Our Lady's Hospice & Care Services, Trinity College Dublin and University College Dublin).

We are seeking the views of up to 150 professionals from palliative care or oncology, and non-professional experts. We will use the secure online platform "Welphi". The study will commence in April 2024, and should be completed within four months. The results will be used to inform development of a European model for the role of specialist palliative care within cancer survivorship.

The only risk of the study is that sometimes people can become emotional or uncomfortable when considering issues surrounding cancer and palliative care services. If this should happen, we advise you to contact your healthcare provider for support.

We hope you would consider taking part. If you would like to find out more, please email Dr Amy Taylor at ataylor@olh.ie.

We look forward to hearing from you.

Kind regards,

Amy

Dr Amy Taylor

Palliative Medicine Specialty Trainee / Clinical Research Fellow

School of Medicine, Trinity College Dublin

Academic Department of Palliative Medicine, Our Lady's Hospice & Care Services

b) *PRiSM Participant Information Leaflet*

Participant Information Leaflet

Study Title	PRiSM project: Specialist Palliative Care's Role in Cancer Survivorship Model <i>Developing European consensus recommendations on the role of specialist palliative care in cancer survivorship to inform a model of care.</i>
Research Site	Academic Department of Palliative Medicine, Our Lady's Hospice & Care Services, Dublin, Ireland.
Principal Investigator	Professor Andrew Davies, Professor of Palliative Medicine, researchteam@olh.ie
Co-Investigator	Dr Amy Taylor, Specialty Trainee Palliative Medicine / Clinical Research Fellow, ataylor@olh.ie
Study Organiser/ Sponsor	Our Lady's Hospice & Care Services, info@olh.ie
Data Controller	Our Lady's Hospice & Care Services
Data Protection Officer	Ms Patricia Pierce, Data Protection Lead Our Lady's Hospice & Care Services, Harold's Cross, Dublin, D6W RY72 OLHDPO@ambitcompliance.ie
Main study contact	Dr Amy Taylor Phone: 0035314986243 Email: ataylor@olh.ie

You are being invited to take part in a research study that is being done by the Academic Department of Palliative Medicine, Dublin, Ireland. Please read the following information to see if this is something that you would like to take part in. If there is anything which is not clear, or if you would like more information, please ask the researchers.

This leaflet has five parts:

Part 1 - The Study

Part 2 - Data Protection

Part 3 - Approval, Organising and Funding

Part 4 - Further Information

Part 5 - Next Steps

Part 1 - The Study

Why is this study being done?

We are doing this study to generate consensus expert opinion on the core functions of specialist palliative care, the use of “cancer survivors”, categorisations/groups of individuals with cancer or a history of cancer, and the role of specialist palliative care for individuals with a history of cancer.

Why have I been invited to take part?

As a professional or non-professional expert in palliative care and / or oncology, your opinion is valued in generating consensus opinion.

Do I have to take part? Can I withdraw?

Participation is voluntary. You can change your mind at any point. If you decide to leave the study, you do not have to give a reason, but if you would be happy to share the reason we would appreciate understanding why. If you wish to withdraw, please contact Dr Amy Taylor at ataylor@olh.ie.

How will the study be carried out?

You will be asked to provide some basic demographic information on age, gender, location (country), and if relevant your job title / role in relation to the area and your specialty. You will join a group of palliative care or oncology professionals and non-professional experts. Each expert group will take part in the same study but separately.

The study will use the Delphi method through online questionnaires using the secure platform Welphi. The first round will provide the opportunity to share your opinions on statements from literature reviews on the areas. All participants will then be provided with anonymised responses from the previous round and asked to comment on their agreement with various statements. This process of providing feedback and reviewing responses will continue until a consensus is achieved within each expert group.

We are aiming for three or four rounds of questionnaires each lasting under 30 minutes and we expect the whole process to be completed within three months. In the event of a consensus not being achieved, or participants have difficulty with the questionnaire, an online meeting may be held to discuss the topics further.

What are the possible benefits of the study?

The aim of the study is to achieve palliative care and oncology expert consensus on the core functions of specialist palliative care, the use of “cancer survivors”, groups of individuals with cancer or a history of cancer, and the role of specialist palliative care for individuals with a history of cancer. This will hopefully raise awareness of the expectations of professional and non-professional experts and help to standardise the role of specialist palliative care for individuals with cancer or a history of cancer, informing model development to be piloted in future studies.

What are the possible risks of the study?

No risks have been identified to you taking part in the study. Sometimes people can become emotional or uncomfortable when considering issues surrounding cancer and palliative care services, and if this should happen we advise you to contact your local organisation or healthcare provider for support.

What will happen to the results of the study?

This study is being carried out as a part of a PhD. A report will be made of the findings and provided to Trinity College Dublin. Study findings will also be submitted for publication in medical journals and presentation at medical conferences. The responses from the Delphi study aim to inform Specialist Palliative Care's Role in Cancer Survivorship Model (PRiSM), which would be investigated during subsequent studies.

Part 2 - Data Protection

What information about me (personal data) will be used for this study?

We will use the following information about you (personal data) for this research study: contact details (name and email), age, gender, and country of residence. If you are a professional, you will also be asked your job title / role and specialty. The personal data we process will be obtained from you directly.

Who will access my personal data?

Co-investigator Dr Amy Taylor will have access to your personal data for the purposes of the study. Processing of your personal data will comply with the European General Data Protection Regulation (GDPR), or the equivalent legislation in other countries. Our Lady's Hospice & Care Services (OLH&CS), Dublin, Ireland, will be the Data Controller for this study.

How is the information kept confidential and secure?

At the beginning of the study, you will be assigned a unique code. This will only be accessible by Dr Amy Taylor. In Welphi, the other participants will be unable to identify you through use of this code, and your online answers will be completely anonymised as even Dr Amy Taylor will be unable to view your specific answers through Welphi.

Recorded information will be stored on a secure encrypted research drive at the Academic Department of Palliative Medicine, Our Lady's Hospice & Care Services, Dublin, Ireland, which is only accessible by the research team.

Your privacy is important to us. We take many steps to make sure that we protect your confidentiality and keep your data safe. Here is how we do this:

- We have undertaken a Risk Assessment of the data protection implication
- All researchers have undertaken additional training in data protection
- All researchers who will have access to the personal data are bound by a professional code of secrecy

- All data is coded so that participants cannot be identified in the study results
- You will not be identifiable in any presentation or publication in relation to the study.

How long will my personal information used for this study be retained for?

Data will be stored for 7 years following completion of the study as per research best practice and then destroyed by a nominated member of the research team.

What is the lawful (legal) basis to use my personal data?

By law, we can use your personal information for scientific research (in the public interest). We will also ask for your explicit consent to use your data as a requirement of the Irish Health Research Regulations. Your personal data will be processed only as required to achieve the outcome of the study and not in any way which may cause damage or distress.

The legal basis for data processing is provided by:

The European General Data Protection Regulation (GDPR) Article 9(2) (j); Article 6(1)(e)

The Data Protection Act 2018.

What are my rights under Data Protection law?

You are entitled to:

- object to our use of your personal data or any further use;
- request access to your personal data and to receive a copy of it (up to the point of anonymisation);
- request that inaccurate personal data be corrected or deleted;
- request restriction of our use of your personal data (if it is inaccurate);
- request deletion of your data.

By law you can exercise the above rights in relation to your personal data, unless the request would make it impossible or very difficult to conduct the research. You can exercise these rights by contacting Dr Amy Taylor or the Data Protection Officer (details below).

Part 3 - Approval, Organising and Funding

Has this study been approved by a research ethics committee?

Trinity College Dublin Faculty of Health Sciences Research Ethics Committee has reviewed and approved the study. Approval was granted on 27th March 2024. An annual report will be provided to the REC and on completion of the study.

Who is organising and funding this study?

This study will be funded by a European Cancer Community Foundation Rising Star Grant, as well as Professor Andrew Davies' Research Fund. There is no commercial or pharmaceutical sponsorship of this research. The research is being conducted as part of a research qualification with Trinity College Dublin.

Will I be paid to take part in the study?

No. Taking part in the study is voluntary and there will be no financial compensation. However, with your permission, we plan to acknowledge all collaborators in the study outputs.

Part 4 – Further Information

Who should I contact for information or concerns?

If you have any concerns or questions, you can contact:

- Principal Investigator: Professor Andrew Davies, Professor of Palliative Medicine, Our Lady's Hospice & Care Services, Harold's Cross, Dublin. Email: researchteam@olh.ie
- Co-investigator: Dr Amy Taylor, Clinical Research Fellow, Our Lady's Hospice & Care Services, Harold's Cross, Dublin. Email: ataylor@olh.ie
- Data Protection Officer: Patricia Pierce, Data Protection Officer, Our Lady's Hospice & Care Services, Harold's Cross, Dublin. Email: OLHDPO@ambitcompliance.ie

Under GDPR, if you are not satisfied with how your data is being processed, you have the right to lodge a complaint with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland. Website: www.dataprotection.ie.

Part 5 – Next Steps

What are the next steps?

If you would like to take part in this study, please contact Dr Amy Taylor (ataylor@olh.ie). We will ask you to please print, sign and return a Consent Form via secure email.

Will I be contacted again?

We will contact you in seven (7) days' time, to give you time to consider your participation in the study. If we do not hear back from you, we will contact you on one further occasion and if we do not hear from you after that, we will not contact you again.

Thank you for taking the time to consider participating in this study.



c) *PRiSM Consent Form*

CONSENT FORM

PRiSM project: Specialist Palliative Care's Role in Cancer Survivorship Model
Developing European consensus recommendations on the role of specialist palliative care in cancer survivorship to inform a model of care.

Study ID:

There are **two sections** in this form.

Section 1 contains statements of understanding and asks you to tick each if you understand. Please ask any questions you may have when reading each of the statements.

Section 2 asks for your informed consent. Please select either 'yes' or 'no' to indicate your choice.

Thank you for participating.

The end of this form is for the researchers to complete.

1. General Understanding	Tick
I confirm that I have read and understood the Information Leaflet for the above study. The information has been fully explained to me and I have been able to ask questions, all of which have been answered to my satisfaction.	☐
I understand that taking part in this study is entirely voluntary. I understand that not taking part will have no negative impact on me.	☐
I understand that I can leave this study at any time without giving a reason. I understand that leaving this study will not affect me in any professional or non-professional way now or in the future.	☐
I understand that I will not be paid for taking part in this study or receive any benefits from any products developed as a result of this research study.	☐
I know how to contact the research team if I need to.	☐
By ticking each box above and choosing my options below and signing this document I agree to participate in the 'PRiSM' study as described in the Participant Information Leaflet.	

2. Consent	
I agree to take part in this research study, having been fully informed of the risks and benefits in the participant information leaflet provided to me.	Yes No ☐ ☐
I agree to the use of information I provide about me (personal data) being used by the research team for this research study as described in the participant information leaflet.	Yes No ☐ ☐

Participant Name (Block Capitals) Participant Signature Date

To be completed by the Principal Investigator or nominee.

I, the undersigned, have taken the time to fully explain to the above participant the nature and purpose of this study in a way that they could understand.

I have explained the risks and possible benefits involved. I have invited them to ask questions on any aspect of the study that concerned them.

I have given a copy of the participant information leaflet and consent form to the participant with contact details of the study team.

Researcher name _____

Title and qualifications _____

Signature _____

Date _____

Copies to be created and retained: 1 for Participant, 1 for PI

d) Baseline Information Sheet

Baseline Information Sheet

(free text response)

Study number	(assigned)
Age	
Gender	
Country of residence	
Professional or non-professional	

If professional:	
Job title / role	
Specialty (if relevant)	

If non-professional	
Affiliated organisation	

e) Round 1 questions

Overview

PRiSM: Specialist Palliative Care's Role in Cancer Survivorship Model

Developing European consensus recommendations on the role of specialist palliative care in cancer survivorship to inform a model of care.

Welcome to Round 1 of this Delphi questionnaire.

Round 1 has four sections. Within each section, you will be asked a series of questions and given the opportunity to select your preferred answer, rate your agreement with certain statements, edit / suggest language, suggest other ideas, or provide free-text responses.

Sections:

1. Definition and core functions of Specialist Palliative Care (SPC)
2. Definition of "cancer survivor"
3. Categorisation of individuals with cancer or a history of cancer
4. Extended role of Specialist Palliative Care (SPC) for individuals with a history of cancer.

Section 1: Definition and core functions of Specialist Palliative Care (SPC)

This section aims to establish consensus about the definition and core functions of specialist palliative care.

There are nine questions. You will be asked to what extent you agree with different definitions of palliative care and to choose your preferred definition, to what extent you agree with a definition of specialist palliative care and to choose your preferred definition, to state your agreement with different "core functions" of specialist palliative care services, to what extent you agree that different types of pain and other physical symptoms should be managed by specialist palliative care services, and to what extent you agree that specialist palliative care services generally have the knowledge and skills to manage these. You can also suggest additional statements and edit / suggest language.

1.1 To what extent to you agree with the following definitions of palliative care:

(Strongly disagree, Moderately Disagree, Neither agree nor disagree, Moderately Agree, Strongly agree)

- ❖ The World Health Organization (WHO) definition of palliative care is:
"Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual" (20).

- ❖ The International Association for Hospice and Palliative Care (IAHPC) definition of palliative care is: “Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers” (22).

1.2 What is your preferred definition of palliative care? (Select one)

- ❖ WHO definition (see above)
- ❖ IAHPC definition (see above)
- ❖ Another definition (please provide definition / reference)

1.3 To what extent do you agree with the following definition of specialist palliative care: (Strongly disagree, Moderately Disagree, Neither agree nor disagree, Moderately Agree, Strongly agree)

- ❖ The European Association for Palliative Care (EAPC) definition of specialist palliative care is: “Specialist palliative care is provided by specialised services for patients with complex problems not adequately covered by other treatment options. Specialist palliative care services require a team approach, combining a multi-professional team with an interdisciplinary mode of work. Team members must be highly qualified and should have their main focus of work in palliative care” (23).

1.4 What is your preferred definition of specialist palliative care? (Select one)

- ❖ EAPC definition (see above)
- ❖ Another definition (please provide definition / reference)

1.5 To what extent do you agree that the following are the “core” functions of specialist palliative care services? (Core functions are those that are usually undertaken by specialist palliative care services)

Rate agreement for each one. (Strongly disagree, Moderately Disagree, Neither agree nor disagree, Moderately Agree, Strongly agree) You can comment and suggest new ideas.

- ❖ Management of pain
- ❖ Management of other physical symptoms
- ❖ Management of psychological problems
- ❖ Emotional support (patient)
- ❖ Emotional support (family)
- ❖ Spiritual support
- ❖ Social assistance

- ❖ Co-ordination of care
- ❖ Advance care planning
- ❖ End-of-life care
- ❖ Bereavement care
- ❖ Rehabilitation
- ❖ Other (please state)

1.6 In terms of pain, to what extent do you agree that specialist palliative care services should be managing the following types of pain:

Rate agreement for each one (Strongly disagree, Moderately Disagree, Neither agree nor disagree, Moderately Agree, Strongly agree)

- ❖ Acute cancer-related pain (pain for < 3 months)
- ❖ Acute cancer treatment-related pain (pain for < 3 months)
- ❖ Acute pain related to non-cancer causes (pain for < 3 months)
- ❖ Chronic cancer-related pain (pain for ≥ 3 months)
- ❖ Chronic cancer treatment-related pain (pain for ≥ 3 months)
- ❖ Chronic pain related to non-cancer causes (pain for ≥ 3 months)
- ❖ Individuals with pain and a previous history of opioid misuse / abuse / addiction
- ❖ Individuals with pain and ongoing problems of opioid misuse / abuse / addiction
- ❖ Other (please state)

1.7 In terms of pain, to what extent do you agree that specialist palliative care services generally have the knowledge and skills to manage the following:

Rate agreement for each one (Strongly disagree, Moderately Disagree, Neither agree nor disagree, Moderately Agree, Strongly agree)

- ❖ Acute cancer-related pain (pain for < 3 months)
- ❖ Acute cancer treatment-related pain (pain for < 3 months)
- ❖ Acute pain related to non-cancer causes (pain for < 3 months)
- ❖ Chronic cancer-related pain (pain for ≥ 3 months)
- ❖ Chronic cancer treatment-related pain (pain for ≥ 3 months)
- ❖ Chronic pain related to non-cancer causes (pain for ≥ 3 months)
- ❖ Patients with a previous history of opioid misuse / abuse / addiction
- ❖ Patients with ongoing problems of opioid misuse / abuse / addiction

1.8 In terms of non-pain symptoms / physical problems, to what extent do you agree that specialist palliative care services should be managing the following types of symptoms:

Rate agreement for each one (Strongly disagree, Moderately Disagree, Neither agree nor disagree, Moderately Agree, Strongly agree)

- ❖ Acute cancer-related symptoms / physical problems (lasting < 3 months)
- ❖ Acute cancer treatment-related symptoms / physical problems (lasting < 3 months)
- ❖ Acute symptoms / physical problems related to non-cancer causes (lasting < 3 months)
- ❖ Chronic cancer-related symptoms / physical problems (lasting ≥ 3 months)
- ❖ Chronic cancer treatment-related symptoms / physical problems (lasting ≥ 3 months)
- ❖ Chronic symptoms / physical problems related to non-cancer causes (lasting ≥ 3 months)

1.9 In terms of non-pain symptoms / physical problems, to what extent do you agree that specialist palliative care services generally have the knowledge and skills to manage the following:

Rate agreement for each one (Strongly disagree, Moderately Disagree, Neither agree nor disagree, Moderately Agree, Strongly agree)

- ❖ Acute cancer-related symptoms / physical problems (lasting < 3 months)
- ❖ Acute cancer treatment-related symptoms / physical problems (lasting < 3 months)
- ❖ Acute symptoms / physical problems related to non-cancer causes (lasting < 3 months)
- ❖ Chronic cancer-related symptoms / physical problems (lasting ≥ 3 months)
- ❖ Chronic cancer treatment-related symptoms / physical problems (lasting ≥ 3 months)
- ❖ Chronic symptoms / physical problems related to non-cancer causes (lasting ≥ 3 months)

Section 2: Definition of “cancer survivor”

This section aims to establish consensus about the definition of “cancer survivor”.

There are two questions. You will be asked to select your preferred definition of a “cancer survivor” and to what extent you agree that different groups of individuals with cancer or a history of cancer should be defined as “cancer survivors”. You can also suggest additional statements and edit / suggest language.

2.1 What is your preferred definition of a “cancer survivor”? (Select one)

- ❖ National Cancer Institute definition: “An individual is considered a cancer survivor from the time of diagnosis through the balance of life. There are many types of survivors, including those living with cancer and those free of cancer” (17).
- ❖ European Society for Medical Oncology definition: “Patients with a diagnosis of cancer who are managed with curative intent, from completion of active therapy (despite eventually on or off maintenance therapy) to long-term follow-up” (76).
- ❖ Another definition (please provide definition / reference)
- ❖ No definition – the term should not be used

2.2 To what extent do you agree that the following groups of individuals should be defined as “cancer survivors”?

Rate agreement for each one (Strongly disagree, Moderately Disagree, Neither agree nor disagree, Moderately Agree, Strongly agree)

- ❖ All individuals with cancer
- ❖ Individuals who are still receiving anticancer treatment (where anticancer treatment includes, for example, chemotherapy, hormone therapy, immunotherapy, targeted therapy, radiotherapy / radiation therapy, surgery)
- ❖ Individuals who have just completed anticancer treatment, and still have some known cancer present
- ❖ Individuals who have just completed anticancer treatment, and have no known cancer present
- ❖ Individuals who completed anticancer treatment at least 1 year beforehand, and have no known cancer present
- ❖ Individuals who completed anticancer treatment at least 5 years beforehand, and have no known cancer present
- ❖ Individuals who completed anticancer treatment at least 10 years beforehand, and have no known cancer present
- ❖ Individuals who have progressive/worsening cancer, and have no other anticancer treatment options
- ❖ Family members, friends, and caregivers of individuals with cancer or a history of cancer
- ❖ No individual should be called a “cancer survivor” i.e. the term should not be used
- ❖ Other (please state)

Section 3: Categorisation of individuals with cancer or a history of cancer

This section aims to establish consensus about categories / groups of individuals with cancer or a history of cancer to inform a model of care.

There are three questions. You will be asked to what extent you agree that a classification for seasons of cancer survivorship and classifications for groups of individuals with cancer or a history of cancer are useful. You can also comment and edit / suggest language.

3.1 To what extent do you agree that the following classification for seasons of cancer survivorship is useful?

Rate agreement (Strongly disagree, Moderately Disagree, Neither agree nor disagree, Moderately Agree, Strongly agree) and comment

- ❖ **Acute survivorship** (Diagnosis, staging and treatment.)
- ❖ **Transitional survivorship** (The transition from active treatment to careful observation and the emotional, social, and medical adaptations that occur.)
- ❖ **Extended survivorship** (A diverse group who are who are (1) alive and "living with cancer" but requiring ongoing treatment for recurrent, active, and often advanced disease; (2) in a complete remission that requires ongoing therapy; or (3) in a complete remission and with a favourable prognosis.
- ❖ **Permanent survivorship** (A diverse group of 4 subgroups including (1) survivors who are "cancer-free but not free of cancer," (2) survivors who are cancer-free but continue to have significant "fall-out" from cancer and its treatment including psychosocial, medical, financial, or legal sequelae, (3) survivors who go on to develop second cancers which may be unrelated to the first cancer or its treatment, or may be more likely due to genetic or environmental factors, and (4) survivors who later develop cancers that are secondary to the initial treatment.) (97).

3.2 To what extent do you agree that the following classification for groups of individuals with cancer or a history of cancer is useful?

Rate agreement (Strongly disagree, Moderately Disagree, Neither agree nor disagree, Moderately Agree, Strongly agree) and comment

- ❖ **Living with cancer** (Begins with diagnosis. The focus is on treatment, getting rid of the cancer, if possible, or controlling the cancer to the point where you can live with it long term.)
- ❖ **Living through cancer** (The period after treatment when you are at risk of your cancer returning (recurrence). This is also a time of rehabilitation.)
- ❖ **Living beyond cancer** (Post-treatment and long-term survivorship) (102).

3.3 To what extent do you agree that the following (new) classification for groups of individuals with cancer or a history of cancer is useful?

Rate agreement (Strongly disagree, Moderately Disagree, Neither agree nor disagree, Moderately Agree, Strongly agree) and comment

- Individuals with cancer before the start of primary anticancer treatment
- Individuals with cancer on anticancer treatment with curative intent (primary or other)
- Individuals with cancer on anticancer treatment with palliative intent (primary or other)
- Individuals with cancer not on anticancer treatment on “watch and wait” / active monitoring
- Individuals with cancer not on anticancer treatment with advanced / progressive disease and no further anticancer treatment options
- Individuals with a history of cancer who have completed anticancer treatment and have no evidence of disease, on active oncology follow-up (risk of recurrence)
- Individuals with a history of cancer who have completed anticancer treatment and have no evidence of disease, not on active oncology follow-up (low risk of recurrence)

Section 4: Extended role of Specialist Palliative Care (SPC) for individuals with a history of cancer.

This section aims to establish consensus about the role of specialist palliative care (SPC) for individuals with a history of cancer. This is the final section.

There are four questions which all relate to individuals with a history of cancer who have completed anticancer treatment and have no evidence of disease. You will be asked to what extent you agree that specialist palliative care services should have a role in supporting essential components of survivorship care for these individuals, to what extent you agree that specialist palliative care services generally have the knowledge and skills to manage these, and to what extent you agree that different issues are barriers to extending the input of specialist palliative care services. You can also suggest additional statements and edit / suggest language.

You will also be asked if you have any other comments about the role of specialist palliative care services for individuals with a history of cancer.

4.1 The Institute of Medicine report “From Cancer Patient to Cancer Survivor: Lost in Transition” describes “essential components of survivorship care” (18). To what extent do you agree that specialist palliative care services should have a role in supporting the following “essential components of survivorship care” in *individuals with a history of cancer who have completed anticancer treatment and have no evidence of disease*:

Rate agreement for each one (Strongly disagree, Moderately Disagree, Neither agree nor disagree, Moderately Agree, Strongly agree).

You can comment and suggest new ideas.

- ❖ Prevention of recurrent and new cancers
- ❖ Prevention of other late effects
- ❖ Surveillance for cancer spread, recurrence, or second cancers
- ❖ Surveillance of physical late effects
- ❖ Surveillance of psychosocial late effects
- ❖ Intervention for pain as a late effect
- ❖ Intervention for other physical late effects
- ❖ Intervention for psychosocial late effects
- ❖ Managing “fear of cancer recurrence”
- ❖ Rehabilitation
- ❖ Supporting occupational issues / return to work
- ❖ Managing financial problems (“financial toxicity”)
- ❖ Supporting concerns related to insurance
- ❖ Supporting caregivers
- ❖ Supporting coordination between specialists and primary care providers
- ❖ Other (please state)

4.2 To what extent do you agree that specialist palliative care services generally have the knowledge and skills to manage the following “essential components of survivorship care” in *individuals with a history of cancer who have completed anticancer treatment and have no evidence of disease*:

Rate agreement for each one (Strongly disagree, Moderately Disagree, Neither agree nor disagree, Moderately Agree, Strongly agree)

- ❖ Prevention of recurrent and new cancers
- ❖ Prevention of other late effects
- ❖ Surveillance for cancer spread, recurrence, or second cancers
- ❖ Surveillance of physical late effects
- ❖ Surveillance of psychosocial late effects
- ❖ Intervention for pain as a late effect
- ❖ Intervention for other physical late effects
- ❖ Intervention for psychosocial late effects
- ❖ Managing “fear of cancer recurrence”
- ❖ Rehabilitation
- ❖ Supporting occupational issues / return to work
- ❖ Managing financial problems (“financial toxicity”)

- ❖ Supporting concerns related to insurance
- ❖ Supporting caregivers
- ❖ Supporting coordination between specialists and primary care providers
- ❖ Other (please state)

4.3 To what extent do you agree that the following are barriers to extending the input of specialist palliative care services to *individuals with a history of cancer who have completed anticancer treatment and have no evidence of disease*:

Rate agreement for each one (Strongly disagree, Moderately Disagree, Neither agree nor disagree, Moderately Agree, Strongly agree).

You can comment and suggest new ideas.

- ❖ Financial resources
- ❖ Human resources
- ❖ Other resources
- ❖ Lack of relevant education and training (e.g. management of chronic cancer treatment-related symptoms / problems)
- ❖ Lack of willingness from palliative care professionals
- ❖ Lack of willingness from oncology professionals
- ❖ Lack of willingness from general practitioners
- ❖ Lack of willingness from patients and families
- ❖ Misperceptions about the nature of palliative care
- ❖ Other (please state)

4.1 Do you have any other comments about the role of specialist palliative care services for individuals with a history of cancer who have completed anticancer treatment and have no evidence of disease?

Free text comment

Appendix 4: PRiSM study approval letters

a) Trinity College Dublin Faculty of Health Sciences Research Ethics Committee

27/03/2024

Title: PRiSM Project

REAMs No: 2786

Dear Amy Taylor,

Your application has been reviewed by the relevant Research Ethics Committee (REC) and we are pleased to inform you that the above project has been approved.

Please note that any documents submitted for GDPR purposes in association with your ethics application are approved by the REC from an ethical perspective only (GDPR compliance is assumed, as per your uploaded letter of approval from the DPO).

It is the responsibility of the researcher/research team to ensure that, if applicable, all aspects of the study are executed in compliance with the General Data Protection Regulation (GDPR), the Health Research Regulations, Data Protection Act 2018, particularly regarding the storage and destruction of data arising from the research, and adhere to any relevant Health & Safety regulations.

Please note the reporting requirements outlined, in particular the need for:

- An immediate report of any serious or unexpected adverse event should be sent immediately to your REC via email. The Procedures for Reporting Adverse Events are outlined in the application. The Adverse Event form are available [here](#).
- Any other unforeseen events should also be reported using this form and sent to your REC via email. The Adverse Event form are available [here](#).
- An end of project report is due one year from the end of project date. The form is available [here](#). This should be sent to your REC via email.
- If the data collection period is longer than 1 year, an annual report should be submitted. The form is available [here](#). This should be sent to your REC via email.

You, and your research team (where applicable), are responsible for conducting the research strictly in the manner outlined in your application and supporting documentation, and in compliance with it. Proposed changes or amendments to the approved study must be submitted to the REC for approval in advance of any changes or amendments being implemented. In the event that the changes or amendments are significant, the REC may require a new submission. This ethical approval expires with the end dates of the project as stated in the application.

If you have any queries regarding this decision, please contact the Chair of your REC.

We wish you all the very best with your research project.

Kind Regards,

The REC

NB. If your study is to be conducted outside TCD, e.g. in a hospital site, please note that Trinity College REC approval does not of itself entitle you to conduct research in an external site. In this regard, the onus is upon you - the researcher, to ensure that all permissions have been obtained, and that any other requirements of the study site have been satisfied

NB. If your study involves a trial of medicinal products or medical devices, apps on humans you must provide a copy of your Clinical Trial Sponsorship from TCD - indicating that you have the appropriate trial insurance and sponsor oversight".

b) *Our Lady's Hospice & Care Services Education and Research Committee*



24/04/2024

Dear Amy Taylor,

Re: “PRISM project: Specialist Palliative Care's Role in Cancer Survivorship Model”

On behalf of the Education and Research Committee, I would like to thank you for submitting the above proposal. I can confirm that the Committee is satisfied with your submission and has given approval for your proposal.

A copy of your completed project should be submitted to the E&R Committee and the Library at Our Lady's Hospice & Care Services on completion. You will also need to complete yearly and end-of-study Report's.

We wish you the very best of luck with your research.

Yours sincerely,

Mary Flanagan, Interim CEO,
OLHC&CS

Professor Andrew Davies,
Professor of Palliative Medicine,
OLHC&CS

Our Lady's Hospice
& Care Services
Harold's Cross,
D6W RY72

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(This paper is not to be used for prescription purposes.)

Appendix 5: PRiSM study supplementary material

Supplementary Tables S1a-e: Specialist palliative care (SPC) expert group results.

S1a. Definition and core functions of Specialist Palliative Care (SPC) – SPC group results.

Statement	Round 1					Round 2					Round 3					rho	p value
	SD	MD	N	MA	SA	SD	MD	N	MA	SA	SD	MD	N	MA	SA		
Section 1: Definition and core functions of Specialist Palliative Care (SPC)																	
Core functions of SPCS																	
Management of pain	0%	0%	0%	5%	95%	2%	0%	0%	1%	96%						0.250*	0.025
	0%		0%	100%		2%		0%	97%								
Management of other physical symptoms	0%	0%	0%	8%	92%	2%	0%	0%	2%	95%						0.325**	0.003
	0%		0%	100%		2%		0%	97%								
Management of psychological problems	0%	0%	2%	24%	74%	2%	0%	0%	17%	80%						0.658**	<0.001
	0%		2%	98%		2%		0%	97%								
Emotional support (patient)	0%	0%	0%	18%	82%	2%	1%	0%	11%	85%						0.586**	<0.001
	0%		0%	100%		3%		0%	96%								
Emotional support (family)	0%	1%	2%	27%	69%	2%	1%	1%	16%	79%						0.620**	<0.001
	1%		2%	96%		3%		1%	95%								
Spiritual support	2%	1%	12%	20%	64%	4%	2%	11%	17%	66%						0.764**	<0.001
	3%		12%	84%		6%		11%	83%								
Social assistance	1%	2%	12%	36%	49%	2%	4%	12%	35%	47%						0.745**	<0.001
	3%		12%	85%		6%		12%	82%								
Co-ordination of care	0%	1%	7%	33%	58%	1%	2%	7%	30%	59%						0.766**	<0.001
	1%		7%	91%		3%		7%	89%								
	0%	2%	1%	23%	74%	2%	0%	1%	19%	78%						0.646**	<0.001

Advance care planning	2%		1%	97%		2%		1%	97%							0.599**	<0.001
End-of-life care	0%	0%	1%	14%	85%	2%	0%	1%	10%	86%							
	0%		1%	99%		2%		1%	96%								
Bereavement care	1%	1%	6%	48%	44%	2%	0%	6%	51%	41%							
	2%		6%	92%		2%		6%	92%								
Rehabilitation	1%	8%	19%	42%	30%	2%	7%	19%	44%	27%							
	9%		19%	72%		9%		19%	71%								
Religious support						11%	17%	35%	27%	10%	10%	16%	34%	35%	5%	0.732**	<0.001
						28%			35%	37%		26%		34%	40%		
Research						1%	2%	5%	35%	57%	0%	3%	1%	24%	73%	0.650**	<0.001
						3%		5%	92%		3%		1%	97%			
Education (other healthcare professionals)						2%	0%	2%	20%	75%	0%	0%	1%	9%	90%	0.577**	<0.001
						2%		2%	95%		0%		1%	99%			
SPCS should manage the following types of pain:																	
Acute cancer-related pain (pain for < 3 months)	0%	4%	8%	20%	68%	1%	0%	6%	20%	73%						0.720**	<0.001
	4%		8%	88%		1%		6%	93%								
Acute cancer treatment-related pain (pain for < 3 months)	1%	7%	11%	32%	49%	2%	1%	11%	22%	63%							
	8%		11%	81%		3%		11%	85%								
Acute pain related to non-cancer causes (pain for < 3 months)	11%	13%	23%	21%	32%	11%	12%	22%	25%	30%							
	24%		23%	53%		23%		23%	55%								
Chronic cancer-related pain	2%	1%	5%	26%	65%	1%	1%	5%	21%	72%						0.687**	<0.001

(pain for≥3 months)	3%		5%	91%		2%		5%	93%								
Chronic cancer treatment-related pain (pain for≥3 months)	2%	4%	8%	32%	54%	2%	2%	9%	28%	58%							
	6%		8%	86%		4%		9%	86%								
Chronic pain related to non-cancer causes (pain for≥3 months)	18%	14%	11%	21%	36%	21%	11%	9%	26%	33%							
	32%		11%	57%		33%		9%	59%								
Individuals with pain and a previous history of opioid misuse / abuse / addiction	6%	12%	15%	26%	40%												
	18%		15%	66%													
Individuals with pain and ongoing problems of opioid misuse / abuse / addiction	5%	13%	20%	19%	43%												
	18%		20%	62%													
Chronic cancer / cancer treatment-related pain – in collaboration with the multidisciplinary chronic pain team						2%	0%	6%	38%	54%	0%	0%	3%	31%	66%	0.659**	<0.001
						2%		6%	92%		0%		3%	97%			
Individuals with cancer / cancer treatment–											1%	1%	11%	42%	44%	1%	0%

related pain and a previous history of opioid misuse / abuse / addiction		2%	11%	86%	1%	5%	94%						
Individuals with cancer / cancer treatment–related pain and ongoing problems of opioid misuse / abuse / addiction		1%	5%	15%	42%	44%	1%	0%	9%	53%	38%	0.719**	<0.001
		6%	15%	76%	1%	9%	91%						
Individuals with chronic cancer / cancer treatment–related pain and a previous history of opioid misuse / abuse / addiction – in collaboration with the multidisciplinary chronic pain team		2%	1%	10%	37%	49%	1%	0%	10%	29%	60%	0.768**	<0.001
		3%	10%	86%	1%	10%	89%						
Individuals with chronic cancer / cancer treatment–related pain and ongoing problems of opioid misuse / abuse /		2%	2%	9%	42%	44%	1%	0%	10%	30%	59%	0.782**	<0.001
		4%	9%	86%	1%	10%	89%						

addiction – in collaboration with the multidisciplinary chronic pain team																	
Individuals with cancer / cancer treatment–related pain and a previous history of opioid misuse / abuse / addiction – in collaboration with addiction services						4%	1%	10%	38%	47%	1%	0%	6%	25%	68%	0.579**	<0.001
Individuals with cancer / cancer treatment–related pain and ongoing problems of opioid misuse / abuse / addiction – in collaboration with addiction services						5%		10%	85%		1%		6%	93%			
Individuals with cancer / cancer treatment–related pain and ongoing problems of opioid misuse / abuse / addiction – in collaboration with addiction services						2%	4%	10%	27%	58%	1%	1%	6%	15%	76%	0.634**	<0.001
						6%		10%	85%		2%		6%	91%			
SPCS generally have the knowledge and skills to manage the following:																	
Acute cancer-related pain (pain for < 3 months)	0%	0%	5%	12%	83%	0%	0%	1%	11%	88%						0.743**	<0.001
	0%		5%	95%		0%		1%	99%								
Acute cancer treatment-	0%	2%	8%	27%	62%	0%	1%	4%	25%	70%						0.700**	<0.001

related pain (pain for < 3 months)	2%		8%	89%		1%		4%	95%					
Acute pain related to non- cancer causes (pain for < 3 months)	6%	13%	23%	23%	36%	5%	10%	23%	23%	38%		0.857**	<0.001	
	19%		23%	59%		15%		24%	61%					
Chronic cancer- related pain (pain for≥3 months)	2%	0%	1%	24%	73%	0%	0%	0%	21%	79%		0.662**	<0.001	
	2%		1%	97%		0%		0%	100%					
Chronic cancer treatment- related pain (pain for≥3 months)	4%	5%	8%	36%	48%	1%	4%	9%	32%	54%		0.868**	<0.001	
	9%		8%	84%		5%		9%	86%					
Chronic pain related to non- cancer causes (pain for≥3 months)	11%	13%	19%	25%	32%	9%	15%	15%	27%	35%		0.902**	<0.001	
	24%		19%	57%		24%		15%	62%					
Individuals with pain and a previous history of opioid misuse / abuse / addiction	6%	14%	21%	37%	21%									
	20%		21%	58%										
Individuals with pain and ongoing problems of opioid misuse / abuse / addiction	6%	18%	23%	33%	20%									
	24%		23%	53%										

Individuals with cancer / cancer treatment–related pain and a previous history of opioid misuse / abuse / addiction		0%	7%	16%	54%	22%	0%	6%	9%	75%	10%	0.763**	<0.001
		7%		16%	76%		6%		9%	85%			
Individuals with cancer / cancer treatment–related pain and ongoing problems of opioid misuse / abuse / addiction		1%	11%	21%	46%	21%	0%	9%	14%	70%	8%	0.753**	<0.001
		12%		21%	67%		9%		14%	78%			
SPCS services should have more education and / or appropriate training in the following areas:													
Interventional pain techniques		5%	5%	7%	35%	48%	3%	3%	4%	38%	54%	0.802**	<0.001
		10%		8%	83%		6%		4%	92%			
Physiotherapy interventions		2%	1%	14%	43%	40%	1%	1%	5%	58%	35%	0.780**	<0.001
		3%		14%	83%		2%		5%	93%			
Occupational therapy interventions		2%	5%	19%	40%	35%	1%	6%	10%	51%	31%	0.830**	<0.001
		7%		19%	75%		7%		10%	82%			
Transcutaneous electrical nerve stimulation (TENS), scrambler therapy		4%	5%	15%	47%	30%	3%	4%	14%	56%	24%	0.774**	<0.001
		9%		15%	77%		7%		14%	80%			
Acupuncture, acupressure		5%	9%	28%	32%	26%	4%	10%	26%	36%	24%	0.835**	<0.001
		14%		29%	58%		14%		26%	60%			

Psychological and behavioural therapies / interventions						1%	0%	11%	44%	43%	0%	0%	9%	49%	43%	0.857**	<0.001					
						1%		11%	87%		0%		9%	92%								
Complementary and alternative therapies						9%	19%	25%	22%	26%	6%	19%	20%	19%	36%	0.835**	<0.001					
						28%		25%	48%		25%		20%	55%								
Pharmacological interventions in addiction recovery						5%	6%	12%	46%	31%	1%	5%	10%	60%	24%	0.742**	<0.001					
						11%		11%	77%		6%		10%	84%								
Psychosocial and behavioural interventions in addiction recovery						7%	10%	19%	36%	28%	4%	8%	20%	48%	21%	0.782**	<0.001					
						17%		18%	66%		12%		20%	69%								
SPCS should manage the following types of non-pain symptoms / physical problems:																						
Acute cancer-related symptoms / physical problems (lasting < 3 months)						0%	4%	8%	20%	68%	1%	1%	4%	16%	78%						0.678**	<0.001
							4%		8%	88%		2%		4%	94%							
Acute cancer treatment-related symptoms / physical problems (lasting < 3 months)						2%	4%	17%	21%	56%	4%	1%	9%	20%	67%						0.686**	<0.001
							6%		17%	77%		5%		9%	87%							
Acute symptoms / physical problems related to non-						6%	8%	20%	27%	38%	5%	7%	11%	31%	46%						0.659**	<0.001

cancer causes (lasting < 3 months)	14%		20%	66%		13%		11%	77%			
Chronic cancer-related symptoms / physical problems (lasting ≥ 3 months)	0%	2%	10%	13%	75%	1%	0%	4%	15%	80%		
	2%		10%	88%		1%		4%	95%			
Chronic cancer treatment-related symptoms / physical problems (lasting ≥ 3 months)	1%	2%	15%	24%	57%	1%	1%	10%	25%	63%		
	3%		15%	81%		2%		10%	88%			
Chronic symptoms / physical problems related to non-cancer causes (lasting ≥ 3 months)	7%	12%	21%	20%	39%	6%	14%	16%	25%	40%		
	19%		21%	59%		20%		16%	65%			
SPCS generally have the knowledge and skills to manage the following:												
Acute cancer-related symptoms / physical problems (lasting < 3 months)	0%	1%	1%	31%	67%	0%	0%	2%	25%	73%		
	1%		1%	98%		0%		2%	98%			

Acute cancer treatment-related symptoms / physical problems (lasting < 3 months)	0%	5%	7%	40%	48%	0%	1%	5%	38%	56%		0.711**	<0.001
	5%		7%	88%		1%		5%	94%				
Acute symptoms / physical problems related to non-cancer causes (lasting < 3 months)	2%	7%	18%	35%	38%	1%	5%	16%	36%	42%		0.735**	<0.001
	9%		18%	73%		6%		16%	78%				
Chronic cancer-related symptoms / physical problems (lasting ≥ 3 months)	0%	1%	4%	27%	68%	0%	2%	2%	22%	73%		0.756**	<0.001
	1%		4%	95%		2%		2%	95%				
Chronic cancer treatment-related symptoms / physical problems (lasting ≥ 3 months)	0%	8%	6%	36%	50%	0%	6%	5%	30%	59%		0.794**	<0.001
	8%		6%	86%		6%		5%	89%				
Chronic symptoms / physical problems related to non-cancer causes	8%	14%	8%	36%	33%	6%	12%	9%	43%	30%		0.818**	<0.001
	22%		8%	69%		18%		9%	73%				

(lasting ≥ 3 months)														
SPCS services should have more training in the following areas:														
Assessment of acute side effects of anticancer treatment (especially novel anticancer treatments)			0%	4%	1%	26%	69%	0%	1%	0%	11%	88%	0.570**	<0.001
			4%		1%	95%		1%		0%	99%			
Management of acute side effects of anticancer treatment (especially novel anticancer treatments)			2%	2%	2%	30%	63%	0%	4%	0%	15%	81%	0.646**	<0.001
			4%		2%	93%		4%		0%	96%			
Assessment of chronic / long-term effects of anticancer treatment (especially novel anticancer treatments)			0%	2%	4%	2%	73%	0%	1%	0%	15%	84%	0.754**	<0.001
			2%		4%	95%		1%		0%	99%			
Management of chronic / long-term effects of anticancer treatment (especially novel anticancer treatments)			0%	2%	4%	30%	64%	0%	1%	3%	19%	78%	0.751**	<0.001
			2%		4%	94%		1%		3%	97%			

Assessment of late / delayed effects of anticancer treatment (especially novel anticancer treatments)		0%	4%	2%	31%	63%	0%	1%	0%	23%	76%	0.770**	<0.001
		4%		2%	94%		1%		0%	99%			
Management of late / delayed effects of anticancer treatment (especially novel anticancer treatments)		0%	4%	2%	36%	58%	0%	3%	1%	25%	71%	0.789**	<0.001
		4%		2%	94%		3%		1%	96%			

Key: SD = strongly disagree; MD = moderately disagree; N = neither agree nor disagree; MA = moderately agree; SA = strongly agree; SPC = specialist palliative care; SPCS = specialist palliative care services; rho = Spearman's rank correlation coefficient between relevant subsequent rounds; * correlation is significant at the 0.05 level (2-tailed); ** correlation is significant at the 0.01 level (2-tailed); shaded box = consensus reached ($\geq 75\%$).

S1b. Definition of “cancer survivor” – SPC group results.

Statement	Round 1					Round 2					Round 3					rho	p value
	SD	MD	N	MA	SA	SD	MD	N	MA	SA	SD	MD	N	MA	SA		
The following groups should be called cancer survivors:																	
All individuals with cancer.	58%	15%	8%	7%	11%	69%	12%	7%	4%	8%						0.825**	<0.001
	73%		8%	18%		82%		7%	12%								
Individuals who are still receiving anticancer treatment.	42%	21%	8%	17%	12%												
	63%		8%	29%													
Individuals who have just completed anticancer treatment, and still have some known cancer present.	38%	23%	7%	19%	13%	44%	23%	7%	16%	9%						0.901**	<0.001
	61%		7%	32%		67%		7%	25%								
Individuals who have just completed anticancer treatment, and have no known cancer present.	14%	5%	12%	26%	43%	10%	5%	11%	19%	56%						0.849**	<0.001
	19%		12%	69%		15%		11%	75%								
Individuals who completed anticancer treatment at least 1 year beforehand, and have no known cancer present.	12%	8%	11%	20%	49%	11%	7%	9%	15%	58%						0.866**	<0.001
	20%		11%	69%		18%		9%	73%								
Individuals who completed anticancer treatment at least 5 years beforehand, and have no known cancer present.	6%	10%	5%	15%	64%	2%	2%	5%	12%	78%						0.684**	<0.001
	16%		5%	79%		4%		5%	90%								

Individuals who completed anticancer treatment at least 10 years beforehand, and have no known cancer present.	7%	6%	7%	12%	68%	2%	2%	6%	7%	81%		0.663**	<0.001									
	13%		7%	80%		4%		6%	88%													
Individuals who have progressive/worsening cancer, and have no other anticancer treatment options.	68%	12%	7%	5%	8%	75%	12%	5%	4%	4%		0.775**	<0.001									
	80%		7%	13%		87%		5%	8%													
Family members, friends, and caregivers of individuals with cancer or a history of cancer.	80%	10%	7%	2%	1%	89%	5%	5%	1%	0%		0.702**	<0.001									
	90%		7%	3%		94%		5%	1%													
No individual should be called a “cancer survivor” i.e. the term should not be used.	25%	24%	32%	7%	12%	28%	17%	38%	7%	9%		0.912**	<0.001									
	49%		32%	19%		45%		38%	16%													
Individuals who are still receiving anticancer treatment with curative intent						32%	28%	19%	12%	9%	51%	26%	11%	8%	4%	0.684**	<0.001					
						60%		19%	21%		77%		11%	12%								
Individuals who are still receiving anticancer treatment with palliative intent											58%	15%	16%	6%	5%	80%	5%	9%	5%	1%	0.626**	<0.001
											73%		16%	11%		85%		9%	6%			

Key: SD = strongly disagree; MD = moderately disagree; N = neither agree nor disagree; MA = moderately agree; SA = strongly agree; SPC = specialist palliative care; SPCS = specialist palliative care services; rho = Spearman's rank correlation coefficient between relevant subsequent rounds; * correlation is significant at the 0.05 level (2-tailed); ** correlation is significant at the 0.01 level (2-tailed); shaded box = consensus reached ($\geq 75\%$).

S1c. Categorisation of people who have/had cancer – SPC group results.

Statement	Round 1					Round 2					Round 3					rho	p value
	SD	MD	N	MA	SA	SD	MD	N	MA	SA	SD	MD	N	MA	SA		
The following classifications for groups of individuals with cancer or a history of cancer are useful:																	
Seasons of survivorship	29%	25%	18%	21%	7%	38%	27%	20%	14%	1%						0.760**	<0.001
	54%		18%	28%		65%		20%	15%								
Living with, through and beyond cancer	2%	11%	8%	48%	31%	1%	9%	6%	56%	28%						0.937**	<0.001
	13%		8%	79%		10%		6%	84%								
New categorisation	6%	4%	7%	43%	40%	4%	2%	5%	52%	37%						0.932**	<0.001
	10%		7%	83%		6%		5%	89%								

Key: SD = strongly disagree; MD = moderately disagree; N = neither agree nor disagree; MA = moderately agree; SA = strongly agree; SPC = specialist palliative care; SPCS = specialist palliative care services; rho = Spearman's rank correlation coefficient between relevant subsequent rounds; * correlation is significant at the 0.05 level (2-tailed); ** correlation is significant at the 0.01 level (2-tailed); shaded box = consensus reached ($\geq 75\%$).

S1d. Extended role of Specialist Palliative Care for individuals with a history of cancer who have completed anticancer treatment and have no evidence of disease – SPC group results.

Statement	Round 1					Round 2					Round 3					rho	p value
	SD	MD	N	MA	SA	SD	MD	N	MA	SA	SD	MD	N	MA	SA		
SPCS <u>should</u> have a role in supporting the following components of care																	
Prevention of recurrent and new cancers	42%	36%	13%	5%	5%												
	78%		13%	10%													
Prevention of other late effects	25%	24%	12%	20%	19%												
	49%		12%	39%													
Surveillance for cancer spread, recurrence, or second cancers	46%	23%	15%	11%	5%												
	69%		15%	16%													
Surveillance of physical late effects	25%	19%	13%	23%	20%												
	44%		13%	43%													
Surveillance of psychosocial late effects	25%	17%	15%	23%	20%												
	42%		15%	43%													
Intervention for pain as a late effect	12%	11%	7%	35%	36%												
	23%		7%	71%													
Intervention for other physical late effects	12%	12%	10%	37%	30%												
	24%		10%	67%													
Intervention for psychosocial late effects	13%	8%	12%	38%	29%												
	21%		12%	67%													
Managing “fear of cancer recurrence”	25%	15%	18%	27%	14%												
	40%		18%	41%													

Rehabilitation	26%	29%	10%	25%	11%												
	55%		10%	36%													
Supporting occupational issues / return to work	27%	31%	17%	18%	7%												
	58%		17%	25%													
Managing financial problems (“financial toxicity”)	33%	29%	23%	11%	5%												
	62%		23%	16%													
Supporting concerns related to insurance	33%	31%	20%	8%	7%												
	64%		20%	15%													
Supporting caregivers	23%	21%	14%	27%	14%												
	44%		14%	41%													
Supporting coordination between specialists and primary care providers	26%	21%	13%	20%	19%												
	47%		13%	39%													
Prevention of second cancers						58%	27%	9%	2%	4%	73%	16%	8%	0%	4%	0.763**	<0.001
						85%			9%	6%		89%		8%	4%		
Surveillance for recurrence or second cancers						62%	21%	9%	5%	4%	79%	9%	5%	4%	4%	0.730**	<0.001
						83%			9%	9%		88%		5%	8%		
Surveillance of physical "late effects"						38%	20%	4%	22%	16%	55%	11%	3%	19%	13%	0.810**	<0.001
						58%			4%	38%		66%		3%	32%		
Surveillance of psychological distress						37%	16%	7%	22%	17%	54%	11%	4%	19%	13%	0.804**	<0.001
						53%			8%	39%		66%		4%	32%		

Management of pain		14%	6%	7%	35%	38%	15%	5%	5%	33%	43%	0.943**	<0.001
		20%		8%	73%		20%		5%	76%			
Management of other physical symptoms / problems		14%	7%	9%	44%	26%	16%	5%	6%	48%	25%	0.927**	<0.001
		21%		9%	70%		21%		6%	73%			
Management of psychological distress		15%	5%	11%	44%	25%	14%	4%	11%	48%	24%	0.956**	<0.001
		20%		11%	69%		18%		11%	72%			
Managing "fear of cancer recurrence"		30%	14%	12%	32%	12%	38%	5%	9%	38%	11%	0.908**	<0.001
		44%		13%	44%		43%		9%	49%			
Rehabilitation		32%	27%	7%	23%	10%	46%	20%	5%	19%	10%	0.829**	<0.001
		59%		8%	33%		66%		5%	29%			
Supporting occupational issues / return to work		36%	30%	16%	12%	6%	49%	21%	15%	9%	6%	0.847**	<0.001
		66%		16%	18%		70%		15%	15%			
Managing financial problems ("financial toxicity")		46%	27%	15%	7%	5%	60%	19%	10%	6%	5%	0.817**	<0.001
		73%		15%	12%		79%		10%	11%			
Supporting caregivers		30%	16%	11%	31%	12%	40%	11%	9%	28%	13%	0.835**	<0.001
		46%		11%	33%		51%		9%	41%			
Coordination between specialists and primary care providers		40%	16%	9%	19%	17%	55%	8%	9%	15%	14%	0.849**	<0.001
		56%		9%	36%		63%		9%	29%			
Developing "survivorship care plans"		33%	12%	20%	25%	10%	48%	9%	14%	23%	8%	0.765**	<0.001
		45%		20%	35%		57%		14%	31%			

SPCS <u>generally</u> have the knowledge and skills to support the following components of care:					
Prevention of recurrent and new cancers	40%	30%	13%	13%	4%
	70%		13%	17%	
Prevention of other late effects	30%	24%	12%	19%	15%
	54%		12%	34%	
Surveillance for cancer spread, recurrence, or second cancers	40%	31%	8%	14%	6%
	71%		8%	29%	
Surveillance of physical late effects	21%	18%	8%	29%	24%
	39%		8%	53%	
Surveillance of psychosocial late effects	20%	14%	8%	32%	25%
	34%		8%	57%	
Intervention for pain as a late effect	8%	6%	11%	32%	43%
	14%		11%	75%	
Intervention for other physical late effects	8%	8%	12%	37%	35%
	16%		12%	72%	
Intervention for psychosocial late effects	11%	11%	8%	38%	32%
	22%		8%	70%	
Managing “fear of cancer recurrence”	13%	19%	24%	25%	19%
	32%		24%	44%	
Rehabilitation	20%	21%	20%	30%	8%
	41%		20%	38%	
Supporting occupational issues / return to work	26%	27%	15%	24%	7%
	53%		15%	31%	

Managing financial problems (“financial toxicity”)	29%	27%	17%	20%	7%												
	56%		17%	27%													
Supporting concerns related to insurance	32%	30%	17%	17%	5%												
	62%		17%	23%													
Supporting caregivers	12%	7%	13%	40%	27%												
	19%		13%	67%													
Supporting coordination between specialists and primary care providers	12%	12%	15%	33%	27%												
	24%		15%	60%													
Prevention of second cancers						57%	23%	9%	7%	4%	70%	20%	4%	5%	1%	0.692**	<0.001
						80%			9%	11%		90%		4%	6%		
53%						25%	5%	11%	6%	68%	18%	4%	8%	4%	0.734**	<0.001	
78%						5%	17%		86%		4%	12%					
Surveillance for recurrence or second cancers						25%	15%	9%	31%	21%	28%	11%	4%	40%	18%	0.920**	<0.001
						40%			9%	52%		39%		4%	58%		
Surveillance of physical "late effects"						22%	9%	10%	36%	23%	23%	8%	6%	46%	18%	0.908**	<0.001
						31%			10%	59%		31%		6%	64%		
Surveillance of psychological distress						6%	4%	7%	35%	48%	4%	1%	8%	35%	53%	0.862**	<0.001
						10%			7%	83%		5%		8%	88%		
Management of pain						6%	4%	10%	43%	37%	4%	0%	10%	51%	35%	0.846**	<0.001
						10%			10%	80%		4%		10%	86%		
Management of other physical symptoms / problems						7%	9%	7%	44%	32%	6%	5%	6%	58%	25%	0.818**	<0.001

Management of psychological distress						16%		7%	76%		11%		6%	83%		0.886**	<0.001
Managing “fear of cancer recurrence”						11%	20%	25%	28%	16%	9%	18%	20%	39%	15%		
Rehabilitation						31%		25%	44%		27%		20%	54%			
						17%	23%	22%	31%	6%	16%	18%	24%	39%	4%	0.871**	<0.001
						40%		22%	37%		34%		24%	43%			
Supporting occupational issues / return to work						27%	35%	11%	20%	7%	26%	41%	8%	18%	8%	0.929**	<0.001
						62%		11%	27%		67%		8%	26%			
Managing financial problems (“financial toxicity”)						32%	37%	10%	17%	4%	33%	43%	8%	14%	4%	0.853**	<0.001
						69%		10%	21%		76%		8%	18%			
Supporting caregivers						12%	2%	12%	49%	23%	14%	1%	8%	59%	19%	0.912**	<0.001
						14%		12%	72%		15%		8%	78%			
Coordination between specialists and primary care providers						11%	10%	12%	42%	25%	11%	6%	11%	54%	18%	0.909**	<0.001
						21%		12%	67%		17%		11%	72%			
Developing "survivorship care plans"						32%	19%	19%	25%	6%	41%	11%	18%	26%	4%	0.797**	<0.001
						51%		19%	31%		52%		18%	30%			
Barriers to extending the input of SPCS to this group:																	
Financial resources	4%	11%	11%	29%	46%	0%	9%	10%	25%	57%						0.812**	<0.001
	15%		11%	75%		9%		10%	82%								
Human resources	5%	5%	6%	24%	61%	0%	2%	7%	21%	69%						0.761**	<0.001
	10%		6%	85%		2%		7%	90%								
Other resources	6%	2%	29%	25%	38%												

	8%		29%	63%																			
Lack of relevant education and training (e.g. management of chronic cancer treatment-related symptoms / problems)	8%	10%	8%	37%	37%	4%	7%	9%	40%	41%												0.795**	<0.001
	18%		8%	74%		11%		9%	81%														
Lack of willingness from palliative care professionals	17%	11%	23%	27%	23%	14%	7%	23%	35%	21%												0.938**	<0.001
	18%		23%	50%		21%		23%	56%														
Lack of willingness from oncology professionals	7%	11%	27%	36%	19%	5%	9%	26%	48%	12%												0.827**	<0.001
	18%		27%	55%		14%		26%	60%														
Lack of willingness from general practitioners	10%	11%	36%	31%	13%	7%	10%	41%	32%	10%												0.900**	<0.001
	21%		36%	44%		17%		41%	42%														
Lack of willingness from patients and families	12%	27%	21%	27%	12%	9%	22%	25%	33%	11%												0.938**	<0.001
	39%		21%	39%		31%		25%	44%														
Misperceptions about the nature of palliative care	4%	4%	19%	24%	50%	2%	2%	20%	19%	57%							0.903**	<0.001					
	8%		19%	74%		4%		20%	76%														
Time resources						0%	4%	15%	22%	59%	0%	5%	10%	16%	69%		0.823**	<0.001					
						4%		15%	81%		5%		10%	85%									
Type of service																							
A dedicated multidisciplinary specialist team is required						6%	6%	9%	37%	42%	1%	5%	5%	30%	59%		0.754**	<0.001					
						12%		9%	79%		6%		5%	89%									

Specialist palliative care services should lead this team		44%	17%	19%	14%	6%	63%	13%	14%	8%	4%	0.752**	<0.001
		61%		19%	20%		76%		14%	12%			
Specialist palliative care services should be a core member of this team i.e. routinely involved in care		22%	22%	15%	21%	20%	26%	26%	9%	21%	18%	0.923**	<0.001
		44%		15%	41%		52%		9%	39%			
Specialist palliative care services should be an extended member of this team i.e. support with relevant problems / issues		11%	11%	11%	38%	28%	9%	10%	8%	54%	20%	0.787**	<0.001
		22%		11%	66%		19%		8%	74%			
Specialist palliative care services should not contribute to this team		53%	20%	14%	6%	7%	66%	14%	10%	3%	8%	0.770**	<0.001
		73%		14%	13%		80%		10%	11%			

Key: SD = strongly disagree; MD = moderately disagree; N = neither agree nor disagree; MA = moderately agree; SA = strongly agree; SPC = specialist palliative care; SPCS = specialist palliative care services; rho = Spearman's rank correlation coefficient between relevant subsequent rounds; * correlation is significant at the 0.05 level (2-tailed); ** correlation is significant at the 0.01 level (2-tailed); shaded box = consensus reached ($\geq 75\%$).

S1e. Extended role of SPC for individuals with stable locally advanced or metastatic cancer – SPC group results.

Statement	Round 2					Round 3					rho	p value
	SD	MD	N	MA	SA	SD	MD	N	MA	SA		
SPCS <u>should</u> have a role in supporting the following components of care:												
Prevention of second cancers	42%	23%	10%	21%	4%	61%	13%	6%	18%	3%	0.810**	<0.001
	66%		10%	25%		74%		6%	21%			
Surveillance for cancer spread, recurrence or second cancers	35%	22%	9%	28%	6%	49%	14%	8%	26%	4%	0.839**	<0.001
	58%		9%	34%		53%		8%	30%			
Surveillance of physical symptoms / problems	6%	5%	7%	32%	49%	3%	3%	4%	30%	61%	0.792**	<0.001
	11%		7%	81%		6%		4%	91%			
Surveillance of psychological distress	5%	5%	9%	36%	46%	3%	3%	4%	34%	58%	0.816**	<0.001
	10%		9%	82%		6%		4%	92%			
Management of pain	0%	0%	2%	28%	69%	0%	0%	0%	14%	86%	0.592**	<0.001
	0%		2%	97%		0%		0%	100%			
Management of other physical symptoms / problems	0%	1%	2%	28%	68%	0%	0%	0%	15%	85%	0.614**	<0.001
	1%		2%	96%		0%		0%	100%			
Management of psychological distress	0%	1%	2%	38%	58%	0%	0%	0%	26%	74%	0.687**	<0.001
	1%		2%	96%		0%		0%	100%			
Support for cultural, spiritual and religious needs	5%	4%	11%	41%	40%	5%	3%	5%	46%	41%	0.815**	<0.001
	9%		11%	81%		8%		5%	87%			
Rehabilitation	7%	12%	14%	37%	30%	4%	9%	14%	46%	28%	0.836**	<0.001
	19%		14%	67%		13%		14%	74%			
Supporting occupational issues / return to work	11%	14%	23%	35%	17%	9%	9%	23%	45%	15%	0.906**	<0.001
	25%		23%	52%		18%		23%	60%			
Managing financial problems (“financial toxicity”)	19%	15%	21%	30%	16%	20%	10%	20%	36%	14%	0.935**	<0.001
	34%		21%	46%		30%		20%	50%			

Supporting caregivers	1%	5%	14%	40%	41%	1%	4%	4%	45%	46%	0.887**	<0.001
	6%		14%	81%		5%		4%	91%			
Care coordination between specialists and primary care providers	4%	16%	15%	41%	25%	4%	11%	13%	54%	19%	0.858**	<0.001
	20%		15%	66%		15%		13%	73%			
Health promotion	7%	19%	28%	32%	14%	6%	15%	31%	39%	9%	0.914**	<0.001
	26%		28%	46%		21%		31%	48%			
Developing “survivorship care plans”	16%	10%	32%	22%	20%	14%	8%	43%	20%	16%	0.883**	<0.001
	26%		32%	42%		22%		43%	36%			
Advance care planning	0%	1%	6%	30%	63%	0%	0%	3%	23%	75%	0.760**	<0.001
	1%		6%	93%		0%		3%	98%			
SPCS <u>generally</u> have the knowledge and skills to support the following components of care:												
Prevention of second cancers	41%	28%	11%	19%	1%	54%	23%	9%	14%	1%	0.804**	<0.001
	69%		11%	20%		77%		9%	15%			
Surveillance for cancer spread, recurrence or second cancers	30%	26%	10%	26%	9%	45%	21%	9%	20%	5%	0.789**	<0.001
	56%		10%	35%		66%		9%	25%			
Surveillance of physical symptoms / problems	4%	2%	6%	22%	65%	0%	0%	5%	19%	76%	0.790**	<0.001
	6%		6%	67%		0%		5%	95%			
Surveillance of psychological distress	2%	1%	6%	28%	62%	0%	0%	5%	21%	74%	0.798**	<0.001
	3%		6%	90%		0%		5%	95%			
Management of pain	0%	1%	1%	16%	81%	0%	0%	1%	10%	89%	0.755**	<0.001
	1%		1%	97%		0%		1%	99%			
Management of other physical symptoms / problems	0%	1%	2%	22%	74%	0%	0%	1%	19%	80%	0.848**	<0.001
	1%		2%	96%		0%		1%	99%			
Management of psychological distress	0%	2%	1%	36%	60%	0%	1%	1%	28%	70%	0.836**	<0.001
	2%		1%	96%		1%		1%	98%			
Support for cultural, spiritual and religious	4%	10%	11%	38%	37%	4%	5%	14%	48%	30%	0.887**	<0.001

needs	14%		11%	75%		9%		14%	78%			
Rehabilitation	9%	20%	20%	35%	17%	8%	15%	21%	46%	10%	0.882**	<0.001
	29%		20%	52%		23%		21%	56%			
Supporting occupational issues / return to work	9%	27%	21%	32%	11%	6%	23%	21%	44%	6%	0.873**	<0.001
	36%		21%	43%		29%		21%	50%			
Managing financial problems (“financial toxicity”)	17%	19%	23%	27%	14%	14%	16%	26%	33%	11%	0.884**	<0.001
	46%		23%	41%		30%		26%	44%			
Supporting caregivers	2%	6%	9%	38%	44%	1%	4%	8%	34%	54%	0.858**	<0.001
	8%		9%	82%		5%		8%	88%			
Care coordination between specialists and primary care providers	4%	6%	17%	41%	32%	3%	5%	13%	53%	28%	0.838**	<0.001
	10%		17%	73%		8%		13%	81%			
Health promotion	11%	28%	31%	22%	7%	9%	28%	40%	18%	6%	0.868**	<0.001
	39%		31%	29%		37%		40%	24%			
Developing “survivorship care plans”	20%	25%	30%	15%	11%	16%	25%	38%	15%	6%	0.746**	<0.001
	45%		30%	26%		41%		38%	21%			
Advance care planning	0%	4%	6%	26%	64%	0%	0%	6%	16%	78%	0.725**	<0.001
	4%		6%	90%		0%		6%	94%			
Barriers to extending the input of SPCS to this group:												
Financial resources	5%	5%	10%	37%	43%	5%	4%	5%	25%	61%	0.734**	<0.001
	10%		10%	80%		9%		5%	86%			
Human resources	1%	5%	7%	31%	56%	1%	3%	5%	21%	70%	0.747**	<0.001
	6%		7%	87%		4%		5%	91%			
Time resources	1%	2%	11%	32%	53%	1%	1%	8%	24%	66%	0.790**	<0.001
	3%		11%	85%		2%		8%	90%			
Lack of relevant education and training (e.g. management of chronic cancer treatment-related symptoms / problems)	14%	21%	14%	37%	15%	10%	13%	10%	55%	13%	0.805**	<0.001
	35%		14%	52%		23%		10%	68%			

Lack of willingness / reluctance from palliative care professionals	20%	23%	17%	25%	15%	18%	28%	10%	36%	9%	0.874**	<0.001
	43%		17%	40%		46%		10%	45%			
Lack of willingness from oncology professionals	6%	23%	15%	40%	16%	5%	14%	15%	58%	9%	0.804**	<0.001
	29%		15%	56%		19%		15%	67%			
Lack of willingness from general practitioners	7%	27%	27%	30%	9%	6%	19%	30%	40%	5%	0.872**	<0.001
	34%		27%	39%		25%		30%	45%			
Lack of willingness from patients and families	16%	21%	30%	28%	5%	10%	18%	40%	30%	3%	0.795**	<0.001
	37%		30%	33%		28%		40%	33%			
Misperceptions about the nature of palliative care	2%	10%	11%	32%	44%	1%	5%	8%	24%	63%	0.712**	<0.001
	12%		11%	76%		6%		8%	87%			
Type of service												
A dedicated multidisciplinary specialist team is required	6%	5%	9%	25%	56%	5%	1%	5%	18%	71%	0.710**	<0.001
	11%		9%	81%		6%		5%	89%			
Specialist palliative care services should lead this team	19%	23%	12%	28%	17%	16%	26%	11%	38%	9%	0.848**	<0.001
	42%		13%	45%		42%		11%	47%			
Specialist palliative care services should be a core member of this team i.e. routinely involved in care	10%	9%	14%	40%	28%	8%	5%	5%	63%	20%	0.755**	<0.001
	19%		14%	68%		13%		5%	83%			
Specialist palliative care services should be an extended member of this team i.e. support with relevant problems / issues	7%	10%	16%	37%	30%	6%	5%	10%	53%	26%	0.719**	<0.001
	17%		16%	67%		11%		10%	79%			
Specialist palliative care services should not contribute to this team	77%	17%	1%	4%	1%	88%	10%	0%	1%	1%	0.667**	<0.001
	94%		1%	5%		98%		0%	2%			
The same team should provide care for both groups.	21%	17%	33%	16%	12%	24%	14%	40%	15%	8%	0.858**	<0.001
	38%		33%	28%		38%		40%	23%			

Key: SD = strongly disagree; MD = moderately disagree; N = neither agree nor disagree; MA = moderately agree; SA = strongly agree; SPC = specialist palliative care; SPCS = specialist palliative care services; rho = Spearman's rank correlation coefficient between

relevant subsequent rounds; * correlation is significant at the 0.05 level (2-tailed); ** correlation is significant at the 0.01 level (2-tailed); shaded box = consensus reached ($\geq 75\%$).

Supplementary Tables S2a-e: Oncology (ONC) expert group results.

S2a Definition and core functions of Specialist Palliative Care (SPC) – ONC group results.

Statement	Round 1					Round 2					Round 3					rho	p value
	SD	MD	N	MA	SA	SD	MD	N	MA	SA	SD	MD	N	MA	SA		
Section 1: Definition and core functions of Specialist Palliative Care (SPC)																	
Core functions of SPCS																	
Management of pain	0%	0%	4%	17%	79%	0%	0%	2%	11%	87%						0.754**	<0.001
	0%		4%	96%		0%		2%	98%								
Management of other physical symptoms	0%	0%	6%	19%	75%	0%	0%	4%	9%	87%						0.696**	<0.001
	0%		6%	94%		0%		4%	96%								
Management of psychological problems	0%	0%	6%	38%	57%	0%	0%	4%	38%	58%						0.893**	<0.001
	0%		6%	95%		0%		4%	96%								
Emotional support (patient)	0%	2%	4%	26%	68%	0%	0%	2%	23%	75%						0.731**	<0.001
	2%		4%	94%		0%		2%	98%								
Emotional support (family)	0%	2%	13%	26%	58%	0%	0%	4%	32%	64%						0.805**	<0.001
	2%		13%	84%		0%		4%	96%								
Spiritual support	0%	9%	26%	34%	30%	0%	8%	21%	47%	25%						0.893**	<0.001
	8%		26%	64%		8%		21%	72%								
Social assistance	0%	8%	30%	38%	25%	0%	8%	32%	42%	19%						0.837**	<0.001
	8%		30%	63%		8%		32%	61%								
Co-ordination of care	0%	2%	11%	28%	58%	0%	0%	4%	34%	62%						0.909**	<0.001
	2%		11%	86%		0%		4%	96%								
Advance care planning	0%	2%	8%	25%	66%	0%	0%	2%	25%	74%						0.793**	<0.001
	2%		8%	91%		0%		2%	98%								

End-of-life care	2%	0%	2%	17%	79%	0%	0%	0%	13%	87%		0.723**	<0.001				
	2%		2%	96%		0%		0%	100%								
Bereavement care	0%	6%	21%	30%	43%	0%	2%	17%	28%	53%							
	6%		21%	73%		2%		17%	81%								
Rehabilitation	2%	11%	28%	32%	26%	2%	9%	30%	36%	23%							
	13%		28%	58%		11%		30%	59%								
Religious support						6%	19%	43%	21%	11%	6%	16%	57%	12%	8%	0.723**	<0.001
						25%		43%	32%		32%		57%	20%			
Research						0%	2%	19%	23%	57%	0%	0%	6%	22%	71%	0.743**	<0.001
						2%		19%	80%		0%		6%	93%			
Education (other healthcare professionals)						0%	2%	4%	26%	68%	0%	0%	0%	10%	90%	0.559**	<0.001
						2%		4%	94%		0%		0%	100%			
SPCS should manage the following types of pain:																	
Acute cancer-related pain (pain for < 3 months)	0%	4%	9%	28%	58%	0%	2%	4%	32%	62%		0.899**	<0.001				
	4%		9%	86%		2%		4%	94%								
Acute cancer treatment-related pain (pain for < 3 months)	4%	4%	13%	30%	49%	0%	4%	4%	38%	55%							
	8%		13%	79%		4%		4%	92%								
Acute pain related to non-cancer causes (pain for < 3 months)	2%	15%	21%	26%	36%	2%	11%	19%	32%	36%							
	17%		21%	62%		13%		19%	68%								
Chronic cancer-related pain (pain for≥3 months)	0%	0%	9%	19%	72%	0%	0%	4%	11%	85%							
	0%		9%	91%		0%		4%	96%								
Chronic cancer treatment-related pain (pain for≥3 months)	0%	0%	11%	28%	60%	0%	0%	4%	17%	79%							
	0%		11%	88%		0%		4%	96%								

Chronic pain related to non-cancer causes (pain for≥3 months)	4%	4%	30%	19%	43%	4%	2%	28%	17%	49%						0.915**	<0.001
	8%		30%	62%		6%		28%	66%								
Individuals with pain and a previous history of opioid misuse / abuse / addiction	8%	8%	13%	26%	45%												
	16%		13%	71%													
Individuals with pain and ongoing problems of opioid misuse / abuse / addiction	8%	6%	15%	30%	42%												
	14%		15%	72%													
Chronic cancer / cancer treatment-related pain – in collaboration with the multidisciplinary chronic pain team						0%	2%	6%	23%	70%	0%	2%	2%	10%	86%	0.636**	<0.001
						2%		6%	93%		2%		2%	96%			
Individuals with cancer / cancer treatment–related pain and a previous history of opioid misuse / abuse / addiction						0%	8%	9%	45%	38%	0%	2%	0%	67%	31%	0.686**	<0.001
						8%		9%	83%		2%		0%	98%			
Individuals with cancer / cancer treatment–related pain and ongoing problems of opioid misuse / abuse / addiction						0%	8%	13%	40%	40%	0%	2%	2%	49%	47%	0.554**	<0.001
						8%		13%	80%		2%		2%	96%			

Individuals with chronic cancer / cancer treatment–related pain and a previous history of opioid misuse / abuse / addiction – in collaboration with the multidisciplinary chronic pain team	0%	2%	9%	23%	66%	0%	4%	6%	8%	82%	0.701**	<0.001
	2%		9%	89%		4%		6%	90%			
Individuals with chronic cancer / cancer treatment–related pain and ongoing problems of opioid misuse / abuse / addiction – in collaboration with the multidisciplinary chronic pain team	0%	2%	6%	26%	66%	0%	4%	2%	16%	78%	0.644**	<0.001
	2%		6%	92%		4%		2%	94%			
Individuals with cancer / cancer treatment–related pain and a previous history of opioid misuse / abuse / addiction – in collaboration with addiction services	0%	4%	11%	27%	58%	0%	2%	4%	14%	80%	0.639**	<0.001
	4%		11%	75%		2%		4%	94%			
Individuals with cancer / cancer treatment–related pain and ongoing problems of opioid	0%	4%	9%	25%	62%	0%	2%	2%	16%	80%	0.572**	<0.001
	4%		9%	87%		2%		2%	96%			

[illegible]

misuse / abuse / addiction															
Individuals with cancer / cancer treatment–related pain and a previous history of opioid misuse / abuse / addiction				0%	8%	13%	42%	38%	0%	2%	4%	73%	20%	0.683**	<0.001
				8%		13%	80%		2%		4%	93%			
Individuals with cancer / cancer treatment–related pain and ongoing problems of opioid misuse / abuse / addiction				2%	9%	13%	38%	38%	0%	2%	4%	65%	29%	0.760**	<0.001
				11%		13%	76%		2%		4%	94%			
SPCS services should have more education and / or appropriate training in the following areas:															
Interventional pain techniques				0%	4%	9%	34%	53%	0%	2%	6%	24%	67%	0.829**	<0.001
				4%		9%	87%		2%		6%	91%			
Physiotherapy interventions				0%	9%	23%	34%	34%	0%	6%	16%	47%	31%	0.890**	<0.001
				9%		23%	68%		6%		16%	78%			
Occupational therapy interventions				0%	15%	21%	30%	34%	0%	12%	14%	35%	39%	0.885**	<0.001
				15%		21%	64%		12%		14%	74%			
Transcutaneous electrical nerve stimulation (TENS), scrambler therapy				0%	13%	21%	36%	30%	0%	8%	18%	53%	20%	0.787**	<0.001
				13%		21%	66%		8%		18%	73%			
Acupuncture, acupressure				4%	13%	21%	42%	21%	2%	10%	22%	57%	8%	0.778**	<0.001
				17%		21%	63%		12%		22%	65%			
Psychological and behavioural	2%	8%	8%	51%	32%	2%	6%	2%	76%	14%	0.719**	<0.001			
	10%		8%	83%		8%		2%	90%						

therapies / interventions																			
Complementary and alternative therapies						9%	9%	28%	34%	19%	4%	8%	29%	51%	8%	0.761**	<0.001		
						18%		28%	53%		12%		29%	59%					
Pharmacological interventions in addiction recovery						0%	9%	21%	40%	30%	0%	6%	18%	67%	8%	0.613**	<0.001		
						9%		21%	70%		6%		18%	75%					
Psychosocial and behavioural interventions in addiction recovery						2%	13%	23%	38%	25%	2%	10%	20%	63%	4%	0.724**	<0.001		
	15%		23%	63%		12%		20%	67%										
SPCS should manage the following types of non-pain symptoms / physical problems:																			
Acute cancer-related symptoms / physical problems (lasting < 3 months)	0%	4%	11%	28%	57%	0%	0%	13%	23%	64%								0.648**	<0.001
		4%		11%	85%		0%		13%	87%									
Acute cancer treatment-related symptoms / physical problems (lasting < 3 months)	0%	11%	15%	28%	45%	0%	6%	15%	26%	53%								0.706**	<0.001
	11%		15%	73%		6%		15%	79%										
Acute symptoms / physical problems related to non-cancer causes (lasting < 3 months)	4%	8%	19%	36%	34%	4%	4%	19%	42%	32%								0.787**	<0.001
	12%		19%	70%		8%		19%	74%										
Chronic cancer-related symptoms / physical problems (lasting ≥ 3 months)	0%	0%	8%	26%	66%	0%	0%	4%	21%	75%	0.381**	0.05							
	0%		8%	92%		0%		4%	96%										

Chronic cancer treatment-related symptoms / physical problems (lasting ≥ 3 months)	0%	2%	11%	34%	53%	0%	2%	6%	25%	68%		0.485**	<0.001
	2%		11%	87%		2%		6%	93%				
Chronic symptoms / physical problems related to non-cancer causes (lasting ≥ 3 months)	2%	4%	21%	32%	42%	2%	4%	13%	36%	45%		0.679**	<0.001
	6%		21%	74%		6%		13%	81%				
SPCS generally have the knowledge and skills to manage the following:													
Acute cancer-related symptoms / physical problems (lasting < 3 months)	0%	8%	9%	28%	55%	0%	4%	9%	15%	72%		0.739**	<0.001
	8%		9%	83%		4%		9%	87%				
Acute cancer treatment-related symptoms / physical problems (lasting < 3 months)	2%	13%	11%	34%	40%	2%	8%	11%	26%	53%		0.816**	<0.001
	15%		11%	74%		10%		11%	97%				
Acute symptoms / physical problems related to non-cancer causes (lasting < 3 months)	2%	9%	21%	36%	32%	2%	4%	23%	42%	30%		0.947**	<0.001
	11%		21%	68%		6%		23%	72%				
Chronic cancer-related symptoms / physical problems (lasting ≥ 3 months)	0%	2%	11%	28%	58%	0%	2%	4%	19%	75%	0.671**	<0.001	
	2%		11%	86%		2%		4%	96%				

Chronic cancer treatment-related symptoms / physical problems (lasting ≥ 3 months)	2%	4%	13%	43%	38%	2%	4%	8%	43%	43%						0.879**	<0.001
	6%			13%	81%		6%		8%	86%							
Chronic symptoms / physical problems related to non-cancer causes (lasting ≥ 3 months)	4%	9%	21%	42%	25%	4%	8%	15%	55%	19%							
	13%			21%	67%		12%		15%	74%							
SPCS services should have more training in the following areas:																	
Assessment of acute side effects of anticancer treatment (especially novel anticancer treatments)						10%	8%	10%	33%	40%	8%	4%	10%	22%	55%	0.892**	<0.001
						18%		10%	73%		12%		10%	77%			
Management of acute side effects of anticancer treatment (especially novel anticancer treatments)						10%	6%	10%	35%	40%	8%	0%	8%	33%	51%	0.902**	<0.001
						16%		10%	75%		8%		8%	84%			
Assessment of chronic / long-term effects of anticancer treatment (especially novel anticancer treatments)						2%	10%	10%	33%	46%	2%	4%	8%	20%	65%	0.826**	<0.001
						12%		10%	79%		6%		8%	85%			

Management of chronic / long-term effects of anticancer treatment (especially novel anticancer treatments)		4%	10%	10%	29%	48%	4%	4%	6%	27%	59%	0.873**	<0.001
		14%		10%	77%		8%		6%	86%			
Assessment of late / delayed effects of anticancer treatment (especially novel anticancer treatments)		6%	13%	8%	33%	40%	4%	10%	6%	22%	57%	0.870**	<0.001
		19%		8%	73%		14%		6%	79%			
Management of late / delayed effects of anticancer treatment (especially novel anticancer treatments)		4%	13%	8%	35%	40%	2%	10%	6%	29%	53%	0.890**	<0.001
		17%		8%	75%		12%		6%	82%			

Key: SD = strongly disagree; MD = moderately disagree; N = neither agree nor disagree; MA = moderately agree; SA = strongly agree; SPC = specialist palliative care; SPCS = specialist palliative care services; rho = Spearman's rank correlation coefficient between relevant subsequent rounds; * correlation is significant at the 0.05 level (2-tailed); ** correlation is significant at the 0.01 level (2-tailed); shaded box = consensus reached ($\geq 75\%$).

S2b. Definition of “cancer survivor” – ONC group results,

Statement	Round 1					Round 2					Round 3					rho	p value
	SD	MD	N	MA	SA	SD	MD	N	MA	SA	SD	MD	N	MA	SA		
Section 2: Definition of “cancer survivor”																	
The following groups should be called cancer survivors:																	
All individuals with cancer.	45%	26%	9%	4%	15%	52%	27%	8%	4%	10%		0.907**	<0.001				
	71%		9%	19%		79%		8%	14%								
Individuals who are still receiving anticancer treatment.	21%	25%	19%	21%	15%												
	46%		19%	36%													
Individuals who have just completed anticancer treatment, and still have some known cancer present.	21%	26%	19%	17%	17%	21%	37%	12%	19%	12%		0.960**	<0.001				
	47%		19%	34%		58%		12%	31%								
Individuals who have just completed anticancer treatment, and have no known cancer present.	8%	9%	8%	15%	60%	6%	6%	6%	21%	62%		0.963**	<0.001				
	17%		8%	75%		12%		6%	83%								
Individuals who completed anticancer treatment at least 1 year beforehand, and have no known cancer present.	9%	9%	4%	25%	53%	6%	4%	2%	27%	62%		0.788**	<0.001				
	18%		4%	78%		10%		2%	89%								
Individuals who completed anticancer treatment at least 5 years beforehand, and have no known cancer present.	8%	6%	2%	11%	74%	2%	2%	2%	8%	87%		0.657**	<0.001				
	14%		2%	85%		4%		2%	95%								

Individuals who completed anticancer treatment at least 10 years beforehand, and have no known cancer present.	8%	8%	2%	15%	68%	0%	2%	2%	13%	83%		0.590**	<0.001				
	16%		2%	83%		2%		2%	96%								
Individuals who have progressive/worsening cancer, and have no other anticancer treatment options.	51%	30%	6%	6%	8%	62%	25%	2%	4%	8%		0.834**	<0.001				
	81%		6%	14%		87%		2%	12%								
Family members, friends, and caregivers of individuals with cancer or a history of cancer.	66%	17%	11%	4%	2%	77%	12%	8%	2%	2%		0.770**	<0.001				
	83%		11%	6%		89%		8%	4%								
No individual should be called a “cancer survivor” i.e. the term should not be used.	51%	13%	17%	11%	8%	56%	13%	17%	12%	2%		0.915**	<0.001				
	64%		17%	19%		69%		17%	14%								
Individuals who are still receiving anticancer treatment with curative intent						17%	31%	13%	23%	15%	18%	35%	4%	31%	12%	0.894**	<0.001
						48%		13%	38%		53%		4%	43%			
Individuals who are still receiving anticancer treatment with palliative intent						50%	21%	8%	12%	10%	63%	14%	2%	12%	8%	0.887**	<0.001
						71%		8%	22%		77%		2%	20%			

Key: SD = strongly disagree; MD = moderately disagree; N = neither agree nor disagree; MA = moderately agree; SA = strongly agree; SPC = specialist palliative care; SPCS = specialist palliative care services; rho = Spearman's rank correlation coefficient between relevant subsequent rounds; * correlation is significant at the 0.05 level (2-tailed); ** correlation is significant at the 0.01 level (2-tailed); shaded box = consensus reached ($\geq 75\%$).

S2c. Categorisation of people who have/had cancer – ONC group results.

Statement	Round 1					Round 2					Round 3					rho	p value
	SD	MD	N	MA	SA	SD	MD	N	MA	SA	SD	MD	N	MA	SA		
The following classifications for groups of individuals with cancer or a history of cancer are useful:																	
Seasons of survivorship	17%	23%	15%	32%	13%	19%	21%	13%	35%	12%						0.908**	<0.001
	40%		15%	43%		40%		13%	47%								
Living with, through and beyond cancer	6%	8%	4%	49%	34%	6%	2%	2%	58%	33%						0.898**	<0.001
	14%		4%	83%		8%		2%	91%								
New categorisation	2%	9%	15%	42%	32%	2%	10%	10%	50%	29%						0.886**	<0.001
	11%		15%	74%		12%		10%	79%								

Key: SD = strongly disagree; MD = moderately disagree; N = neither agree nor disagree; MA = moderately agree; SA = strongly agree; SPC = specialist palliative care; SPCS = specialist palliative care services; rho = Spearman's rank correlation coefficient between relevant subsequent rounds; * correlation is significant at the 0.05 level (2-tailed); ** correlation is significant at the 0.01 level (2-tailed); shaded box = consensus reached ($\geq 75\%$).

S2d. Extended role of Specialist Palliative Care for individuals with a history of cancer who have completed anticancer treatment and have no evidence of disease – ONC group results.

Statement	Round 1					Round 2					Round 3					rho	p value	
	SD	MD	N	MA	SA	SD	MD	N	MA	SA	SD	MD	N	MA	SA			
Section 4: Extended role of Specialist Palliative Care for individuals with a history of cancer who have completed anticancer treatment and have no evidence of disease																		
SPCS <u>should</u> have a role in supporting the following components of care																		
Prevention of recurrent and new cancers	42%	30%	9%	11%	8%													
	72%		9%	19%														
Prevention of other late effects	28%	23%	9%	26%	13%													
	51%		9%	39%														
Surveillance for cancer spread, recurrence, or second cancers	45%	30%	9%	8%	8%													
	75%		9%	16%														
Surveillance of physical late effects	26%	21%	6%	30%	17%													
	47%		6%	47%														
Surveillance of psychosocial late effects	25%	21%	9%	28%	17%													
	46%		9%	45%														
Intervention for pain as a late effect	13%	6%	8%	43%	30%													
	19%		8%	73%														
Intervention for other physical late effects	13%	11%	13%	36%	26%													
	24%		13%	62%														
Intervention for psychosocial late effects	15%	8%	17%	36%	25%													
	23%		17%	61%														

Managing “fear of cancer recurrence”	23%	25%	8%	32%	13%												
	48%		8%	45%													
Rehabilitation	23%	21%	13%	30%	13%												
	44%		13%	43%													
Supporting occupational issues / return to work	26%	26%	8%	26%	13%												
	52%		8%	39%													
Managing financial problems (“financial toxicity”)	28%	30%	11%	25%	6%												
	58%		11%	31%													
Supporting concerns related to insurance	36%	25%	9%	26%	4%												
	61%		9%	30%													
Supporting caregivers	19%	19%	13%	32%	17%												
	38%		13%	49%													
Supporting coordination between specialists and primary care providers	19%	25%	8%	32%	17%												
	44%		8%	49%													
Prevention of second cancers						54%	25%	4%	10%	8%	65%	22%	0%	6%	6%	0.837**	<0.001
						79%			4%	18%		87%		0%	12%		
Surveillance for recurrence or second cancers						52%	31%	8%	2%	8%	63%	27%	6%	0%	4%	0.802**	<0.001
						83%			8%	10%		90%		6%	4%		
Surveillance of physical “late effects”						29%	21%	2%	35%	13%	37%	10%	0%	43%	10%	0.947**	<0.001
						50%			2%	48%		47%		0%	53%		
Surveillance of psychological distress						29%	17%	6%	35%	13%	33%	8%	0%	53%	6%	0.876**	<0.001
						46%			6%	48%		41%		0%	59%		

Management of pain						13%	4%	8%	50%	25%	10%	4%	4%	59%	22%	0.839**	<0.001
						17%			8%	75%		14%		4%	81%		
Management of other physical symptoms / problems						13%	8%	13%	42%	23%	12%	6%	6%	55%	20%	0.880**	<0.001
						21%			13%	65%		18%		6%	75%		
Management of psychological distress						15%	10%	12%	44%	19%	18%	8%	6%	55%	12%	0.856**	<0.001
						25%			12%	63%		26%		6%	67%		
Managing “fear of cancer recurrence”						23%	27%	6%	33%	12%	27%	24%	4%	37%	8%	0.977**	<0.001
						50%			6%	45%		51%		4%	45%		
Rehabilitation						23%	21%	12%	31%	13%	29%	16%	12%	37%	6%	0.952**	<0.001
						44%			12%	44%		45%		12%	43%		
Supporting occupational issues / return to work						27%	29%	6%	27%	12%	33%	29%	4%	29%	6%	0.922**	<0.001
						56%			6%	39%		62%		4%	35%		
Managing financial problems (“financial toxicity”)						31%	33%	6%	25%	6%	35%	33%	6%	22%	4%	0.932**	<0.001
						64%			6%	31%		68%		6%	26%		
Supporting caregivers						19%	21%	10%	35%	15%	24%	12%	8%	47%	8%	0.880**	<0.001
						40%			10%	50%		36%		8%	55%		
Coordination between specialists and primary care providers						19%	25%	4%	35%	17%	24%	18%	0%	43%	14%	0.875**	<0.001
						44%			4%	53%		42%		0%	57%		
Developing “survivorship care plans”						25%	19%	17%	27%	12%	37%	12%	8%	35%	8%	0.937**	<0.001
						44%			17%	39%		49%		8%	43%		
SPCS <u>generally</u> have the knowledge and skills to support the following components of care:																	
Prevention of	30%	34%	19%	17%	0%												

recurrent and new cancers	64%	19%	17%		
Prevention of other late effects	13%	40%	17%	23%	8%
	53%		17%	31%	
Surveillance for cancer spread, recurrence, or second cancers	32%	34%	21%	11%	2%
	66%		21%	13%	
Surveillance of physical late effects	11%	25%	21%	28%	15%
	36%		21%	43%	
Surveillance of psychosocial late effects	9%	23%	21%	34%	13%
	32%		21%	47%	
Intervention for pain as a late effect	8%	6%	11%	43%	32%
	14%		11%	75%	
Intervention for other physical late effects	6%	15%	17%	36%	26%
	21%		17%	62%	
Intervention for psychosocial late effects	8%	13%	17%	45%	17%
	21%		17%	62%	
Managing “fear of cancer recurrence”	17%	19%	19%	36%	9%
	36%		19%	45%	
Rehabilitation	23%	19%	25%	26%	8%
	42%		25%	34%	
Supporting occupational issues / return to work	23%	25%	21%	25%	8%
	48%		21%	33%	
Managing financial problems (“financial toxicity”)	28%	19%	28%	19%	6%
	47%		28%	25%	

Supporting concerns related to insurance	28%	19%	34%	13%	6%												
	47%		34%	19%													
Supporting caregivers	15%	15%	9%	34%	26%												
	30%		9%	60%													
Supporting coordination between specialists and primary care providers	13%	15%	21%	32%	19%												
	28%		21%	51%													
Prevention of second cancers						35%	42%	15%	8%	0%	37%	55%	8%	0%	0%	0.725**	<0.001
						77%		15%	8%		92%		8%	0%			
Surveillance for recurrence or second cancers						35%	40%	17%	6%	2%	41%	47%	10%	2%	0%	0.670**	<0.001
						75%		17%	8%		88%		10%	2%			
Surveillance of physical "late effects"						10%	31%	17%	37%	6%	4%	39%	18%	35%	4%	0.739**	<0.001
						41%		17%	43%		43%		18%	39%			
Surveillance of psychological distress						8%	23%	19%	42%	8%	4%	24%	10%	55%	6%	0.872**	<0.001
						31%		19%	50%		28%		10%	61%			
Management of pain						6%	4%	10%	58%	23%	2%	0%	6%	76%	16%	0.729**	<0.001
						10%		10%	81%		2%		6%	92%			
Management of other physical symptoms / problems						6%	13%	13%	50%	17%	4%	6%	6%	76%	8%	0.688**	<0.001
						19%		13%	67%		10%		6%	84%			
Management of psychological distress						6%	12%	17%	56%	10%	2%	10%	6%	73%	8%	0.770**	<0.001
						18%		17%	66%		12%		6%	81%			
Managing "fear of cancer recurrence"						17%	21%	13%	42%	6%	16%	10%	14%	57%	2%	0.845**	<0.001
						39%		13%	48%		26%		14%	59%			

Rehabilitation		25%	19%	23%	27%	6%	29%	10%	29%	29%	4%	0.959**	<0.001	
		44%		23%	33%		39%		29%	33%				
Supporting occupational issues / return to work		27%	23%	21%	25%	4%	33%	20%	20%	22%	4%	0.880**	<0.001	
		50%		21%	29%		53%		20%	26%				
Managing financial problems (“financial toxicity”)		31%	17%	35%	15%	2%	33%	14%	37%	14%	2%	0.951**	<0.001	
		48%		35%	17%		47%		37%	16%				
Supporting caregivers		15%	15%	8%	42%	19%	8%	16%	6%	55%	14%	0.869**	<0.001	
		30%		8%	61%		24%		6%	69%				
Coordination between specialists and primary care providers		12%	19%	17%	38%	13%	6%	18%	14%	53%	8%	0.845**	<0.001	
		31%		17%	51%		24%		14%	61%				
Developing “survivorship care plans”	19%	29%	21%	23%	8%	18%	33%	18%	24%	6%	0.877**	<0.001		
	48%		21%	31%		51%		18%	30%					
Barriers to extending the input of SPCS to this group:														
Financial resources	6%	9%	21%	25%	40%	2%	8%	19%	21%	50%		0.877**	<0.001	
	15%		21%	65%		10%		19%	71%					
Human resources	4%	6%	15%	28%	47%	0%	4%	15%	23%	58%		0.823**	<0.001	
	10%		15%	75%		4%		15%	81%					
Other resources	4%	8%	36%	25%	28%									
	12%		36%	53%										
Lack of relevant education and training (e.g. management of chronic cancer treatment-related	8%	15%	21%	28%	28%	2%	13%	23%	29%	33%	0.853**	<0.001		
	23%		21%	56%		15%		23%	62%					

symptoms / problems)																			
Lack of willingness from palliative care professionals	2%	19%	32%	28%	19%	0%	17%	35%	35%	13%								0.870**	<0.001
	21%		32%	47%		17%		33%	48%										
Lack of willingness from oncology professionals	9%	8%	19%	43%	21%	8%	6%	19%	52%	15%								0.876**	<0.001
	17%		19%	64%		14%		19%	67%										
Lack of willingness from general practitioners	9%	6%	28%	42%	15%	8%	6%	29%	44%	13%								0.919**	<0.001
	15%		28%	57%		14%		29%	57%										
Lack of willingness from patients and families	9%	17%	30%	26%	17%	8%	15%	35%	29%	13%								0.971**	<0.001
	26%		30%	43%		23%		35%	42%										
Misperceptions about the nature of palliative care	4%	2%	23%	38%	34%	2%	2%	21%	38%	37%								0.918**	<0.001
	6%		23%	72%		4%		21%	75%										
Time resources						0%	4%	15%	31%	50%	0%	4%	10%	16%	69%			0.807**	<0.001
						4%		15%	81%		4%		10%	85%					
Type of service																			
A dedicated multidisciplinary specialist team is required						6%	6%	6%	35%	48%	8%	2%	2%	24%	63%			0.767**	<0.001
						12%		6%	83%		10%		2%	87%					
Specialist palliative care services should lead this team						35%	35%	17%	12%	2%	39%	41%	10%	8%	2%			0.844**	<0.001
						70%		17%	14%		80%		10%	10%					
Specialist palliative care services should be a core member of this team i.e. routinely involved in care						10%	31%	13%	29%	17%	8%	41%	8%	31%	12%			0.922**	<0.001
						41%		13%	46%		49%		8%	43%					

Specialist palliative care services should be an extended member of this team i.e. support with relevant problems / issues		2%	10%	12%	52%	25%	2%	0%	10%	76%	12%	0.713**	<0.001
		12%		12%	77%		2%		10%	88%			
Specialist palliative care services should not contribute to this team		54%	17%	8%	17%	4%	65%	18%	6%	10%	0%	0.808**	<0.001
		71%		8%	31%		83%		6%	10%			

Key: SD = strongly disagree; MD = moderately disagree; N = neither agree nor disagree; MA = moderately agree; SA = strongly agree; SPC = specialist palliative care; SPCS = specialist palliative care services; rho = Spearman's rank correlation coefficient between relevant subsequent rounds; * correlation is significant at the 0.05 level (2-tailed); ** correlation is significant at the 0.01 level (2-tailed); shaded box = consensus reached (>=75%).

S2e. Extended role of SPC for individuals with stable locally advanced or metastatic cancer – ONC group results.

Statement	Round 2					Round 3					rho	p value
	SD	MD	N	MA	SA	SD	MD	N	MA	SA		
Section 5: Extended role of Specialist Palliative Care for <i>individuals with stable locally advanced or metastatic cancer</i>												
SPCS <u>should</u> have a role in supporting the following components of care:												
Prevention of second cancers	37%	37%	6%	13%	8%	47%	41%	0%	8%	4%	0.781**	<0.001
	74%		6%	21%		88%		0%	12%			
Surveillance for cancer spread, recurrence or second cancers	33%	27%	17%	17%	6%	47%	37%	6%	8%	2%	0.728**	<0.001
	60%		17%	23%		84%		6%	10%			
Surveillance of physical symptoms / problems	4%	10%	10%	44%	33%	4%	8%	4%	55%	29%	0.869**	<0.001
	14%		10%	67%		12%		4%	84%			
Surveillance of psychological distress	4%	10%	12%	40%	35%	2%	10%	4%	51%	33%	0.788**	<0.001
	14%		12%	75%		12%		4%	84%			
Management of pain	2%	0%	0%	35%	63%	0%	0%	0%	20%	80%	0.611**	<0.001
	2%		0%	98%		0%		0%	100%			
Management of other physical symptoms / problems	4%	2%	6%	40%	48%	0%	0%	4%	33%	63%	0.686**	<0.001
	6%		6%	88%		0%		4%	96%			
Management of psychological distress	2%	2%	6%	50%	40%	0%	2%	0%	57%	41%	0.728**	<0.001
	4%		6%	90%		2%		0%	98%			
Support for cultural, spiritual and religious needs	2%	8%	23%	48%	19%	2%	4%	18%	63%	12%	0.694**	<0.001
	10%		23%	67%		6%		18%	75%			
Rehabilitation	6%	13%	21%	40%	19%	2%	10%	14%	57%	16%	0.693**	<0.001
	19%		21%	59%		12%		14%	73%			
Supporting occupational issues / return to work	10%	31%	15%	31%	13%	2%	39%	6%	45%	8%	0.806**	<0.001
	41%		15%	44%		41%		6%	53%			

Managing financial problems (“financial toxicity”)	13%	23%	27%	29%	8%	10%	18%	24%	39%	8%	0.706**	<0.001
	36%		27%	37%		28%		24%	47%			
Supporting caregivers	4%	4%	19%	52%	21%	2%	2%	8%	67%	20%	0.660**	<0.001
	8%		19%	73%		4%		8%	87%			
Care coordination between specialists and primary care providers	4%	13%	13%	37%	33%	2%	8%	10%	51%	29%	0.787**	<0.001
	17%		13%	70%		12%		10%	80%			
Health promotion	8%	12%	23%	46%	12%	4%	6%	18%	63%	8%	0.666**	<0.001
	20%		23%	58%		10%		18%	71%			
Developing “survivorship care plans”	13%	21%	13%	35%	17%	8%	20%	8%	49%	14%	0.856**	<0.001
	34%		13%	52%		28%		8%	63%			
Advance care planning	2%	2%	4%	35%	58%	0%	2%	0%	29%	69%	0.637**	<0.001
	4%		4%	93%		2%		0%	98%			
SPCS <u>generally have</u> the knowledge and skills to support the following components of care:												
Prevention of second cancers	37%	27%	13%	23%	0%	47%	27%	6%	20%	0%	0.749**	<0.001
	64%		13%	23%		74%		6%	20%			
Surveillance for cancer spread, recurrence or second cancers	29%	25%	21%	17%	8%	43%	31%	16%	6%	4%	0.695**	<0.001
	54%		21%	25%		74%		16%	10%			
Surveillance of physical symptoms / problems	0%	6%	13%	44%	37%	0%	6%	4%	65%	24%	0.815**	<0.001
	6%		13%	81%		6%		4%	89%			
Surveillance of psychological distress	0%	4%	12%	46%	38%	0%	4%	2%	67%	27%	0.795**	<0.001
	4%		12%	84%		4%		2%	94%			
Management of pain	0%	0%	0%	27%	73%	0%	0%	0%	16%	84%	0.698**	<0.001
	0%		0%	100%		0%		0%	100%			
Management of other physical symptoms / problems	0%	0%	4%	40%	56%	0%	0%	2%	35%	63%	0.853**	<0.001
	0%		4%	96%		0%		2%	98%			
Management of psychological distress	0%	2%	6%	50%	42%	0%	2%	4%	57%	37%	0.922**	<0.001

	2%		6%	92%		2%		4%	94%			
Support for cultural, spiritual and religious needs	6%	10%	25%	31%	29%	4%	6%	24%	43%	22%	0.849**	<0.001
	16%		25%	60%		10%		24%	65%			
Rehabilitation	6%	29%	15%	37%	13%	4%	29%	10%	45%	12%	0.968**	<0.001
	35%		15%	50%		33%		10%	57%			
Supporting occupational issues / return to work	8%	37%	19%	29%	8%	8%	41%	12%	31%	8%	0.917**	<0.001
	44%		19%	37%		49%		12%	39%			
Managing financial problems (“financial toxicity”)	10%	31%	29%	25%	6%	8%	39%	27%	20%	6%	0.870**	<0.001
	41%		29%	31%		47%		27%	26%			
Supporting caregivers	2%	6%	13%	50%	29%	2%	6%	6%	63%	22%	0.860**	<0.001
	8%		13%	79%		8%		6%	85%			
Care coordination between specialists and primary care providers	2%	8%	15%	48%	27%	2%	6%	10%	57%	24%	0.924**	<0.001
	10%		15%	75%		8%		10%	81%			
Health promotion	12%	13%	33%	35%	8%	6%	10%	31%	47%	6%	0.798**	<0.001
	25%		33%	43%		16%		31%	53%			
Developing “survivorship care plans”	15%	19%	23%	29%	13%	10%	18%	24%	35%	12%	0.836**	<0.001
	34%		23%	42%		28%		24%	47%			
Advance care planning	2%	0%	4%	37%	58%	0%	0%	0%	37%	63%	0.878**	<0.001
	2%		4%	95%		0%		0%	100%			
Barriers to extending the input of SPCS to this group:												
Financial resources	2%	4%	8%	46%	40%	0%	6%	4%	49%	41%	0.727**	<0.001
	6%		8%	86%		6%		4%	90%			
Human resources	0%	2%	2%	44%	52%	0%	0%	0%	35%	65%	0.813**	<0.001
	2%		2%	96%		0%		0%	100%			
Time resources	0%	4%	4%	40%	52%	0%	4%	2%	27%	67%	0.812**	<0.001
	4%		4%	92%		4%		2%	94%			

Lack of relevant education and training (e.g. management of chronic cancer treatment-related symptoms / problems)	13%	10%	17%	38%	21%	6%	8%	14%	55%	16%	0.768**	<0.001
	23%		17%	59%		14%		14%	71%			
Lack of willingness / reluctance from palliative care professionals	17%	21%	21%	31%	10%	10%	20%	18%	43%	8%	0.909**	<0.001
	39%		21%	41%		30%		18%	51%			
Lack of willingness from oncology professionals	6%	15%	21%	44%	13%	4%	18%	14%	49%	14%	0.915**	<0.001
	21%		21%	57%		22%		14%	63%			
Lack of willingness from general practitioners	4%	23%	27%	37%	10%	4%	20%	14%	51%	10%	0.899**	<0.001
	27%		27%	47%		24%		14%	61%			
Lack of willingness from patients and families	10%	27%	23%	25%	15%	6%	31%	16%	41%	6%	0.940**	<0.001
	37%		23%	40%		37%		16%	47%			
Misperceptions about the nature of palliative care	0%	10%	8%	50%	33%	0%	8%	6%	57%	29%	0.894**	<0.001
	10%		8%	83%		8%		6%	86%			
Type of service												
A dedicated multidisciplinary specialist team is required	4%	2%	8%	13%	73%	0%	2%	4%	8%	86%	0.635**	<0.001
	6%		8%	86%		2%		4%	94%			
Specialist palliative care services should lead this team	10%	25%	23%	23%	19%	6%	33%	24%	24%	12%	0.852**	<0.001
	35%		23%	42%		39%		24%	36%			
Specialist palliative care services should be a core member of this team i.e. routinely involved in care	2%	12%	12%	25%	50%	0%	6%	8%	20%	65%	0.585**	<0.001
	14%		12%	75%		6%		8%	85%			
Specialist palliative care services should be an extended member of this team i.e. support with relevant problems / issues	2%	13%	12%	31%	42%	2%	8%	6%	24%	59%	0.760**	<0.001
	15%		12%	73%		10%		6%	83%			
Specialist palliative care services should not contribute to this team	79%	13%	6%	2%	0%	92%	6%	2%	0%	0%	0.530**	<0.001
	92%		6%	2%		98%		2%	0%			
The same team should provide care for both groups.	23%	21%	12%	21%	23%	31%	20%	8%	20%	20%	0.910**	<0.001
	44%		12%	44%		51%		8%	40%			

Key: SD = strongly disagree; MD = moderately disagree; N = neither agree nor disagree; MA = moderately agree; SA = strongly agree; SPC = specialist palliative care; SPCS = specialist palliative care services; rho = Spearman's rank correlation coefficient between relevant subsequent rounds; * correlation is significant at the 0.05 level (2-tailed); ** correlation is significant at the 0.01 level (2-tailed); shaded box = consensus reached ($\geq 75\%$).

Supplementary Table S3: Comparison of levels of agreement between SPC and ONC groups regarding final statements

Statement	x ² (1)	p value	n
Section: Definition and core functions of Specialist Palliative Care (SPC)			
Core functions of SPCS			
Management of pain	0.082	0.775	53
Management of other physical symptoms	0.353	0.553	53
Management of psychological problems	0.353	0.553	53
Emotional support (patient)	0.489	0.484	53
Emotional support (family)	0.144	0.704	53
Spiritual support	4.484	0.034	53
Social assistance	15.684	<0.001	53
Co-ordination of care	2.883	0.090	53
Advance care planning	0.489	0.484	53
End-of-life care	N/A		
Bereavement care	7.109	0.008	53
Rehabilitation	4.479	0.034	53
Religious support	7.837	0.005	49
Research	0.726	0.394	49
Education (other healthcare professionals)	N/A		
SPCS should manage the following types of pain:			
Acute cancer-related pain (pain for < 3 months)	0.234	0.629	53
Acute cancer treatment-related pain (pain for < 3 months)	2.211	0.137	53
Acute pain related to non-cancer causes (pain for < 3 months)	3.965	0.046	53
Chronic cancer-related pain (pain for≥3 months)	1.017	0.313	53
Chronic cancer treatment-related pain (pain for≥3 months)	4.355	0.037	53
Chronic pain related to non-cancer causes (pain for≥3 months)	0.997	0.318	53

Individuals with pain and a previous history of opioid misuse / abuse / addiction	0.503	0.478	49
Individuals with pain and ongoing problems of opioid misuse / abuse / addiction	1.503	0.220	49
Chronic cancer / cancer treatment-related pain – in collaboration with the multidisciplinary chronic pain team	0.503	0.478	49
Individuals with cancer / cancer treatment-related pain and a previous history of opioid misuse / abuse / addiction	1.503	0.220	49
Individuals with cancer / cancer treatment-related pain and ongoing problems of opioid misuse / abuse / addiction	1.907	0.167	49
Individuals with chronic cancer / cancer treatment-related pain and a previous history of opioid misuse / abuse / addiction – in collaboration with the multidisciplinary chronic pain team	0.058	0.810	49
Individuals with chronic cancer / cancer treatment-related pain and ongoing problems of opioid misuse / abuse / addiction – in collaboration with the multidisciplinary chronic pain team	1.306	0.253	49
Individuals with cancer / cancer treatment-related pain and a previous history of opioid misuse / abuse / addiction – in collaboration with addiction services	0.134	0.714	49
Individuals with cancer / cancer treatment-related pain and ongoing problems of opioid misuse / abuse / addiction – in collaboration with addiction services	1.355	0.244	49
SPCS generally have the knowledge and skills to manage the following:			
Acute cancer-related pain (pain for < 3 months)	8.894	0.003	53
Acute cancer treatment-related pain (pain for < 3 months)	0.066	0.798	53
Acute pain related to non-cancer causes (pain for < 3 months)	10.193	0.001	53
Chronic cancer-related pain (pain for ≥ 3 months)	N/A		
Chronic cancer treatment-related pain (pain for ≥ 3 months)	4.355	0.037	53
Chronic pain related to non-cancer causes (pain for ≥ 3 months)	5.499	0.019	53
Individuals with cancer / cancer treatment-related pain and a previous history of opioid misuse / abuse / addiction	3.029	0.082	49
Individuals with cancer / cancer treatment-related pain and ongoing problems of opioid misuse / abuse / addiction	7.537	0.006	49
SPCS services should have more education and / or appropriate training in the following areas:			

Interventional pain techniques	0.240	0.877	49
Physiotherapy interventions	15.784	<0.001	49
Occupational therapy interventions	2.768	0.096	49
Transcutaneous electrical nerve stimulation (TENS), scrambler therapy	1.306	0.253	49
Acupuncture, acupressure	0.575	0.448	49
Psychological and behavioural therapies / interventions	0.122	0.727	49
Complementary and alternative therapies	0.347	0.556	49
Pharmacological interventions in addiction recovery	2.420	0.120	49
Psychosocial and behavioural interventions in addiction recovery	0.044	0.834	49
SPCS should manage the following types of non-pain symptoms / physical problems:			
Acute cancer-related symptoms / physical problems (lasting < 3 months)	4.475	0.034	53
Acute cancer treatment-related symptoms / physical problems (lasting < 3 months)	2.309	0.129	53
Acute symptoms / physical problems related to non-cancer causes (lasting < 3 months)	0.251	0.617	53
Chronic cancer-related symptoms / physical problems (lasting ≥ 3 months)	0.144	0.704	53
Chronic cancer treatment-related symptoms / physical problems (lasting ≥ 3 months)	1.110	0.292	53
Chronic symptoms / physical problems related to non-cancer causes (lasting ≥ 3 months)	6.611	0.010	53
SPCS generally have the knowledge and skills to manage the following:			
Acute cancer-related symptoms / physical problems (lasting < 3 months)	24.929	<0.001	53
Acute cancer treatment-related symptoms / physical problems (lasting < 3 months)	19.306	<0.001	53
Acute symptoms / physical problems related to non-cancer causes (lasting < 3 months)	1.143	0.285	53
Chronic cancer-related symptoms / physical problems (lasting ≥ 3 months)	0.066	0.798	53
Chronic cancer treatment-related symptoms / physical problems (lasting ≥ 3 months)	0.239	0.625	53

Chronic symptoms / physical problems related to non-cancer causes (lasting ≥ 3 months)	0.016	0.898	53
SPCS services should have more training in the following areas:			
Assessment of acute side effects of anticancer treatment (especially novel anticancer treatments)	171.000	<0.001	49
Management of acute side effects of anticancer treatment (especially novel anticancer treatments)	21.066	<0.001	49
Assessment of chronic / long-term effects of anticancer treatment (especially novel anticancer treatments)	64.474	<0.001	49
Management of chronic / long-term effects of anticancer treatment (especially novel anticancer treatments)	14.763	<0.001	49
Assessment of late / delayed effects of anticancer treatment (especially novel anticancer treatments)	139.592	<0.001	49
Management of late / delayed effects of anticancer treatment (especially novel anticancer treatments)	28.487	<0.001	49
Section: Definition of “cancer survivor”			
The following groups should be called “cancer survivors”:			
All individuals with cancer.	0.294	0.588	52
Individuals who have just completed anticancer treatment, and still have some known cancer present.	1.030	0.310	52
Individuals who have just completed anticancer treatment, and have no known cancer present.	2.000	0.157	52
Individuals who completed anticancer treatment at least 1 year beforehand, and have no known cancer present.	6.441	0.011	52
Individuals who completed anticancer treatment at least 5 years beforehand, and have no known cancer present.	0.995	0.319	52
Individuals who completed anticancer treatment at least 10 years beforehand, and have no known cancer present.	2.773	0.096	52
Individuals who have progressive/worsening cancer, and have no other anticancer treatment options.	1.300	0.254	52

Family members, friends, and caregivers of individuals with cancer or a history of cancer.	3.071	0.080	52
No individual should be called a “cancer survivor” i.e. the term should not be used.	0.249	0.618	52
Individuals who are still receiving anticancer treatment with curative intent	49.133	<0.001	49
Individuals who are still receiving anticancer treatment with palliative intent	16.641	<0.001	49
Section: Categorisation of individuals with cancer or a history of cancer			
The following classifications for groups of individuals with cancer or a history of cancer are useful:			
Seasons of survivorship	40.540	<0.001	52
Living with, through and beyond cancer	1.577	0.209	52
New categorisation	5.327	0.021	52
Section: Extended role of Specialist Palliative Care for individuals with a history of cancer who have completed anticancer treatment and have no evidence of disease			
SPCS <u>should</u> have a role in supporting the following components of care			
Prevention of second cancers	9.577	0.002	49
Surveillance for recurrence or second cancers	0.825	0.364	49
Surveillance of physical "late effects"	10.828	<0.001	49
Surveillance of psychological distress	17.767	<0.001	49
Management of pain	1.150	0.284	49
Management of other physical symptoms / problems	0.223	0.637	49
Management of psychological distress	0.360	0.548	49
Managing “fear of cancer recurrence”	0.291	0.589	49
Rehabilitation	4.744	0.029	49
Supporting occupational issues / return to work	14.906	<0.001	49
Managing financial problems (“financial toxicity”)	11.367	<0.001	49

Supporting caregivers	4.656	0.031	49
Coordination between specialists and primary care providers	19.246	<0.001	49
Developing "survivorship care plans"	3.857	0.050	49
SPCS generally have the knowledge and skills to support the following components of care:			
Prevention of second cancers	N/A		
Surveillance for recurrence or second cancers	4.185	0.041	49
Surveillance of physical "late effects"	7.030	0.008	49
Surveillance of psychological distress	0.134	0.715	49
Management of pain	0.843	0.359	49
Management of other physical symptoms / problems	0.266	0.606	49
Management of psychological distress	0.026	0.873	49
Managing "fear of cancer recurrence"	0.583	0.445	49
Rehabilitation	1.944	0.163	49
Supporting occupational issues / return to work	0.061	0.805	49
Managing financial problems ("financial toxicity")	0.047	0.829	49
Supporting caregivers	1.849	0.174	49
Coordination between specialists and primary care providers	2.393	0.122	49
Developing "survivorship care plans"	0.009	0.925	49
Barriers to extending the input of SPCS to this group:			
Financial resources	4.027	0.045	51
Human resources	5.388	0.020	51
Time resources	0.019	0.892	49
Lack of relevant education and training (e.g. management of chronic cancer treatment-related symptoms / problems)	11.770	<0.001	51
Lack of willingness from palliative care professionals	0.895	0.344	51
Lack of willingness from oncology professionals	1.410	0.235	51
Lack of willingness from general practitioners	5.926	0.015	51

Lack of willingness from patients and families	0.033	0.856	51
Misperceptions about the nature of palliative care	0.038	0.846	51
Type of service			
A dedicated multidisciplinary specialist team is required	0.045	0.832	49
Specialist palliative care services should lead this team	0.058	0.810	49
Specialist palliative care services should be a core member of this team i.e. routinely involved in care	0.346	0.556	49
Specialist palliative care services should be an extended member of this team i.e. support with relevant problems / issues	4.978	0.026	49
Specialist palliative care services should not contribute to this team	0.002	0.962	49
Section: Extended role of Specialist Palliative Care for <i>individuals with stable locally advanced or metastatic cancer</i>.			
SPCS <u>should</u> have a role in supporting the following components of care:			
Prevention of second cancers	1.842	0.175	49
Surveillance for cancer spread, recurrence or second cancers	9.144	0.002	49
Surveillance of physical symptoms / problems	3.470	0.062	49
Surveillance of psychological distress	3.470	0.062	49
Management of pain	N/A		
Management of other physical symptoms / problems	N/A		
Management of psychological distress	N/A		
Support for cultural, spiritual and religious needs	6.440	0.011	49
Rehabilitation	0.002	0.967	49
Supporting occupational issues / return to work	0.983	0.321	49
Managing financial problems ("financial toxicity")	0.184	0.668	49
Supporting caregivers	0.729	0.393	49
Care coordination between specialists and primary care providers	1.236	0.266	49
Health promotion	11.251	<0.001	49

Developing “survivorship care plans”	15.457	<0.001	49
Advance care planning	0.042	0.837	49
SPCS <u>generally have</u> the knowledge and skills to support the following components of care:			
Prevention of second cancers	1.124	0.289	49
Surveillance for cancer spread, recurrence or second cancers	5.721	0.017	49
Surveillance of physical symptoms / problems	2.794	0.095	49
Surveillance of psychological distress	0.130	0.718	49
Management of pain	N/A		
Management of other physical symptoms / problems	0.211	0.646	49
Management of psychological distress	2.638	0.104	49
Support for cultural, spiritual and religious needs	4.178	0.041	49
Rehabilitation	0.016	0.899	49
Supporting occupational issues / return to work	2.469	0.116	49
Managing financial problems (“financial toxicity”)	5.908	0.015	49
Supporting caregivers	0.143	0.705	49
Care coordination between specialists and primary care providers	0.082	0.775	49
Health promotion	23.187	<0.001	49
Developing “survivorship care plans”	19.261	<0.001	49
Advance care planning	N/A		
Barriers to extending the input of SPCS to this group:			
Financial resources	0.529	0.467	49
Human resources	N/A		
Time resources	0.819	0.366	49
Lack of relevant education and training (e.g. management of chronic cancer treatment-related symptoms / problems)	0.345	0.557	49
Lack of willingness / reluctance from palliative care professionals	0.718	0.397	49
Lack of willingness from oncology professionals	0.193	0.660	49

Lack of willingness from general practitioners	5.212	0.022	49
Lack of willingness from patients and families	4.657	0.031	49
Misperceptions about the nature of palliative care	0.010	<i>0.919</i>	49
Type of service			
A dedicated multidisciplinary specialist team is required	1.306	<i>0.253</i>	49
Specialist palliative care services should lead this team	1.786	<i>0.181</i>	49
Specialist palliative care services should be a core member of this team i.e. routinely involved in care	0.351	<i>0.554</i>	49
Specialist palliative care services should be an extended member of this team i.e. support with relevant problems / issues	0.717	<i>0.397</i>	49
Specialist palliative care services should not contribute to this team	N/A		
The same team should provide care in these areas to both groups.	9.427	0.002	49

dof = degrees of freedom = 1 for all statements

For a significance level of 0.05 and one degree of freedom, the critical value is 3.841.

Key: SPC = specialist palliative care expert group; ONC = oncology expert group; SPCS = specialist palliative care services; $\chi^2(1)$ = Chi square test for goodness of fit comparing the levels of agreement of the ONC group with the SPC group for each statement, for one degree of freedom; N/A = unable to perform χ^2 test as at least one group achieved 100% agree / disagree and comparison is not possible; n = number of participants in ONC expert comparison group who responded to the statement; Italicised, bold p value = significant ($p < 0.05$); pale grey box = statement achieved SPC consensus but not ONC consensus; dark grey box = statement achieved ONC consensus but not SPC consensus

Appendix 6: POST study materials

a) *Case Report Form (Ireland)*



POST:

Palliative care and Oncology Survey on Terminology

What do individuals known to palliative care and
oncology services think about the terminology
used to describe them?

Case Report Form: Ireland

Centre Identification Number:

Patient Identification Number:

Date of Study Entry:

Instructions for Researchers on Completing Case Report Form

- This Case Report Form (CRF) can be given to the Participant for completion, or completed with the Participant by the Researcher on their behalf
- It is the responsibility of the Researcher to fill in all sections
- Please write clearly
- You are advised in the relevant questions to tick one box, or all that apply
- Please note that Eastern Cooperative Oncology Group (ECOG) Performance Status should be determined by participant perception
- If not applicable, please write N/A
- If not recorded, please write NR
- Please use dd/mmm/yyyy format to record dates e.g. 25Sep2023
- Please initial entries
- Please cross out mistakes with a single line e.g. ~~mistake~~
- Please initial and date corrections e.g. ~~mistake~~ correction AB25Sep2023

To be completed by Researcher

Group 1: Individuals with a diagnosis of cancer known to palliative care services

Inclusion criteria:	Yes	No
• Diagnosis of cancer	☐	☐
• Under the care of palliative care services as an inpatient, outpatient or community patient	☐	☐
• Age ≥ 18 years	☐	☐
• Able to speak / read English (enough to complete questionnaire)	☐	☐

Exclusion criteria:	Yes	No
• Unable to provide consent	☐	☐
• Unable to complete questionnaire	☐	☐

Group 2: Individuals with a diagnosis of cancer receiving anti-cancer treatment known to oncology services

Inclusion criteria:	Yes	No
• Diagnosis of cancer	☐	☐
• Under the care of oncology services and currently receiving an anticancer regimen of any kind	☐	☐
• Age ≥ 18 years	☐	☐
• Able to speak / read English (enough to complete questionnaire)	☐	☐

Exclusion criteria:	Yes	No
• Unable to provide consent	☐	☐
• Unable to complete questionnaire	☐	☐

To be completed by Researcher

Current cancer treatment (tick all that apply)

Chemotherapy	
Hormone Therapy	
Immunotherapy	
Targeted Therapy	
Radiotherapy / Radiation Therapy	
Surgery	
Not on any anticancer treatment	

Cancer treatment intent (tick one)

Curative (aiming to permanently eradicate disease)	
Palliative (aiming to control disease or relieve / control cancer-related symptoms)	
Not applicable	

To be completed by Researcher / Participant

Section 1: Basic information

1.1 Country of residence (tick one box)

Australia	Canada	Ireland	United Kingdom	United States of America

1.2 Current age (insert numbers)

1.3 Gender (tick one box)

Female	Male	Non-binary /Other

1.4 Marital status (tick one box)

Single	Married/in a similar relationship	Divorced/separated	Widowed

1.5 Educational attainment (highest level) (tick one box)

Educational attainment	Examples in Ireland	Tick one
Less than primary education	Early childhood or pre-school	
Primary education	Primary education	
Lower secondary education	Junior Cycle Profile of Achievement (JCPA) or equivalent	
Upper secondary education	Leaving Certificate or equivalent	
Post-secondary non-tertiary education	Further education, such as Post Leaving Certificate course or equivalent	
Short-cycle tertiary education	Higher education, non-degree qualification from third level institution (universities, institutes of technology, and colleges of education)	
Bachelor's or equivalent level	Higher education, Bachelor's degree from third level institution	
Master's or equivalent level	Higher education, Master's degree from third level institution	
Doctoral or equivalent level	Higher education, Doctoral degree from third level institution	
Not elsewhere classified		

1.6 Ethnicity (Ireland): (tick one box)

White Irish	
White Irish Traveller	
Any other White background	
Black or Black Irish - African	
Black or Black Irish - Any other Black background	
Asian or Asian Irish - Chinese	
Asian or Asian Irish - Any other Asian background	
Other, including mixed background	

1.7 Cancer diagnosis (tick one box – main diagnosis)

Breast	Endocrine	Gastrointestinal	Gynaecological	Haematological

Head & Neck	Lung	Neurological	Sarcoma	Skin

Unknown primary	Urological	Other (please state)

To be completed by Participant (Researcher can fill in form)

1.8 How would you best describe your level of activity? (tick one box)

Eastern Cooperative Oncology Group (ECOG) Performance Status

0 - Fully active, able to carry on all pre-disease performance without restriction	
1 - Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work	
2 - Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours	
3 - Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours	
4 - Completely disabled. Cannot carry on any selfcare. Totally confined to bed or chair	

Section 2: Terminology

A variety of terms have been used to describe people that use healthcare services (e.g. patients, service users). We would like to know your opinion about these terms, and specifically how much you would like or dislike to be described by these terms.

2.1 What do you think about being described as a “PATIENT” (tick one box)?

Strongly dislike	Moderately dislike	Neutral	Moderately like	Strongly like

2.2 What do you think about being described as a “CLIENT” (tick one box)?

Strongly dislike	Moderately dislike	Neutral	Moderately like	Strongly like

2.3 What do you think about being described as a “CONSUMER” (tick one box)?

Strongly dislike	Moderately dislike	Neutral	Moderately like	Strongly like

2.4 What do you think about being described as a “CUSTOMER” (tick one box)?

Strongly dislike	Moderately dislike	Neutral	Moderately like	Strongly like

2.5 What do you think about being described as a “SERVICE USER” (tick one box)?

Strongly dislike	Moderately dislike	Neutral	Moderately like	Strongly like

2.6 What do you think about being described as an “ONCOLOGY PATIENT” (tick one box)?

Strongly dislike	Moderately dislike	Neutral	Moderately like	Strongly like

2.7 What do you think about being described as a “CANCER PATIENT” (tick one box)?

Strongly dislike	Moderately dislike	Neutral	Moderately like	Strongly like

2.8 What do you think about being described as a “PATIENT WITH CANCER” (tick one box)?

Strongly dislike	Moderately dislike	Neutral	Moderately like	Strongly like

2.9 What do you think about being described as a “PERSON LIVING WITH CANCER” (tick one box)?

Strongly dislike	Moderately dislike	Neutral	Moderately like	Strongly like

2.10 How important do you think the choice of term used to describe you is?

Very unimportant	Slightly unimportant	Neither important nor unimportant	Slightly important	Very important

Section 3: Cancer Survivor Terminology

We would like to ask your views about the term “CANCER SURVIVORS”.

3.1 In your opinion, which of the following groups should be called “CANCER SURVIVORS”? (tick all that apply)

Any individual with a diagnosis of cancer	
Individuals who are still receiving anticancer treatment	
Individuals who have just completed anticancer treatment, and still have some known cancer present	
Individuals who have just completed anticancer treatment, and have no known cancer present	
Individuals who completed anticancer treatment at least 1 year beforehand, and have no known cancer present	
Individuals who completed anticancer treatment at least 5 years beforehand, and have no known cancer present	
Individuals who completed anticancer treatment at least 10 years beforehand, and have no known cancer present	
Individuals who have progressive/worsening cancer, and have no other anticancer treatment options	
The term should not be used for any individual	

There are different definitions of “cancer survivor”. The National Cancer Institute in the USA suggests that “an individual is considered a cancer survivor from the time of diagnosis through the balance of life. There are many types of survivors, including those living with cancer and those free of cancer.”

3.2 What do you think about this definition of a “CANCER SURVIVOR” (tick one box)?

Strongly dislike	Moderately dislike	Neutral	Moderately like	Strongly like

3.3 What would you think about being described as a “CANCER SURVIVOR” (tick one box)?

Strongly dislike	Moderately dislike	Neutral	Moderately like	Strongly like

3.4 Do you have any other comments about the term, “CANCER SURVIVOR”?

Thank you for completing this questionnaire.

Participant Information Leaflet

Study Title: POST: Palliative care and Oncology Survey on Terminology

What do individuals known to palliative care and oncology services think about the terminology used to describe them?

Sites	Our Lady's Hospice & Care Services, Dublin St James's Hospital, Dublin
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Data Controller	Our Lady's Hospice & Care Services
Data Processor	Claddagh Statistical Consultancy Service, Limerick St James's Hospital, Dublin
Data Protection Officer	Ms Patricia Pierce, Data Protection Officer Our Lady's Hospice & Care Services, Harold's Cross, Dublin, D6W RY72, OLHDPO@ambitcompliance.ie

Participant Information Leaflet

Study Title: POST: Palliative care and Oncology Survey on Terminology

What do individuals known to palliative care and oncology services think about the terminology used to describe them?

We would like to invite you to take part in this research study.

Before you decide whether to take part, it is important to understand why the research is being done and what it will involve. Please take time to read the following information carefully and, if you wish, discuss it with friends, relatives or your doctor. Do ask us about anything that is unclear or if you would like more information. Take time to decide whether you wish to take part.

This leaflet has 5 parts:

Part 1 – The Study

Part 2 – Data Protection

Part 3 – Costs, Funding and Approval

Part 4 – Future Research

Part 5 – Further Information

Part 1 – The Study

Why is this study being done?

We are doing this study to understand the views of individuals with cancer known to cancer and palliative care services about the terms used to describe them.

Why have I been invited to take part?

You are being invited to take part because you have a diagnosis of cancer and are known to cancer or palliative care services. We are seeking the opinions of 766 individuals in Ireland who are known to hospital, hospice and community services. As part of this study, we are also seeking the opinions of participants from Australia, Canada, the United Kingdom, and the United States of America.

Do I have to take part? Can I withdraw?

Taking part is voluntary, so you do not have to take part. Deciding not to take part will not affect your current or future medical care. If you do wish to take part, you will be given this information leaflet to keep and asked to sign a consent form. You are still free to withdraw at any time. You don't have to give a reason for not taking part or for opting out. If you wish to withdraw, please email Dr Amy Taylor at ataylor@olh.ie.

How will the study be carried out?

The study consists of just one visit in the healthcare institution you are already attending, or in your home if you are a community patient. The visit can be done in person, over the telephone or via video conference depending on your preference.

What will happen to me if I decide to take part?

The study visit will take place on the day the research team meet you, or if you prefer you may return or be contacted at a time that is more convenient to you. The visit will last around 15 minutes and will be a one-off visit. You will be asked to complete a questionnaire that has three sections, which will ask some personal demographic details and your opinion about the terms used to describe people who use healthcare services. On completion, the research team will not contact you again.

What will happen to the information I provide?

All information you provide will be treated as confidential. If you consent to take part in the study, members of the research team may look at your medical records. The information collected for the study will be coded with a key and kept securely until destroyed. You will not be identified in any report or publication that arises as a result of the study. Please see Part 2 for further information.

Are there any benefits to taking part in this research?

Taking part in this study will not directly benefit you. However, research performed with your information may help us to better understand the views of individuals known to cancer and palliative care services about the terms used to describe them. By participating, you are helping to advance such understanding for individuals with cancer in the future.

Are there any risks if I take part?

The risks in taking part in this study are low. It is unlikely that you will be harmed in any way. Sometimes individuals can become uncomfortable or emotional when answering questions that relate to their health, healthcare or personal demographics. If you find this is the case, the questionnaire can be stopped at any time. The researchers are healthcare professionals trained in providing support, and may also talk to you about seeking further support for you from your clinical team if they think that would be helpful.

Will I be told the outcome of the study?

The findings from the study will be presented in various medical meetings and published in appropriate medical journals. No information which reveals your identity will be disclosed. You will not directly be informed of the outcome of the study.

Part 2 – Data Protection

What information about me (personal data) will be used as part of this study?

Will my medical records be accessed?

You will be asked to provide your country of residence, age, gender, marital status, educational background, and ethnicity. You will also be asked to select your category of cancer diagnosis and activity level. You will then be asked a series of questions about your opinion on different terms used to describe people who use healthcare services, how important you feel the choice of term is, and more specific questions about one term. The researcher will complete two questions about whether you are on anticancer treatment, and may check your medical records with your permission for this purpose.

What will happen to my personal data?

In this study, we will not collect personal data such as name, contact details or hospital number. Most of the personal data we process is obtained from you directly, but we might also obtain personal data about you from your medical notes. Your data will be processed only as required to achieve the outcome of the study and not in any way which may cause damage or distress.

The information you provide will be coded as soon as you agree to take part, when you will be assigned a study number. This means the researchers will not be able to identify you. The coded research data will be uploaded onto an online database called Research Electronic Data Capture (REDCap), which is located on a secure server at the University College Dublin Clinical Research Facility. This will only be accessible to relevant members of the research team. Your Consent Form and data collection sheets will be stored in locked cupboards in a locked office at St James's Hospital or the Academic Department of Palliative Medicine, Our Lady's Hospice & Care Services. Your data will be stored for 5 years following completion of the study and then destroyed.

An anonymised form of this database may be shared with third parties, such as Claddagh Statistical Consultancy Service, or other academic services / research institutions outside of the European Economic Area (EEA), for the purposes of data analysis. You will not be identifiable in this database.

Processing of your personal data will comply with the European General Data Protection Regulation (GDPR), or the equivalent legislation in other countries. Our Lady's Hospice & Care Services (OLH&CS), Dublin, Ireland, will be the Data Controller responsible for this

study. This means that OLH&CS is responsible for complying with data protection laws in respect to any personal data which is used for this study.

Who will access and use my personal data as part of this study?

- Principal Investigator Professor Andrew Davies
- Co-Investigators Dr Norma O’Leary, Dr Cliona Grant, Dr Amy Taylor, and Ms Norah Fagan.

Will my personal data be kept confidential? How will my data be kept safe?

Your privacy is important to us. We take many steps to make sure that we protect your confidentiality and keep your data safe. Here is how we do this:

- We have undertaken a Risk Assessment of the data protection implication
- All researchers have undertaken additional training in data protection
- All researchers who will have access to the personal data are bound by a professional code of secrecy
- All data is coded so that participants cannot be identified in the study results
- You will not be identifiable in any presentation or publication in relation to the study.

What is the lawful basis to use my personal data?

By law,¹ we can use your personal information for scientific research² (in the public interest³). Processing of your personal data will comply with these regulations, and equivalent legislation in the relevant countries. We will also ask for your explicit consent to use your data as a requirement of the Irish Health Research Regulations.

¹ The European General Data Protection Regulation (GDPR)

² Article 9(2)(j)

³ Article 6(1)(e)

What are my rights?

You are entitled to:

- The right to access your data and receive a copy of it
- The right to restrict or object to processing of your data
- The right to object to any further processing of the information we hold about you (except where it is de-identified)
- The right to have inaccurate information about you corrected or deleted
- The right to receive your data in a portable format and to have it transferred to another data controller
- The right to request deletion of your data

By law you can exercise these rights in relation to your personal data, unless the request would make it impossible or very difficult to conduct the research.

You can exercise these rights by contacting your study researcher at ataylor@olh.ie or the Data Protection Officer, Our Lady's Hospice & Care Services (OLH&CS), Harold's Cross, Dublin, Ireland, Email: OLHDPO@ambitcompliance.ie, Website: <https://olh.ie/data-protection-privacy-notice/>

If you are unhappy with how your data has been processed, and you have raised this concern with OLH, you can lodge a complaint with the Data Protection Commission in Ireland or the local data protection authority in your country of residence.

Part 3 – Cost, Funding and Approval

Has this study been approved by a research ethics committee?

Yes, this study has been approved by St James's Hospital/Tallaght University Hospital Joint Research Ethics Committee.

Who is organising and funding this study? Will the results be used for commercial purposes?

This study is organised by Principal Investigator Professor Andrew Davies and funded by Professor Andrew Davies' Research Fund. The results will not be used for commercial purposes.

Is there any payment for taking part? Will it cost me anything if I agree to take part?

No, we are not paying individuals to take part in the study.

Part 4 – Future Research

Will my personal data be used in future studies?

If you agree, the information we collect for this study may be provided to researchers running related research studies. This may be in this organisation, or other organisations, including universities, or healthcare institutions involved in research. Your information will only be used for research relating to the terminologies used to describe individuals who use healthcare services. Any information shared for future research will not identify you and cannot be used to contact you. The information will only be used for the purpose of research.

Part 5 – Further Information

Who should I contact for information or complaints?

If you have any concerns or questions, you can contact:

- Principal Investigator: Professor Andrew Davies, Professor of Palliative Medicine, Our Lady's Hospice & Care Services, Harold's Cross, Dublin. Email: researchteam@olh.ie
- Co-investigator: Dr Amy Taylor, Clinical Research Fellow, Our Lady's Hospice & Care Services, Harold's Cross, Dublin. Email: ataylor@olh.ie
- Data Protection Officer: Patricia Pierce, Data Protection Officer, Our Lady's Hospice & Care Services, Harold's Cross, Dublin. Email: OLHDPO@ambitcompliance.ie

Under GDPR, if you are not satisfied with how your data is being processed, you have the right to lodge a complaint with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland. Website: www.dataprotection.ie.

**Thank you for reading this information sheet,
and for considering taking part in this research.**

CONSENT FORM

POST: Palliative care and Oncology Survey on Terminology

What do individuals known to palliative care and oncology services think about the terminology used to describe them?

Centre ID:

Identification Number for study:

To be completed by the **PARTICIPANT**:

There are 3 sections in this form. Each section has a statement and asks you to tick "Yes" or "No". The end of this form is for the researchers to complete.

Please ask any questions you may have when reading each of the statements.

Please tick "Yes" if you agree with the statement.

Thank you for participating.

General

I confirm that I have read and understood the Information Leaflet for the above study and the information within the leaflet has been fully explained to me.	YES ☐	NO ☐
I have had the opportunity to discuss the study, ask questions about the study and I have received satisfactory answers to all my questions.	YES ☐	NO ☐
I understand that the study is entirely voluntary and, if I decide that I do not want to take part, I can stop taking part in this study at any time without giving a reason. I understand that not taking part will not affect my future medical care.	YES ☐	NO ☐
I understand that medical notes and records may be looked at by my Study Doctor and his/her study team at St James's Hospital or Our Lady's Hospice & Care Services where it is relevant to do research. I agree that these individuals can access my medical records. I understand that all information will be kept private and confidential and that my name will not be disclosed.	YES ☐	NO ☐
I also agree to allow non-medical researchers to access my medical records and understand that my data will be kept confidential and that my name will not be disclosed.	YES ☐	NO ☐
I understand that I will not be paid for taking part in the study.	YES ☐	NO ☐
<i>I know how to contact the research team if I need to.</i>	YES ☐	NO ☐
I agree to be contacted by researchers by phone or video conference if I choose to take part in the study in this way.	YES ☐	NO ☐
I consent to take part in this research study having been fully informed of the risks, benefits and purpose of the study as set out in the Information Leaflet which I have been provided with.	YES ☐	NO ☐
I understand that there are no direct benefits to me from participating in this study. I understand that results from analysis of my personal information will not be given to me.	YES ☐	NO ☐

Data Protection		
I agree to allow personal information about me to be shared with third parties including academic research services / institutions for the purposes of completing the research as laid out in this information leaflet.	YES ☐	NO ☐
I understand that my personal data may be transferred outside the EEA and that the protections of my data in these countries is not equivalent to the data protection in Ireland. I understand the researchers will protect my data using all available resources.	YES ☐	NO ☐
I give my explicit consent to have my data processed as part of this research study.	YES ☐	NO ☐
Future Use of Information		
I give permission for my personal information to be stored for <i>possible future research related</i> to the current study on the terminologies used to describe individuals known to healthcare services <i>without further consent</i> being required but only if the research is approved by a Research Ethics Committee.	YES ☐	NO ☐
I understand <i>I will not be paid for any</i> future use of my personal information or products derived from it.	YES ☐	NO ☐

Participant's Name (Block Capitals):	
Participant's Signature:	
Date:	

To be completed by the **RESEARCHER**:

I have fully explained the purpose and nature (including benefits and risks) of this study to the participant in a way that he/she could understand. I have invited him/her to ask questions on any aspect of the study.	YES ☐	NO ☐
I confirm that I have given a copy of the information leaflet and consent form to the participant.	YES ☐	NO ☐

Researcher's Name (Block Capitals):	
Researcher's Title & Qualifications:	
Researcher's Signature:	
Date:	

2 copies to be made: 1 for patient, 1 for PI.

Appendix 7: POST study approval letters

a) St James's Hospital / Tallaght University Hospital Joint Research Ethics Committee



Project ID: 3602

Dr Amy Taylor ,
Our Lady's Hospice and Care Services/Trinity College Dublin

Andrew Davies, Our Lady's Hospice & Care Services

Approval Date: 4 December 2023

Submission Number: 3186

Submission Title: POST: Palliative care and Oncology Survey on Terminology
Submission Date: 17.Nov.2023 11:25

Dear Dr Taylor ,

On behalf of the Chair and members of the SJH/TUH Joint Research Ethics Committee I wish to inform you that your study has received **FULL APPROVAL**. Your study can now proceed.

The following documents were reviewed and approved:

Document Type	File Name	Date	Version
Principle Investigator C.V.	Summary CV Professor Andrew Davies	29.Mar.2023	1
Data Collection Case Report Form	Appendices 3 and 4 CRF Group 1 and Group 2 Ireland v2	25.Jul.2023	2
Survey/Questionnaire	Appendices 3 and 4 CRF Group 1 and Group 2 Ireland v2	25.Jul.2023	2
Telephone Script	Appendix 5 Telephone Script for Researcher	25.Jul.2023	1
Participant Information Leaflet	Appendix 1 Participant Information Leaflet Ireland v2	01.Aug.2023	2

Document Type	File Name	Date	Version
Participant Consent Form	Appendix 2 Consent Form Ireland v2	01.Aug.2023	2
Default	POST Study Protocol Ireland v2	01.Aug.2023	2
Default	Resubmission response to letter with comments	10.Aug.2023	1
Default	Clinical Indemnity Scheme Certificate	11.Aug.2023	1
Default	Response to provisional approval letter 141123	14.Nov.2023	1

Please note that ethical approval for this study is only active under the following conditions:

- 1. Applicants must submit an annual report for ongoing projects.*
- 2. Applicants must submit an end of study declaration/end of study report upon completion of the study.*
- 3. All adverse events must be reported to the JREC.*
- 4. All changes (minor and substantial) to documentation/study must be submitted to the JREC using the amendment request form and the changes must be tracked/highlighted clearly. Approval from the JREC is required before implementation of the changes.*

It is the responsibility of the researcher/research team to ensure all aspects of the study are executed in compliance with the General Data Protection regulation (GDPR), Health Research Regulations and the Data Protection Act 2018.

Yours sincerely,

Dr Sadhbh O'Neill

Research Ethics & Clinical Trials Manager,

SJH/TUH Joint Research Ethics Committee

The SJH/TUH Joint Research and Ethics Committee operates in compliance with and is constituted in accordance with the European Communities (Clinical Trials on Medicinal Products for Human Use) Regulations 2004 & ICH GCP guidelines.

b) *The Research Ethics Committee of St. Vincent's Healthcare Group*



St. Vincent's University Hospital
Elm Park, Dublin 4, Ireland

T +353 1 221 4000
www.stvincents.ie

Professor Andrew Davies
Palliative Medicine
Our Lady's Hospice and Care Services
Harold's Cross
Dublin 6W.

15th September 2023

Ref No: RS23-058

Study Title: Palliative care and Oncology Survey on Terminology

What do individuals known to palliative care and oncology services think about the terminology used to describe them?

Documents: Amy Taylor GCP Certificate; Amy Taylor PIL-Combined-with-Data-Confidentiality-Agreement-2022 v1; Amy Taylor Research-Study-Checklist-Declaration-Signatory-v1; Amy Taylor SVHG-Research-Study-Registration-Form-2022; Andrew Davies GCP Certificate; Appendices 3 and 4 CRF Group 1 and Group 2 Ireland v1; Amy Taylor POST Study Protocol Ireland v2; Amy Taylor Standard-REC-Application-Form v2; Appendices 3 and 4 CRF Group 1 and Group 2 Ireland v1; Appendix 1 Participant Information Leaflet Ireland v2; Appendix 2 Consent Form Ireland v2; Appendix 5 Telephone Script for Researcher v1

Dear Professor Andrew Davies,

Following review of the responses and clarifications received, this study has been granted full Ethics approval.

Please note, it is the responsibility of the Principal Investigator to retain full file copies of all documentation submitted and received in respect of this application.

Yours sincerely,

Professor Carel Le Roux
Chairperson
SVHG Research Ethics Committee



St. Vincent's Healthcare Group Board of Directors: Chairman: Mr. James Menton, Dr. David Brophy, Mr. John Compton, Mr. Gerard Flood, Prof. Michael Keane, Mr. Myles Lee, Ms. Sharen McCabe, Prof. Patrick Murray, Mr. Frank O'Riordan, Mr. William Shannon.
Registered in Dublin, Ireland. Company Registration No: 338585. CHY No: 14187.
Registered Office: Elm Park, Dublin 4.

c) *Our Lady's Hospice & Care Services Education and Research Committee*



04/10/2023

Dear Amy Taylor,

Re: "POST: Palliative care and Oncology Survey on Terminology - What do individuals known to palliative care and oncology services think about the terminology used to describe them?"

On behalf of the Education and Research Committee, I would like to thank you for submitting the above proposal. I can confirm that the Committee is satisfied with your submission and has given approval for your proposal.

A copy of your completed project should be submitted to the E&R Committee and the Library at Our Lady's Hospice & Care Services on completion. You will also need to complete yearly and end-of-study Report's.

We wish you the very best of luck with your research.

Yours sincerely,

Mary Flanagan, Interim CEO,
OLHC&CS

Professor Andrew Davies,
Professor of Palliative Medicine,
OLHC&CS

Our Lady's Hospice
& Care Services
Harold's Cross,
D6W RY72

www.olh.ie/education-research



*Respite
Rehabilitation
Reassurance*

Founded in 1879 by Religious Sisters of Charity

For list of Company Directors please refer to our website: www.olh.ie (About Us/Governance)
Our Lady's Hospice Ltd operating as Our Lady's Hospice & Care Services. Company Registration No. 352404. Charity Registration No. CHY1144

(This paper is not to be used for prescription purposes.)

d) Clinical Research Ethics Committee of the Cork Teaching Hospitals

COISTE EITICE UM THAIGHDE CLINICIÚIL Clinical Research Ethics Committee of the Cork Teaching Hospitals

Tel: +353-21-4901901
Email: crec@ucc.ie

University College Cork
Lancaster Hall
6 Little Hanover Street
Cork
Ireland

CREC Review Reference Number: ECM 4 (i) 05/03/2024

Date: 27th February 2024

Professor Andrew Davies
Professor of Palliative Medicine
Education and Research Centre
Our Lady's Hospice and Care Services
Harolds Cross
Dublin

Study Title: POST Study: Palliative care and Oncology Survey on Terminology "What do individuals known to palliative care and oncology services think about the terminology used to describe them?"

Dear Professor Davies

Approval is granted to carry out the above study at:

Marymount Hospice, Cork

The following documents have been approved:

Document	Approved	Version	Date
Application Form	Yes		Signed: 6 th February 2024
Proof of Insurance (CIS)	Yes		
CV for Chief Investigator	Yes		
Study Protocol	Yes	1	2 nd February 2024
Participant Information Leaflet	Yes	1	29 th January 2024
Consent Form	Yes	1	29 th January 2024
Case Report Form Group 1	Yes	1	11 th January 2024
Case Report Form Group 2	Yes	1	11 th January 2024
Telephone Script for Researcher	Yes	1	29 th January 2024
Data Protection Impact Assessment	Yes	2	2 nd February 2024
Data Sharing Agreement	Yes	1	18 th January 2024
Garda Vetting Certificate K Dennehy	Yes		11 th October 2020

We note that the co-investigator(s) involved in this project will be:

Name	Appointment Details
Dr Karie Dennehy	Consultant in Palliative Medicine
Professor Michaela Higgins	Consultant in Medical Oncology and Clinical Professor
Dr Des McMahon	Consultant in Palliative Medicine
Dr Norma O'Leary	Consultant in Palliative Medicine
Dr Cliona Grant	Consultant in Medical Oncology
Dr Michael Cushen	Consultant in Palliative Medicine
Dr Michael Lucey	Consultant in Palliative Medicine
Dr Amy Taylor	Specialty Registrar in Palliative Medicine.

The date of this letter is the date of authorization of the study.

Please keep a copy of this signed approval letter in your study master file for audit purposes. The study must be carried out in accordance with General Data Protection Regulation and Health Research Regulation 2018/2021.

You should note that ethical approval will lapse if you do not adhere to the following conditions:

- Submission of an Annual Progress Report/Annual Renewal Survey (due annually from the date of this approval letter). ~~We would encourage you to keep note of this date as the CREC will not issue a reminder.~~
- Submit any change to study documentation (minor or major) to CREC for review and approval. Amendments must be submitted on an amendment application form and revised study documents must clearly highlight the changes and contain a new version number and date. Amendments cannot be implemented without written approval from CREC.
- Notify CREC of discontinuation of the study
- Submit an End of Trial Declaration Form and Final Study Report/Study Synopsis when the study has been completed.

Yours sincerely



Professor David Kerins
Chairman
Clinical Research Ethics Committee
of the Cork Teaching Hospitals

The Clinical Research Ethics Committee of the Cork Teaching Hospitals, UCC, is a recognised Ethics Committee under Regulation 7 of the European Communities (Clinical Trials on Medicinal Products for Human Use) Regulations 2004, and is authorised by the Department of Health and Children to carry out the ethical review of clinical trials of investigational medicinal products. The Committee is fully compliant with the Regulations as they relate to Ethics Committees and the conditions and principles of Good Clinical Practice.

e) *Health Service Executive South Eastern Area Research Ethics Committee*



Oifig Eitice Taighde
Ospidéal Ollscoile
Port Láirge
X91 ER8E

Research Ethics Office
University Hospital Waterford
Waterford
X91 ER8E

<https://www.hseresearch.ie/>

Prof. Andrew Davies
Education and Research Centre
Our Lady's Hospice and Care Services
Harold's Cross
Dublin
D6W RY72

5th June 2024

Re: "POST: Palliative care and Oncology Survey on Terminology. What do individuals known to palliative care and oncology services think about the terminology used to describe them"

Dear Prof. Davies,

The Research Ethics Committee, HSE, South East has reviewed the above named study on the meeting date of 27th May 2024 and offer a Favourable Opinion of your research study.

The following documents were reviewed in this process.

1. Research Ethics Standard Application Form V1_21.03.2024
2. Consent Form V2_30.05.2024
3. Participant Information Leaflet V2_30.05.2024
4. Survey POST
 - 4a. Survey POST CRF Group 1 (Case Report from Ireland) V1_14.02.2024
 - 4b. Survey POST CRF Group 2 (Case Report from Ireland) V1_14.02.2024
5. DPIA Screener
6. Protection Impact Assessment
7. Telephone/Video Conference Script for Researcher V1_14.02.2024
8. Data Sharing Agreement (Our Lady's Hospice & Care Services and South East Palliative Care Centre)
9. GDPR Certificates
10. C.V. of Principal Investigator – Prof. Andrew Davies
11. State Indemnity
12. Ethical Approval Letters:
 - 12a. CREC Prof. David Kerins Chairman 02.2024
 - 12b. SJH/TUH Joint Research Ethics Committee: Dr. Sadhbh O'Neill 12.2023
 - 12c. SVHG Research Ethics Committee: Prof. Carel Le Roux 09.2023
13. Declaration P.I: Prof. Andrew Davies
14. Letter to Head of Service: Dr. Brian Creedon



15. Letter of Support: Dr. Brian Creedon Lead Consultant SEPCC
16. POST Study Protocol V1_14.02.2024
17. Cover Letter (signed by co-investigator Amy Taylor)

The above application and listed documents have received a favourable opinion from an ethical perspective only. It is the responsibility of the PI/Sponsor/Data controller to ensure and monitor compliance with any relevant legislation in the site where the study is due to take place.

Should future amendments be necessary for this research, it is required that you submit an amendment request to the REC, HSE, South East. Retrospective approval for such amendments cannot be undertaken and the research team will be responsible for any changes made to the study post ethical approval.

The PI/Sponsor/Data controller is advised to conduct data protection / DPIA reviews of ongoing projects at regular intervals.

With regards to ethical oversight for the duration of your research:
A report of your research progress, a copy of your annual report and/or completed research report for this study is anticipated by HSE, REC, South East in compliance with the HSE National Framework RGMS.

We wish you every success with your research.

A handwritten signature in black ink, appearing to read 'Ruairi MacNiocaill', written over a horizontal line.

Prof. Ruairi MacNiocaill
Chairperson
Research Ethics Committee
HSE, South Eastern Area

Cc. Dr. Laura Mulqueen – South East Palliative Care Centre, Dunmore Wing,
University Hospital Waterford, Dunmore Road, Waterford.

Cc. Dr. Amy Taylor – Academic Department of Palliative Care, Education and
Research Centre, Our Lady's Hospice and Care Services, Harold's Cross, Dublin, D6W
RY72.

f) *Health Service Executive Mid-Western Area University of Limerick Hospitals
Group Research Ethics Committee*



Ospidéal na hOllscoile, Luimneach
University Hospital Limerick,

Research Directorate,
Mid-West Region.
Tel: 061 482817
nicola.moloney@hse.ie

30th September, 2024.

Dr. Michael Lucey,
Consultant in Palliative Care,
Milford Care Centre.

Re/ Protocol Title
POST - Palliative Care and Oncology Survey on Terminology. What do Individuals Known to
Palliative Care and Oncology Services think about the Terminology Used to Describe Them.
REC Ref: 0099.

Dear Dr. Lucey,

The above referenced study was presented to the Research Ethics Committee meeting on
Wednesday, 25th September, 2024. The following documents have been reviewed and approved;

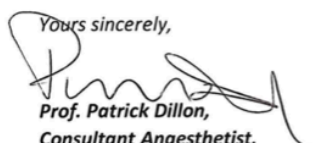
- Standard Application Form, dated 2nd August, 2024.
- Local Committee Declaration & Signatory Page, dated 15th May, 2024.
- Letter from Our Lady's Hospice and Care Service, dated 10th July, 2024.
- Letter of Support from Consultant, dated 15th May, 2024.
- Appendix 1 - Participant Information Leaflet, Version 1, dated 14th February, 2024.
- Appendix 2 - Participant Consent Form, Version 1, dated 14th February, 2024.
- Appendix 3 - Case Report Form (CRF) Ireland Group 1, Version 1, dated 14th February, 2024.
- Appendix 4 - Case Report Form (CRF) Ireland Group 2, Version 1, dated 14th February, 2024.
- Appendix 5 - Telephone Script for Researcher, Version 1, 14th February, 2024.
- Protocol, Version 1, dated 21st March, 2024.
- GDPR Certificate for overall Principal Investigator.
- GDPR Certificate for Local Principal Investigator.
- GDPR Certificates for Co-Investigator.
- Curriculum Vitae for the overall Principal Investigator.

While this letter is granting ethical approval for your study, it is also necessary that you ensure you
have local site access approval to conduct this research.

You are obliged to inform us as soon as your study is complete or if it terminates early for any reason.

It is the responsibility of the researcher/ research team to ensure all aspect of the study are executed
in compliance with the General Data Protection Regulation (GDPR) along with the Data Protection
Acts 1988- 2018 and the Health Research Regulations.

I wish you every success with your study.

Yours sincerely,

Prof. Patrick Dillon,
Consultant Anaesthetist,
Chairperson, Research Ethics Committee.

g) *Health Service Executive Midland Area Research Ethics Committee*



Reference Research Ethics Committee Midlands Area
and Corporate Division (HSE Dublin & Midlands)

E-mail: REC.B.CorporateMidlands@hse.ie

Webpage: www.hse.ie/rrecmidlands/

25th October 2024

Dr Amy Taylor
Academic Department of Palliative Medicine, Education and Research Centre
Our Lady's Hospice and Care Services
Harold's Cross
Dublin, Dublin, D6W RY72

Correspondent's email: ataylor@olh.ie

Principal Investigator: Prof. Andrew Davies, Professor of Palliative Medicine at Trinity College Dublin, University College Dublin, and Our Lady's Hospice & Care Services, Dublin

Application reference: RRECB0924AD

Study: POST: Palliative care and Oncology Survey on Terminology: What do individuals known to palliative care and oncology services think about the terminology used to describe them?

Dear Dr Taylor,

Thank you for submitting the additional information and clarifications received on October 4th 2024 requested by the RREC following its meeting on September 17th 2024. Same have been appended to your original application.

Following review of the additional information, the Committee grants a **Favourable Opinion**.

The date of this letter is the date of authorisation of your study. Please keep a copy of this letter on your master file for audit purposes. The study must be carried out in accordance with the General Data Protection Regulation and Health Research Regulation 2018/2021.

You should note that ethical approval will lapse if you do not adhere to the following conditions:

1. Submission of an Annual Progress Report/Annual Renewal Survey (due annually from the date of this approval letter). **We would encourage you to keep note of this date, as this RREC may not issue a reminder.**
2. Report unexpected adverse events, serious adverse events or any event that may affect ethical acceptability of the study.
3. Submit any change to study documentation (minor or major) to this RREC for review and approval. Please contact this RREC and we will provide you with necessary form. Amendments cannot be implemented without written approval from this RREC.
4. Notify this RREC of discontinuation of the study.
5. Submit an annual update, end of study notification, and a final report to this RREC.

We would like to take this opportunity to wish you every success with your work and we look forward to receiving your annual update.

Yours sincerely,

A handwritten signature in blue ink, appearing to read 'Una Fallon'.

Dr Úna Fallon MCRN 014313
Chairperson - RREC Midlands Area and Corporate Division (HSE Dublin & Midlands)

h) London - Surrey Research Ethics Committee



**Health Research
Authority**

London - Surrey Research Ethics Committee

2 Redman Place
Stratford
London
E20 1JQ

Telephone:
Fax:

Please note: This is an acknowledgement letter
from the REC only and does not allow you to start
your study at NHS sites in England until you
receive HRA Approval

12 October 2023

Professor Andrew Davies
Professor of Palliative Medicine
Our Lady's Hospice & Care Services
Academic Department of Palliative Medicine
Our Lady's Hospice & Care Services
Harold's Cross, Dublin 6W
D6W RY72

Dear Professor Davies

Study title:	What do individuals known to palliative care and oncology services think about the terminology used to describe them?
REC reference:	23/LO/0834
Protocol number:	3602
IRAS project ID:	328818

Thank you for your letter of 12th October 2023. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 09 October 2023

Documents received

The documents received were as follows:

Document	Version	Date
Non-validated questionnaire [Appendix 3 Case Report Form Group 1 UK v2 101023 IRAS 328818]	2	10 October 2023
Non-validated questionnaire [Appendix 4 Case Report Form Group 2 UK v2 101023 IRAS 328818]	2	10 October 2023
Other [Letter with responses to REC comments 101023 IRAS 328818]	1	10 October 2023
Participant consent form [Appendix 2 Consent Form UK v2 101023 IRAS 328818]	2	10 October 2023
Participant information sheet (PIS) [Appendix 1 Participant Information Leaflet UK v2 101023 IRAS 328818]	2	10 October 2023
Research protocol or project proposal [POST Study Protocol UK v2 101023 IRAS 328818]	2	10 October 2023

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	Version	Date
Covering letter on headed paper [Cover letter 060923 v1 IRAS 328818]	1	06 September 2023
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Confirmation of indemnity 180823 IRAS 328818]	1	18 August 2023
IRAS Application Form [IRAS_Form_18092023]		18 September 2023
Letter from funder [Funding letter 280823 v1 IRAS 328818]	1	28 August 2023
Letter from sponsor [Letter from sponsor 060923 v1 IRAS 328818]	1	06 September 2023
Non-validated questionnaire [Appendix 5 Telephone Script for Researcher v1 250723 IRAS 328818]	1	25 July 2023
Non-validated questionnaire [Appendix 3 Case Report Form Group 1 UK v2 101023 IRAS 328818]	2	10 October 2023
Non-validated questionnaire [Appendix 4 Case Report Form Group 2 UK v2 101023 IRAS 328818]	2	10 October 2023
Other [Letter with responses to REC comments 101023 IRAS 328818]	1	10 October 2023
Participant consent form [Appendix 2 Consent Form UK v2 101023 IRAS 328818]	2	10 October 2023
Participant information sheet (PIS) [Appendix 1 Participant Information Leaflet UK v2 101023 IRAS 328818]	2	10 October 2023
Research protocol or project proposal [POST Study Protocol UK v2 101023 IRAS 328818]	2	10 October 2023
Summary CV for Chief Investigator (CI) [Summary CV Chief Investigator IRAS 328818]		
Summary of any applicable exclusions to sponsor insurance (non-NHS sponsors only) [Letter from sponsor 060923 v1 IRAS 328818]	1	06 September 2023

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

IRAS Project ID: 328818	Please quote this number on all correspondence

Yours sincerely



Mr Michael Pettit
Chair

E-mail: surrey.rec@hra.nhs.uk

Copy to: Dr Amy Taylor, Our Lady's Hospice & Care Services

Lead Nation **England:** approvals@hra.nhs.uk

i) *Health and Social Care Research Ethics Committee B*



Health and Social Care Research Ethics Committee B (HSC REC B)

14 February 2024

Andrew Davies
Our Lady's Hospice & Care Services
Academic Department of Palliative Medicine, Our Lady's Hospice & Care Services, Harold's
Cross Road
Dublin
D6W RY72

Dear Dr Davies

Study title:	What do individuals known to palliative care and oncology services think about the terminology used to describe them?
REC reference:	24/NI/0006
Protocol number:	3602
IRAS project ID:	338819

Thank you for your letter of 12 February 2024, responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the [Chair](#).

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Good practice principles and responsibilities

The [UK Policy Framework for Health and Social Care Research](#) sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of [research transparency](#):

1. [registering research studies](#)
2. [reporting results](#)
3. [informing participants](#)
4. [sharing study data and tissue](#)

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the



Office for Research Ethics Committees Northern Ireland (ORECNI)
Lissue Industrial Estate West, 5 Rathdown Walk, LISBURN, BT28 2RF
Tel: (028) 95 361400 General Email: info.orecni@hscni.net

procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a public registry before the first participant is recruited and no later than six weeks after. For this purpose, 'clinical trials' are defined as:

- clinical trial of an investigational medicinal product
- clinical investigation or other study of a medical device
- combined trial of an investigational medicinal product and an investigational medical device
- other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice.

A 'public registry' means any registry on the WHO list of primary registries or the ICMJE list of registries provided the registry facilitates public access to information about the UK trial.

Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by the HRA (for more information on registration and requesting a deferral see: [Research registration and research project identifiers](#)).

Where a deferral is agreed we expect the sponsor to publish a [minimal record](#) on a publicly accessible registry. When the deferral period ends, the sponsor should publish the full record on the same registry, to fulfil the condition of the REC favourable opinion.

If you have not already included registration details in your IRAS application form you should notify the REC of the registration details as soon as possible.

Where the study is registered on ClinicalTrials.gov, please inform deferrals@hra.nhs.uk and the Research Ethics Committee (REC) which issued the final ethical opinion so that our records can be updated.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter. Where a deferral is agreed, [a minimum research summary](#) will still be published in [the research summaries database](#). At the end of the deferral period, we will publish the [full research summary](#).

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: [Research summaries - Health Research Authority \(hra.nhs.uk\)](#)

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at [Managing your approval - Health Research Authority \(hra.nhs.uk\)](https://www.hra.nhs.uk/managing-your-approval/health-research-authority)

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering letter on headed paper [Cover letter 141223 v1 IRAS 338819]	1	14 December 2023
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Confirmation of insurance 180823]	1	18 August 2023
IRAS Application Form [IRAS_Form_15122023]		15 December 2023
Letter from funder [Funding letter 280823 v1 IRAS 338819]	1	28 August 2023
Letter from sponsor [Letter from sponsor 060923 v1 IRAS 338819]	1	06 September 2023
Non-validated questionnaire [Appendix 3 CRF Group 1 UK v3 061123 IRAS 338819]	3	06 November 2023
Non-validated questionnaire [Appendix 4 CRF Group 1 UK v3 061123 IRAS 338819]	3	06 November 2023
Non-validated questionnaire [Appendix 5 Telephone Script for Researcher v2 290124 IRAS 338819]	2	29 January 2024
Other [POST 328818 REC full approval 12.10.23]	1	12 October 2023
Other [POST 328818_Letter_of_HRA_Approval_16.10.23]	1	16 October 2023
Other [Appendix 6 Distress Protocol v1 290124 IRAS 338819]	1	29 January 2024
Other [Letter with responses to comments 120224 IRAS 338819]	1	12 February 2024
Other [Summary CV Clare White Site Lead 300124]	1	30 January 2024
Other [Medical Malpractice Policy Northern Ireland Hospice]	1	07 April 2023
Other [Confirmation of liabilities Northern Ireland Hospice]	1	18 April 2023
Other [Summary CV Charlotte Leach UK Lead 090124]	1	09 January 2024
Participant consent form [Appendix 2 Consent Form UK v3 290124 IRAS 338819]	3	29 January 2024

Participant information sheet (PIS) [Appendix 1 Participant Information Leaflet UK v4 290124 IRAS 338819]	4	29 January 2024
Research protocol or project proposal [POST Study Protocol UK v5 290124 IRAS 338819]	5	29 January 2024
Summary CV for Chief Investigator (CI) [Summary CV Chief Investigator v1 010823 IRAS 338819]	1	01 August 2023
Summary of any applicable exclusions to sponsor insurance (non-NHS sponsors only) [Letter from sponsor 060923 v1 IRAS 338819]	1	14 December 2023

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: [Quality assurance - Health Research Authority \(hra.nhs.uk\)](https://www.hra.nhs.uk/quality-assurance)

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities— see details at: [Learning - Health Research Authority \(hra.nhs.uk\)](https://www.hra.nhs.uk/learning)

IRAS project ID: 338819 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

Denise Newbitt

p.p

Dr Anne Moorhead
Chair

Email: recb@hscni.net

Enclosures: "After ethical review – guidance for researchers"

Appendix 8: POST study supplementary materials

Supplementary Table S4: Participant personal characteristics – ethnicity (all categories).

	SPC group		Onc group	
<i>Ethnicity</i>	Ireland	UK	Ireland	UK
<i>Ethnicity – Ireland n (%)</i>				
White Irish	290 (93.5%)		340 (88.8%)	
White Irish Traveller	1 (0.3%)		0 (0.0%)	
Any other White background	12 (3.9%)		33 (8.6%)	
Black or Black Irish - African	4 (1.3%)		1 (0.3%)	
Black or Black Irish - another other Black background	1 (0.3%)		0 (0.0%)	
Asian or Asian Irish - Chinese	0 (0.0%)		1 (0.3%)	
Asian or Asian Irish - any other Asian background	1 (0.3%)		2 (0.5%)	
Other including mixed background	1 (0.3%)		6 (1.6%)	
<i>Ethnicity - UK (England) n (%)</i>				
White				
English/Welsh/Scottish/ Northern Irish/British		264 (88.0%)		310 (92.5%)
Irish		6 (2.0%)		3 (0.9%)
Gypsy or Irish Traveller		0 (0.0%)		0 (0.0%)
Any other White background		8 (2.7%)		7 (2.1%)
Mixed/Multiple ethnic groups				

White and Black Caribbean		0 (0.0%)		0 (0.0%)
White and Black African		2 (0.7%)		0 (0.0%)
White and Asian		0 (0.0%)		1 (0.3%)
Any other Mixed/ Multiple ethnic background		2 (0.7%)		1 (0.3%)
Asian/Asian British		0 (0.0%)		0 (0.0%)
Indian		0 (0.0%)		4 (1.2%)
Pakistani		0 (0.0%)		0 (0.0%)
Bangladeshi		1 (0.3%)		0 (0.0%)
Chinese		0 (0.0%)		1 (0.3%)
Any other Asian background		2 (0.7%)		1 (0.3%)
Black/ African/Caribbean/Black British				
African		1 (0.3%)		4 (1.2%)
Caribbean		0 (0.0%)		2 (0.6%)
Any other Black/African/Caribbean background		0 (0.0%)		0 (0.0%)
Other ethnic group				
Arab		0 (0.0%)		1 (0.3%)
Any other ethnic group		0 (0.0%)		0 (0.0%)
Ethnicity - UK (Northern Ireland) n (%)				
White		14 (4.7%)		0 (0.0%)
Irish Traveller		0 (0.0%)		0 (0.0%)
Mixed/Multiple ethnic groups				
White and Black Caribbean		0 (0.0%)		0 (0.0%)
White and Black African		0 (0.0%)		0 (0.0%)
White and Asian		0 (0.0%)		0 (0.0%)

Any other Mixed/Multiple ethnic background		0 (0.0%)		0 (0.0%)
Asian/Asian British				
Indian		0 (0.0%)		0 (0.0%)
Pakistani		0 (0.0%)		0 (0.0%)
Bangladeshi		0 (0.0%)		0 (0.0%)
Chinese		0 (0.0%)		0 (0.0%)
Any other Asian background		0 (0.0%)		0 (0.0%)
Black/African/Caribbean/Black British				
African		0 (0.0%)		0 (0.0%)
Caribbean		0 (0.0%)		0 (0.0%)
Any other Black/ African/ Caribbean background		0 (0.0%)		0 (0.0%)
Other ethnic group				
Arab		0 (0.0%)		0 (0.0%)
Any other ethnic group		0 (0.0%)		0 (0.0%)

Key: SPC = participants with cancer known to specialist palliative care services;
Onc = participants with cancer known to oncology services on anticancer treatment.

Supplementary Table S5: Perceptions of all participants towards other terms used in healthcare.

Terminology	Dislike n (%)	Neutral n (%)	Like n (%)
Patient	37 (2.8%)	642 (48.3%)	649 (48.9%)
Client	927 (69.8%)	297 (22.4%)	104 (7.8%)
Consumer	1083 (81.6%)	194 (14.6%)	51 (3.8%)
Customer	1113 (83.8%)	170 (12.8%)	45 (3.4%)
Service user	777 (58.5%)	393 (29.6%)	158 (11.9%)
Oncology patient	140 (10.5%)	514 (38.7%)	674 (50.8%)
Cancer patient	318 (23.9%)	542 (40.8%)	468 (35.2%)
Patient with cancer	302 (22.7%)	526 (39.6%)	500 (37.7%)
Person living with cancer	296 (22.3%)	479 (36.1%)	553 (41.6%)

Key: SPC =participants with cancer known to specialist palliative care services;
Onc=participants with cancer known to oncology services on anticancer treatment;
n=1328.

Supplementary Table S6: Mann-Whitney U tests to determine differences between the SPC and Onc group perspectives towards terms used to describe people with cancer in healthcare.

Term	Group	Median	Mann-Whitney U	p value
Patient	SPC	3	232632.000	0.034
	Onc	4		
Client	SPC	2	217216.500	0.788
	Onc	2		
Consumer	SPC	1	221850.500	0.640
	Onc	1		
Customer	SPC	1	230785.500	0.048
	Onc	1		
Service user	SPC	2	226456.500	0.260
	Onc	2		
Oncology patient	SPC	3	237553.500	0.005
	Onc	4		
Cancer patient	SPC	3	221535.000	0.703
	Onc	3		
Patient with cancer	SPC	3	214404.000	0.492
	Onc	3		
Person living with cancer	SPC	3	213280.500	0.396
	Onc	3		
Cancer survivor (definition)	SPC	3	236449.500	0.010
	Onc	3		
Cancer survivor (personal description)	SPC	2	253265.500	<0.001
	Onc	3		
Importance of choice of term	SPC	4	224662.000	0.394
	Onc	4		

Key: SPC = participants with cancer known to specialist palliative care services; Onc = participants with cancer known to oncology services on anticancer treatment; Total n=1328; SPC n=610; Onc n=718; shaded cell = significant after Bonferroni's correction ($\alpha=0.004$); interpretation of median values: Likert scale 1-5: 1 = strongly dislike; 2 = moderately dislike; 3 = neutral; 4 = moderately like; 5 = strongly like.

Supplementary Tables S7a-c: Bivariate analyses between participant and clinical / cancer-related characteristics and dislike of the term cancer survivor using the Chi-square test of independence.

S7a: Bivariate analyses between participant and clinical / cancer-related characteristics and dislike of the term cancer survivor using the Chi-square test of independence for all participants.

	Number of participants n (%)	Dislike being described as cancer survivor n (%)	χ^2 (dof)	<i>p-value</i>	Cramer's V	Adj. residual
Total	1328	618 (46.5%)				
Characteristic						
Group						
SPC	610 (45.9%)	321 (52.6%)	16.351 (1)	<0.001	0.112	
Onc	718 (54.1%)	297 (41.4%)				
Region						
Ireland	693 (52.2%)	385 (55.6%)	46.632 (1)	<0.001	0.189	
UK	635 (47.8%)	233 (36.7%)				
Age (years)						
<65	643 (48.4%)	306 (47.6%)	0.477 (1)	0.490	0.020	
≥65	685 (51.6%)	312 (45.5%)				
Gender						
Female	681 (51.3%)	329 (48.3%)	1.627 (1)	0.202	0.037	
Male	647 (48.7%)	289 (44.7%)				
Relationship status						
Not in a relationship	442 (33.3%)	214 (48.4%)	0.831 (1)	0.362	0.027	
Married / in a similar relationship	886 (66.7%)	404 (45.6%)				

Educational attainment						
Low	343 (25.8%)	162 (47.2%)	17.607 (2)	<0.001	0.115	0.3
Medium	400 (30.1%)	153 (38.3%)				-4.0
High	585 (44.1%)	303 (51.8%)				3.4
Ethnicity						
White Irish	630 (47.4%)	356 (56.5%)	48.184 (2)	<0.001	0.190	6.9
Other	110 (8.3%)	42 (38.2%)				-5.9
White British / similar**	588 (44.3%)	220 (37.4%)				1.8
ECOG PS						
ECOG 0-1	644 (48.6%)	268 (41.6%)	11.595 (1)	<0.001	0.095	
ECOG 2-4	681 (51.4%)	348 (51.1%)				
Anticancer treatment status / intent						
Curative-intent treatment	276 (20.8%)	110 (39.9%)	8.039 (2)	0.018	0.078	-2.5
Palliative-intent treatment	682 (51.4%)	319 (46.8%)				0.2
Not on treatment	370 (27.9%)	189 (51.1%)				2.1
Anticancer treatment type						
Chemotherapy	597 (45.0%)	261 (43.7%)	3.258 (1)	0.071	0.051	
N/A	731 (55.0%)	357 (48.8%)				
Hormone Therapy	108 (8.1%)	59 (54.6%)	2.751 (1)	0.097	0.048	
N/A	1220 (91.9%)	559 (45.8%)				
Immunotherapy	189 (14.2%)	80 (42.3%)	1.377 (1)	0.241	0.034	
N/A	1139 (85.8%)	538 (47.2%)				
Targeted Therapy	204 (15.4%)	104 (51.0%)	1.708 (1)	0.191	0.038	
N/A	1124 (84.6%)	514 (45.7%)				

Radiotherapy / Radiation Therapy	82 (6.2%)	31 (37.8%)	2.317 (1)	0.128	0.045	
N/A	1246 (93.8%)	587 (47.1%)				
Surgery	6 (0.5%)	4 (66.7%)	-	0.426*	0.027	
N/A	1322 (99.5%)	614 (46.4%)				
Cancer diagnosis						
Breast	211 (15.9%)	110 (52.1%)	12.116 (5)	0.033	0.096	1.8
Gastrointestinal	360 (27.1%)	169 (46.9%)				0.2
Lung	168 (12.7%)	86 (51.2%)				1.3
Urological	146 (11.0%)	66 (45.2%)				-0.3
Gynaecological	112 (8.4%)	57 (50.9%)				1.0
Other	331 (24.9%)	130 (39.3%)				-3.1

Key: SPC =participants with cancer known to specialist palliative care services; Onc=participants with cancer known to oncology services on anticancer treatment; ECOG PS= Eastern Cooperative Oncology Group Performance Status; CS = cancer survivor; χ^2 (dof) = Chi square test of independence (degrees of freedom); bold p value in shaded cell = significant ($p < 0.05$); Cramer's V for 2x2 tables: small=0.1, medium=0.3, large=0.50 (Cohen's criteria (434)); Cramer's V for 2x3 tables: small=0.07, medium=0.21, large=0.35 for 2x3 table (351,434); adj residual = adjusted residual, only calculated when a significant difference was observed for variables with > 2 categories: ± 1.96 significant at the 5% level (433); **p-value* generated using Fisher's exact test where assumptions of χ^2 test violated; **White English / Welsh / Scottish / Northern Irish / British.

S7b: Bivariate analyses between participant and clinical / cancer-related characteristics and dislike of the term cancer survivor using the Chi-square test of independence for SPC groups (overall and according to regional subgroup).

	SPC IE						SPC UK						SPC all					
	No. particip ants n (%)	Dislike of CS n (%)	χ^2 (dof)	<i>p</i> - <i>value</i>	Cram- er's V	Adj res	No. particip ants n (%)	Dislike of CS n (%)	χ^2 (dof)	<i>p</i> - <i>value</i>	Cram- er's V	Adj res	No. particip ants n (%)	Dislike of CS n (%)	χ^2 (dof)	<i>p</i> - <i>value</i>	Cram- er's V	Adj res
	310	183 (59.0%)					300	138 (46.0%)					610	321 (52.6%)				
Characteristic																		
Region																		
IE													310 (50.8%)	183 (59.0%)	9.870 (1)	0.002	0.130	
UK													300 (49.2%)	138 (46.0%)				
Age (years)																		
<65	114 (36.8%)	70 (61.4%)	0.278 (1)	0.598	0.037		107 (35.7%)	58 (54.2%)	4.009 (1)	0.045	0.123		221 (36.2%)	128 (57.9%)	3.572 (1)	0.059	0.080	
≥65	196 (63.2%)	113 (57.7%)					193 (64.3%)	80 (41.5%)					389 (63.8%)	193 (49.6%)				
Gender																		
Female	150 (48.4%)	96 (64.0%)	2.581 (10)	0.108	0.098		146 (48.7%)	154 (51.3%)	0.006 (1)	0.937	0.011		296 (48.5%)	164 (55.4%)	1.575 (1)	0.209	0.054	
Male	160 (51.6%)	87 (54.4%)					68 (46.6%)	70 (45.5%)					314 (51.5%)	157 (50.0%)				

Relationship status																		
Not in a relationship	133 (42.9%)	69 (37.7%)	4.423 (1)	0.035	0.126		108 (36.0%)	52 (48.1%)	0.193 (1)	0.660	0.032		241 (39.5%)	121 (50.2%)	0.779 (1)	0.377	0.039	
Married / similar	177 (57.1%)	114 (64.4%)					192 (64.0%)	86 (44.8%)					369 (60.5%)	200 (54.2%)				
Educational attainment																		
Low	136 (43.9%)	73 (53.7%)	3.895 (2)	0.143	0.112		60 (20.0%)	22 (36.7%)	13.84 3 (2)	<0.001	0.214	-1.6	196 (32.1%)	95 (48.5%)	16.26 7 (2)	<0.001	0.163	-1.4
Medium	57 (18.4%)	33 (57.9%)					128 (42.7%)	49 (38.3%)					185 (30.3%)	82 (44.3%)				-2.7
High	117 (37.7%)	77 (65.8%)					112 (37.3%)	67 (59.8%)					229 (37.5%)	144 (62.9%)				3.9
Ethnicity																		
White Irish	290 (93.5%)	170 (58.6%)	0.106 (1)	0.744	0.032								290 (47.5%)	170 (58.6%)	8.151 (2)	0.017	0.115	2.8
Other	20 (6.5%)	13 (65.0%)					22 (7.3%)	10 (45.5%)	0.000 (1)	1.000	0.003		42 (6.9%)	21 (50.0%)				-0.4
White British /similar **							278 (92.7%)	128 (46.0%)					278 (45.6%)	130 (46.8%)				-2.7
ECOG PS																		
ECOG 0-1	57 (18.4%)	26 (45.6%)	4.445 (1)	0.035	0.128		89 (29.7%)	36 (40.4%)	1.268 (1)	0.260	0.072		146 (24.0%)	62 (42.5%)	7.302 (1)	0.007	0.113	
ECOG 2-4	252 (81.6%)	156 (61.9%)					211 (70.3%)	102 (48.3%)					463 (76.0%)	258 (55.7%)				

Anticancer tx status																		
Not on tx	186 (60.0%)	106 (57.0%)	0.605 (1)	0.437	0.051		184 (61.3%)	83 (45.1%)	0.074 (1)	0.786	0.023		370 (60.7%)	189 (51.1%)	0.746 (1)	0.388	0.038	
On tx	124 (40.0%)	77 (62.1%)					116 (38.7%)	55 (47.4%)					240 (39.3%)	132 (55.0%)				
Anticancer treatment type																		
CT	61 (19.7%)	35 (57.4%)	0.022 (1)	0.882	0.017		56 (18.7%)	24 (42.9%)	0.140 (1)	0.708	0.030		117 (19.2%)	59 (50.4%)	0.182 (1)	0.670	0.021	
Not on CT	249 (80.3%)	148 (59.4%)					244 (81.3%)	114 (46.7%)					493 (80.8%)	262 (53.1%)				
HT	24 (7.7%)	17 (70.3%)	1.016 (1)	0.314	0.070		32 (10.7%)	14 (43.8%)	0.007 (1)	0.934	0.016		56 (9.2%)	31 (55.4%)	0.084 (1)	0.772	0.017	
Not on HT	286 (92.3%)	166 (58.0%)					268 (89.3%)	124 (46.3)					554 (90.8%)	290 (52.3%)				
IT	30 (9.7%)	18 (60.0%)	0.000 (1)	1.000	0.006		19 (6.3%)	11 (57.9%)	0.701 (1)	0.403	0.062		49 (8.0%)	29 (59.2%)	0.656 (1)	0.418	0.039	
Not on IT	280 (90.3%)	165 (58.9%)					281 (93.7%)	127 (45.2%)					561 (92.0%)	292 (52.0%)				
TT	34 (11.0%)	20 (58.8%)	0.000 (1)	1.000	0.001		19 (6.3%)	13 (68.4%)	3.198 (1)	0.074	0.117		53 (8.7%)	33 (62.3%)	1.761 (1)	0.184	0.060	
Not on TT	276 (89.0%)	163 (59.1%)					281 (93.7%)	125 (44.5%)					557 (91.3%)	288 (51.7%)				
RT	9 (2.9%)	5 (55.6%)	0.000	1.000 *	0.012		17 (5.7%)	6 (35.3%)	0.437 (1)	0.508	0.053		26 (4.3%)	11 (42.3%)	0.767 (1)	0.381	0.044	
Not on RT	301 (97.1%)	178 (59.1%)					283 (94.35)	132 (46.6%)					584 (95.7%)	310 (53.1%)				

Cancer diagnosis																	
Breast	40 (12.9%)	27 (67.5%)	1.715 (5)	0.887	0.074		28 (9.3%)	16 (57.1%)	7.814 (5)	0.167	0.160		68 (11.1%)	43 (63.2%)	6.363 (5)	0.272	0.102
GI	97 (31.3%)	56 (57.7%)					80 (26.7%)	35 (43.8%)					177 (29.0%)	91 (51.4%)			
Lung	70 (22.6%)	40 (57.1%)					49 (16.3%)	25 (51.0%)					119 (19.5%)	65 (54.6%)			
Urol	24 (7.7%)	13 (53.2%)					53 (17.7%)	28 (52.8%)					77 (12.6%)	41 (53.2%)			
GYN	33 (10.6%)	19 (57.6%)					26 (8.7%)	13 (50.0%)					59 (9.7%)	32 (54.2%)			
Other	46 (14.8%)	28 (60.9%)					64 (21.3%)	21 (32.8%)					110 (18.0%)	49 (44.5%)			

Key: SPC =participants with cancer known to specialist palliative care services; CS = cancer survivor; IE=Ireland; UK=United Kingdom; ECOG PS= Eastern Cooperative Oncology Group Performance Status; tx = treatment; CT = chemotherapy; HT = hormone therapy; IT = immunotherapy; TT = targeted therapy; RT = radiotherapy / radiation therapy; GI = gastrointestinal; Urol = urological; GYN = gynaecological; χ^2 (dof) = Chi square test of independence (degrees of freedom); bold p value in shaded cell = significant ($p < .05$); Cramer's V for 2x2 tables: small=0.1, medium=0.3, large=0.50 (Cohen's criteria (434)); Cramer's V for 2x3 tables: small=0.07, medium=0.21, large=0.35 for 2x3 table (351,434); adj res = adjusted residual, only calculated when a significant difference was observed for variables with > 2 categories: ± 1.96 significant at the 5% level (433); **p-value* generated using Fisher's exact test where assumptions of χ^2 test violated; **White English / Welsh / Scottish / Northern Irish / British.

S7c: Bivariate analyses between participant and clinical / cancer-related characteristics and dislike of the term cancer survivor using the Chi-square test of independence for SPC groups (overall and according to regional subgroup).

	Onc IE						Onc UK						Onc all					
	No. particip ants n (%)	Dislike of CS n (%)	χ^2 (dof)	<i>p</i> - <i>value</i>	Cram- er's V	Adj res	No. particip ants n (%)	Dislike of CS n (%)	χ^2 (dof)	<i>p</i> - <i>value</i>	Cram- er's V	Adj res	No. particip ants n (%)	Dislike of CS n (%)	χ^2 (dof)	<i>p</i> - <i>value</i>	Cram- er's V	Adj res
	383	202 (52.7%)					335	95 (28.4%)					718	297 (41.4%)				
Characteristic																		
Region																		
IE													383 (53.3%)	202 (52.7%)	42.805 (1)	<0.00 1	0.247	
UK													335 (46.7%)	95 (28.4%)				
Age (years)																		
<65	257 (67.1%)	130 (50.6%)	1.208 (1)	0.272	0.062		165 (49.3%)	170 (50.7%)	0.300 (1)	0.864	0.016		422 (58.8%)	178 (42.2%)	0.205 (1)	0.651	0.020	
≥65	126 (32.9%)	72 (57.1%)					48 (29.1%)	47 (27.6%)					296 (41.2%)	119 (40.1%)				
Gender																		
Female	221 (57.7%)	117 (52.9%)	0.000	1.000	0.005		164 (49.0%)	48 (29.3%)	0.058 (1)	0.810	0.020		385 (53.6%)	165 (42.9%)	0.635 (1)	0.425	0.033	
Male	162 (42.3%)	85 (52.5%)					171 (51.0%)	47 (27.5%)					333 (46.4%)	132 (39.6%)				

Relationship status																			
Not in a relation-ship	112 (29.2%)	67 (59.8%)	2.794	0.095	0.091		89 (26.6%)	26 (29.2%)	0.005 (10)	0.943	0.011		201 (28.0%)	93 (46.3%)	2.494 (1)	0.114	0.062		
Married / similar	271 (70.8%)	135 (49.8%)					246 (74.4%)	69 (28.0%)					517 (72.0%)	204 (39.5%)					
Educational attainment																			
Low	109 (28.5%)	62 (56.9%)	1.299 (2)	0.522	0.058		38 (11.3%)	5 (13.2%)	10.73 2 (2)	0.005	0.174	-2.2	147 (20.5%)	67 (45.6%)	8.978 (2)	0.011	0.111	1.2	
Med-ium	80 (20.9%)	39 (48.8%)					135 (40.3%)	32 (23.7%)					-1.6	215 (29.9%)				71 (33.0%)	-3.0
High	194 (50.7%)	101 (52.7%)					162 (48.4%)	58 (35.8%)					2.9	356 (49.6%)				159 (44.7%)	1.8
Ethnicity																			
White Irish	340 (88.8%)	186 (54.7%)	4.013 (1)	0.045	0.111								340 (47.4%)	186 (54.7%)	47.931 (2)	<0.001	0.257	6.9	
Other	43 (11.2%)	16 (37.2%)					25 (7.5%)	5 (20.0%)	0.538 (1)	0.463	0.053		68 (9.5%)	21 (30.9%)				-1.8	
White British / similar **							310 (92.5%)	90 (29.0%)						310 (43.2%)	90 (29.0%)	-5.8			
ECOG PS																			
ECOG 0/1	275 (71.8%)	137 (49.8%)	2.941	0.086	0.093		223 (67.0%)	69 (30.9%)	2.065 (1)	0.151	0.086		498 (69.6%)	206 (41.4%)	0.000 (1)	1.000	0.001		
ECOG 2-4	108 (28.2%)	65 (60.2%)					110 (33.0%)	25 (22.7%)					218 (30.4%)	90 (41.3%)					

Anticancer treatment intent																		
Cur	164 (42.8%)	79 (48.2%)	2.094	0.148	0.079		105 (31.3%)	28 (26.7%)	0.111 (1)	0.739	0.025		269 (37.5%)	107 (39.8%)	0.349 (1)	0.555	0.025	
Pall	219 (57.2%)	123 (56.2%)					230 (68.7%)	67 (29.1%)					449 (62.5%)	190 (42.3%)				
Anticancer treatment type																		
CT	242 (63.2%)	131 (54.1%)	0.370 (1)	0.543	0.036		238 (71.0%)	71 (29.8%)	0.646 (1)	0.422	0.051		480 (66.9%)	202 (42/1%)	0.225 (1)	0.635	0.021	
Not on CT	141 (36.8%)	71 (50.4%)					97 (29.0%)	24 (24.7%)					238 (33.1%)	95 (39.9%)				
HT	38 (9.9%)	21 (55.3%)	0.025 (1)	0.875	0.017		14 (4.2%)	7 (50.0%)	2.348 (1)	0.076 *	0.100		52 (7.2%)	28 (53.8%)	3.067 (1)	0.080	0.071	
Not on HT	345 (90.1%)	181 (52.5%)					321 (95.8%)	88 (27.4%)					666 (92.8%)	269 (40.4%)				
IT	75 (19.6%)	38 (50.7%)	0.074 (1)	0.785	0.021		65 (19.4%)	13 (20.0%)	2.286 (1)	0.131	0.091		140 (19.5%)	51 (36.4%)	1.504 (1)	0.220	0.049	
Not on IT	308 (80.4%)	164 (53.2%)					270 (80.6%)	82 (30.4%)					578 (80.5%)	246 (42.6%)				
TTT	111 (29.0%)	57 (51.4%)	0.055 (1)	0.814	0.018		40 (11.9%)	14 (35.0%)	0.650 (1)	0.420	0.054		151 (21.0%)	71 (47.0%)	2.234 (1)	0.135	0.059	
Not in TT	272 (71.0%)	145 (53.3%)					295 (88.1%)	81 (27.5%)					567 (79.0%)	226 (39.9%)				
RT	16 (4.2%)	10 (62.5%)	0.295 (1)	0.587	0.041		40 (11.9%)	10 (25.0%)	0.099 (1)	0.753	0.027		56 (7.8%)	20 (35.7%)	0.567 (1)	0.452	0.033	
Not on RT	367 (95.8%)	192 (52.3%)					295 (88.1%)	85 (28.8%)					662 (92.2%)	277 (41.8%)				

Cancer diagnosis																	
Breast	121 (31.6%)	59 (48.8%)	1.875 (5)	0.866	0.070		22 (6.6%)	8 (36.4%)	7.578 (5)	0.181	0.150		143 (19.9%)	67 (46.9%)	5.450 (5)	0.362	0.087
GI	85 (22.2%)	45 (52.9%)					98 (29.3%)	33 (33.7%)					183 (25.5%)	78 (42.6%)			
Lung	23 (6.0%)	14 (60.9%)					26 (7.8%)	7 (26.9%)					49 (6.8%)	21 (42.9%)			
Urol	31 (8.1%)	18 (58.1%)					38 (11.3%)	12 (18.4%)					69 (9.6%)	25 (36.2%)			
GYN	23 (6.0%)	13 (56.5%)					30 (9.05)	12 (40.0%)					53 (7.4%)	25 (47.2%)			
Other	100 (26.1%)	53 (53.0%)					121 (36.1%)	28 (23.1%)					221 (30.8%)	81 (36.7%)			

Key: Onc=participants with cancer known to oncology services on anticancer treatment; CS = cancer survivor; IE=Ireland; UK=United Kingdom; ECOG PS= Eastern Cooperative Oncology Group Performance Status;; Cur = curative; Pall = palliative; CT = chemotherapy; HT = hormone therapy; IT = immunotherapy; TT = targeted therapy; RT = radiotherapy / radiation therapy; GI = gastrointestinal; Urol = urological; GYN = gynaecological; χ^2 (dof) = Chi square test of independence (degrees of freedom); bold p value in shaded cell = significant ($p < 0.05$); Cramer's V for 2x2 tables: small=0.1, medium=0.3, large=0.50 (Cohen's criteria (434)); Cramer's V for 2x3 tables: small=0.07, medium=0.21, large=0.35 for 2x3 table (351,434); adj res = adjusted residual , only calculated when a significant difference was observed for variables with > 2 categories: ± 1.96 significant at the 5% level (433); **p-value* generated using Fisher's exact test where assumptions of χ^2 test violated; **White English / Welsh / Scottish / Northern Irish / British.

Supplementary Tables S8a-g: Correlation matrices of independent variables using Cramer's V outputs from the Chi-square test of independence.

S8a: Correlation matrices of independent variables (data for all participants, n=1328)

A) Personal characteristics

Characteristic	Region	Gender	Age	Relationship status	Educational attainment	Ethnicity
Region	-	0.047	0.107	0.046	0.278	0.959
Gender	0.047	-	0.127	0.116	0.046	0.070
Age	0.107	0.127	-	0.051	0.210	0.144
Relationship status	0.046	0.116	0.051	-	0.060	0.053
Educational attainment	0.278	0.046	0.210	0.060	-	0.228
Ethnicity	0.959	0.070	0.144	0.053	0.228	-

B) Clinical and cancer-related characteristics

Characteristic	Group status	ECOG status	Cancer type	Treatment status	Chemo-therapy	Hormone therapy	Immuno-therapy	Targeted therapy	Radio-therapy
Group status	-	0.454	0.254	0.717	0.478	0.035	0.164	0.171	0.073
ECOG status	0.454	-	0.189	0.437	0.285	0.064	0.126	0.121	0.030
Cancer type	0.254	0.189	-	0.242	0.214	0.394	0.248	0.285	0.079
Treatment status	0.717	0.437	0.242	-	0.587	0.188	0.293	0.282	0.180
Chemo-therapy	0.478	0.285	0.214	0.587	-	0.225	0.125	0.095	0.013
Hormone therapy	0.035	0.064	0.394	0.188	0.225	-	0.090	0.064	0.008
Immuno-therapy	0.164	0.126	0.248	0.293	0.125	0.090	-	0.066	0.033
Targeted therapy	0.171	0.121	0.285	0.282	0.095	0.064	0.066	-	0.075
Radiotherapy	0.073	0.030	0.079	0.180	0.013	0.008	0.033	0.075	-

Key: ECOG PS = Eastern Cooperative Oncology Group Performance Status; shaded cell = strong correlation (Cramer's V >0.5 (434)).

S8b: Correlation matrices of independent variables (data for participants in the SPC Ireland group, n=310)

A) Personal characteristics

Characteristic	Gender	Age	Relationship status	Educational attainment	Ethnicity
Gender	-	0.078	0.074	0.128	0.018
Age	0.078	-	0.120	0.198	0.072
Relationship status	0.074	0.120	-	0.125	0.091
Educational attainment	0.128	0.198	0.125	-	0.182
Ethnicity	0.018	0.072	0.091	0.182	-

B) Clinical and cancer-related characteristics

Characteristic	ECOG PS	Cancer type	Treatment status	Chemo-therapy	Hormone therapy	Immuno-therapy	Targeted therapy	Radio-therapy
ECOG PS	-	0.075	0.240	0.141	0.080	0.069	0.206	0.017
Cancer type	0.075	-	0.307	0.174	0.507	0.274	0.279	0.156
Treatment status	0.240	0.307	-	0.606	0.355	0.401	0.430	0.212
Chemotherapy	0.141	0.174	0.606	-	0.113	0.222	0.06	0.011
Hormone therapy	0.080	0.507	0.355	0.113	-	0.054	0.169	0.022
Immuno- therapy	0.069	0.274	0.401	0.222	0.054	-	0.08	0.073
Targeted therapy	0.206	0.279	0.430	0.06	0.169	0.08	-	0.061
Radiotherapy	0.017	0.156	0.212	0.011	0.022	0.073	0.061	-

Key: ECOG PS = Eastern Cooperative Oncology Group Performance Status; shaded cell = strong correlation (Cramer's V >0.5 (434)).

S8c: Correlation matrices of independent variables (data for participants in the SPC UK group, n=300)

A) Personal characteristics

Characteristic	Gender	Age	Relationship status	Educational attainment	Ethnicity
Gender	-	0.124	0.159	0.099	0.008
Age	0.124	-	0.050	0.275	0.084
Relationship status	0.159	0.050	-	0.065	0.082
Educational attainment	0.099	0.275	0.065	-	0.076
Ethnicity	0.008	0.084	0.082	0.076	-

B) Clinical and cancer-related characteristics

Characteristic	ECOG PS	Cancer type	Treatment status	Chemo-therapy	Hormone therapy	Immuno-therapy	Targeted therapy	Radio-therapy
ECOG PS	-	0.163	0.279	0.269	0.059	0.191	0.101	0.064
Cancer type	0.163	-	0.344	0.192	0.461	0.202	0.360	0.103
Treatment status	0.279	0.344	-	0.603	0.435	0.327	0.327	0.309
Chemotherapy	0.269	0.192	0.603	-	0.082	0.019	0.016	0.031
Hormone therapy	0.059	0.461	0.435	0.082	-	0.046	0.087	0.009
Immuno-therapy	0.191	0.202	0.327	0.019	0.046	-	0.213	0.005
Targeted therapy	0.101	0.36	0.327	0.016	0.087	0.213	-	0.055
Radiotherapy	0.064	0.103	0.309	0.031	0.009	0.005	0.055	-

Key: ECOG PS = Eastern Cooperative Oncology Group Performance Status; shaded cell = strong correlation (Cramer's V >0.5 (434)).

S8d: Correlation matrices of independent variables (data for all participants in the SPC group, n=610)

A) Personal characteristics

Characteristic	Region	Gender	Age	Relationship status	Educational attainment	Ethnicity
Region	-	0.003	0.012	0.071	0.305	0.965
Gender	0.003	-	0.101	0.114	0.002	0.009
Age	0.012	0.101	-	0.037	0.199	0.079
Relationship status	0.071	0.114	0.037	-	0.105	0.073
Educational attainment	0.305	0.002	0.199	0.105	-	0.231
Ethnicity	0.965	0.009	0.079	0.073	0.231	-

B) Clinical and cancer-related characteristics

Characteristic	ECOG PS	Cancer type	Treatment status	Chemotherapy	Hormone therapy	Immuno-therapy	Targeted therapy	Radio-therapy
ECOG PS	-	0.098	0.256	0.205	0.074	0.117	0.14	0.023
Cancer type	0.098	-	0.292	0.098	0.454	0.213	0.293	0.090
Treatment status	0.256	0.292	-	0.605	0.395	0.367	0.383	0.262
Chemotherapy	0.205	0.098	0.605	-	0.097	0.116	0.042	0.021
Hormone therapy	0.074	0.454	0.395	0.097	-	0.052	0.124	0.017
Immuno-therapy	0.117	0.213	0.367	0.116	0.052	-	0.037	0.027
Targeted therapy	0.14	0.293	0.383	0.042	0.124	0.037	-	0.007
Radiotherapy	0.023	0.090	0.262	0.021	0.017	0.027	0.007	-

Key: ECOG PS = Eastern Cooperative Oncology Group Performance Status; shaded cell = strong correlation (Cramer's V >0.5 (434)).

S8e: Correlation matrices of independent variables (data for participants in the Onc Ireland group, n=383)

A) Personal characteristics

Characteristic	Gender	Age	Relationship status	Educational attainment	Ethnicity
Gender	-	0.154	0.121	0.132	0.070
Age	0.154	-	0.039	0.249	0.126
Relationship status	0.121	0.039	-	0.072	0.101
Educational attainment	0.132	0.249	0.072	-	0.173
Ethnicity	0.070	0.126	0.101	0.173	-

B) Clinical and cancer-related characteristics

Characteristic	ECOG PS	Cancer type	Treatment status	Chemo-therapy	Hormone therapy	Immuno-therapy	Targeted therapy	Radio-therapy
ECOG PS	-	0.231	0.132	0.045	0.130	0.017	0.009	0.015
Cancer type	0.231	-	0.408	0.465	0.358	0.393	0.283	0.139
Treatment status	0.132	0.408	-	0.234	0.083	0.174	0.122	0.109
Chemotherapy	0.045	0.465	0.234	-	0.417	0.401	0.276	0.024
Hormone therapy	0.130	0.358	0.083	0.417	-	0.164	0.038	0.018
Immuno-therapy	0.017	0.393	0.174	0.401	0.164	-	0.185	0.103
Targeted therapy	0.009	0.283	0.122	0.276	0.038	0.185	-	0.105
Radiotherapy	0.015	0.139	0.109	0.024	0.018	0.103	0.105	-

Key: ECOG PS = Eastern Cooperative Oncology Group Performance Status; shaded cell = strong correlation (Cramer's V >0.5 (434)).

S8f: Correlation matrices of independent variables (data for participants in the Onc Ireland group, n=335)

A) Personal characteristics

Characteristic	Gender	Age	Relationship status	Educational attainment	Ethnicity
Gender	-	0.086	0.141	0.051	0.085
Age	0.086	-	0.002	0.159	0.084
Relationship status	0.141	0.002	-	0.073	0.035
Educational attainment	0.051	0.159	0.073	-	0.205
Ethnicity	0.085	0.084	0.035	0.205	-

B) Clinical and cancer-related characteristics

Characteristic	ECOG PS	Cancer type	Treatment status	Chemo-therapy	Hormone therapy	Immuno-therapy	Targeted therapy	Radio-therapy
ECOG PS	-	0.194	0.074	0.084	0.052	0.040	0.015	0.173
Cancer type	0.194	-	0.238	0.306	0.302	0.301	0.139	0.125
Treatment status	0.074	0.238	-	0.162	0.012	0.201	0.169	0.168
Chemotherapy	0.084	0.306	0.162	-	0.228	0.419	0.394	0.130
Hormone therapy	0.052	0.302	0.012	0.228	-	0.027	0.031	0.031
Immuno-therapy	0.040	0.301	0.201	0.419	0.027	-	0.111	0.064
Targeted therapy	0.015	0.139	0.169	0.394	0.031	0.111	-	0.107
Radiotherapy	0.173	0.125	0.168	0.130	0.031	0.064	0.107	-

Key: ECOG PS = Eastern Cooperative Oncology Group Performance Status; shaded cell = strong correlation (Cramer's V >0.5 (434)).

S8g: Correlation matrices of independent variables (data for participants in the Onc group, n=718)

A) Personal characteristics

Characteristic	Region	Gender	Age	Relationship status	Educational attainment	Ethnicity
Region	-	0.088	0.181	0.030	0.259	0.955
Gender	0.088	-	0.135	0.132	0.074	0.116
Age	0.181	0.135	-	0.013	0.175	0.201
Relationship status	0.030	0.132	0.013	-	0.025	0.066
Educational attainment	0.259	0.074	0.175	0.025	-	0.229
Ethnicity	0.955	0.116	0.201	0.066	0.229	-

B) Clinical and cancer-related characteristics

Characteristic	ECOG PS	Cancer type	Treatment status	Chemo-therapy	Hormone therapy	Immuno-therapy	Targeted therapy	Radio-therapy
ECOG PS	-	0.157	0.110	0.010	0.103	0.028	0.000	0.101
Cancer type	0.157	-	0.284	0.377	0.351	0.344	0.260	0.131
Treatment status	0.110	0.284	-	0.191	0.061	0.185	0.110	0.118
Chemotherapy	0.010	0.377	0.191	-	0.351	0.408	0.326	0.049
Hormone therapy	0.103	0.351	0.061	0.351	-	0.110	0.040	0.021
Immuno-therapy	0.028	0.344	0.185	0.408	0.110	-	0.150	0.078
Targeted therapy	0.000	0.260	0.110	0.326	0.040	0.150	-	0.125
Radiotherapy	0.101	0.131	0.118	0.049	0.021	0.078	0.125	-

Key: ECOG PS = Eastern Cooperative Oncology Group Performance Status; shaded cell = strong correlation (Cramer's V >0.5 (434)).

Supplementary Table S9: Variance inflation factors for variables in Models A and B according to group analysis.

Characteristic	All data	SPC			Onc		
		Ireland	UK	All	Ireland	UK	All
Model A: Personal characteristics							
Region	1.114	-	-	1.111	-	-	1.129
Age	1.073	1.064	1.109	1.058	1.095	1.037	1.095
Gender	1.005	1.028	1.053	1.025	1.053	1.037	1.045
Relationship status	1.008	1.051	1.034	1.030	1.037	1.028	1.021
Educational attainment (med)	1.692	1.224	1.882	1.536	1.433	2.767	1.895
Educational attainment (high)	1.642	1.232	1.955	1.455	1.512	2.848	1.853
Ethnicity	-	1.053	1.010		1.054	1.056	-
Model B: Clinical / cancer-related characteristics							
Group (SPC/Onc)	1.315						
ECOG PS	1.275	1.068	1.121	1.082	1.085	1.104	1.061
Cancer type							
Gastrointestinal	2.002	2.512	3.044	2.734	1.611	4.157	2.019
Lung	1.653	2.146	2.430	2.263	1.478	2.176	1.535
Urological	1.535	1.486	2.436	1.877	1.455	2.516	1.552
Gynaecological	1.416	1.700	1.781	1.726	1.208	2.257	1.373
Other	1.937	1.838	2.647	2.171	2.075	4.533	2.220

<i>Anticancer treatment status</i>	-	1.173	1.238	1.172	
<i>Anticancer treatment intent</i>	-				1.293 1.200 1.185
<i>Current anticancer treatment type</i>					
Chemotherapy	-				2.773 2.067 2.251
Hormone Therapy	-				1.958 1.256 1.565
Immunotherapy	-				1.858 1.649 1.698
Targeted Therapy	-				1.454 1.534 1.478
Radiotherapy / Radiation Therapy	-				1.072 1.201 1.113

Key: SPC =participants with cancer known to specialist palliative care services; Onc=participants with cancer known to oncology services on anticancer treatment; ECOG PS= Eastern Cooperative Oncology Group Performance Status; *White English / Welsh / Scottish / Northern Irish / British; VIF ≥ 5 indicative of multicollinearity (no relevant values) (442).

Supporting information: Condition indices (CI)

- All data: The maximum CI for Model A was 6.647; the maximum CI for Model B was 6.251.
- SPC group: The maximum CI for Model A was 6.083; the maximum CI for Model B was 8.133.
- SPC IE: The maximum CI for Model A was 4.535; the maximum CI for Model B was 8.057.
- SPC UK: The maximum CI for Model A was 11.615; the maximum CI for Model B was 8.607.
- Onc group: The maximum CI for Model A was 7.340; The maximum CI was for Model B 10.991.
- Onc IE: The maximum CI for Model A was 5.707; the maximum CI for Model B was 10.949.
- Onc UK: The maximum CI for Model A was 12.796; the maximum CI for Model B was 14.148

CI >30 indicative of multicollinearity (442) (no relevant values).

Appendix 9: Supplementary Table S10: Representative categorical quotes from POST study according to participant treatment status, intent and involvement with SPCS.

Themes, categories, sub-categories and representative quotes for cancer patients' stance on the term "cancer survivor"			
Theme	Category	Sub-category	Representative quote
There is uncertainty around "cancer survivor"	"Cancer survivor" can be unclear	Lacks clarity	It just doesn't make sense. <i>Onc, curative</i> This is very grey - it needs to be clearer than that. If cancer recurs, what are you then? <i>Onc, palliative</i> It's like saying you're not sick anymore when they're not. It's a confusing thing to say to someone. <i>SPC, no treatment</i>
		Uncertainty surrounding cancer	No way! That's wrong. I'm on treatment, going along the road and waiting for all those tests to tell me if the treatment is working or not. <i>Onc, curative</i> I don't know if I'll be ok, so you can't call me a survivor. <i>Onc, palliative</i> As my cancer is "incurable" I feel like a limbo state – I am living with cancer. I haven't beaten or survived it. <i>Onc, palliative</i> There's too much uncertainty with any cancer diagnosis. <i>SPC, no treatment</i>

		More education is needed	I think the education around it needs to be better - to take the fear out of it. <i>SPC, palliative</i>
	"Cancer survivor" can lead to assumptions	False impression	It could give a false sense of security and lead to utter disappointment when the cancer is found to have returned. <i>SPC, no treatment</i> I think being called a survivor when you still have cancer present is misleading. <i>Onc, palliative</i> I don't feel that most people understand or know the definition, therefore assume "survivor!" means cured. On that basis, i would prefer the term wasn't used as it creates a tier or tiers of people with curable and incurable cancer" <i>Onc, curative</i>
		Cancer can recur	It can always come back, so are you ever really a survivor? <i>SPC, no treatment</i> The word "survivor" is the issue for me. I don't think there are any guarantees with this disease - are you ever really clear? It might come back again. How does that fit with the definition of "survivor"? <i>Onc, curative</i>
		The cancer experience is never really over	That's bulls***. Once you have it - every time they find something else. It's all gone, but I'll never be free of cancer. So no one should ever say that to me. <i>Onc, curative</i> Cancer is with you from the day you are diagnosed, you think about cancer and it will affect you from then on. <i>Onc, palliative</i>

			The term cancer survivor doesn't accurately reflect the problems that people live with after successful cancer treatment. It suggests that they have simply had a problem which is now fixed, but doesn't capture the ongoing losses and struggles. <i>SPC, palliative treatment</i> You either have cancer or you haven't. I'm not surviving, I'm existing. And once you have it, it's always in your head, even if you're cancer-free for some of that time. <i>SPC, no treatment</i> You're never free, are you? <i>SPC, no treatment</i>
		Implies responsibility	It's almost as if you get cancer you must have done something wrong...So the question about surviving or not - it's like it's something to do with you. In most cases it's not about that, it's not about how hard you've worked. Those words are like a win or lose - down to skill. <i>Onc, curative</i> It implies failure in those who are unable to be cured and strength in those who achieve cure. To attribute responsibility to a patient for their outcome, which is beyond their control, is unhelpful. <i>Onc, palliative</i> The issue with the phrase "Cancer Survivor" is that it implies you have some control over the cancer, and you don't really. <i>SPC, palliative treatment</i>

			I don't think cancer survivor should be used for anybody, as it is not by choice that you are in this battle. Even with the possibility of defeating cancer you wouldn't choose to enter the battle. <i>SPC, no treatment</i>
	The need for a term is questionable	A term is unnecessary	Do we say the same for other life-threatening diseases or accident survivors? <i>Onc, curative</i> I don't think people free of cancer should be called a cancer survivor – leave it behind. <i>Onc, palliative</i> I do not think there is any relevance to using the terminology. I think it is irrelevant. <i>SPC, palliative treatment</i> I don't see why we need a term at all. <i>SPC, no treatment</i>
		Indifference towards the term	The term cancer survivor doesn't bother me. We know from birth that we will die so the label "survivor" is temporary anyway <i>Onc, curative</i> It's a bit silly to be worried about that in life when you're dying of cancer. <i>Onc, palliative</i> I myself would be called anything if I was cleared of all cancers. <i>SPC, palliative treatment</i> I imagine someone younger would have a different opinion or care more. <i>SPC, no treatment</i>

Challenges with applying “cancer survivor” universally	Use of the term should be an individual’s choice	Individuality	When it comes to terms you are using about the person you are talking to it is important to ask them what terms they are comfortable with, just as you might ask them how they like to be addressed when you first meet them. <i>Onc, palliative</i> How can you classify each individual when each person is having a different array of challenges? Fixing a few words would not fix the disease. <i>SPC, palliative treatment</i> I want to be known as my name and not a number. I am individual. There is only one “you” in the world. <i>SPC, no treatment</i>
	Labels are not always appropriate	Dislike of being labelled	I do not like being labelled having beaten a disease and moved on hopefully to resume a normal healthy life. <i>Onc, curative</i> I hate it. It's a label and it's not a good label. I'm not on a journey, I haven't bought a ticket - don't tell me to stay positive. <i>Onc, palliative</i> It...a label that means nothing. <i>SPC, no treatment</i>
		Dislike of being defined by cancer	I wouldn't want that to define me, to be the only thing that defines me. <i>Onc, curative</i> I think it means the rest of your life is defined by your cancer. <i>Onc, palliative</i>

			I prefer to avoid the word “cancer” – I’d rather not think about it. <i>Onc, palliative</i> I don't want to be defined as the guy who has cancer. I'm still the same person I was before I had cancer. <i>SPC, palliative treatment</i>
	The term is inappropriate for people who still have cancer	People who still have cancer have not survived it	I can't be a survivor if I still have cancer. <i>Onc, curative</i> It's like calling people in a shipwreck survivors - you're not a survivor if you're still on the ship. <i>Onc, palliative</i> I'm not a survivor, they're not the same as me. <i>SPC, palliative treatment</i> I'm never going to be free of cancer so I won't ever be a survivor. <i>SPC, no treatment</i>
		Some people with cancer will die from cancer	How can you call someone who is not going to get better a cancer survivor, when the cancer is going to kill them? <i>Onc, curative</i> How can you be called a survivor if you're not going to survive? <i>Onc, palliative</i> Only in that personally for me, I am going to die anyway, no matter what they do. The treatment may only give me a little longer than otherwise, therefore I do not consider myself a cancer survivor because I haven't survived it. It will kill me.

			<i>SPC, palliative treatment</i> It's not nice for the people who are dying from cancer to hear that term. It's a slap in the face. <i>SPC, no treatment</i>
		It is not appropriate for people with a limited prognosis	I've been given an expected length of time to live, so how can you call me a survivor? You couldn't possibly call me a cancer survivor. <i>Onc, palliative</i> I see where (the definition) is coming from, but certainly not if you're terminally ill! <i>SPC, palliative treatment</i> In the past I was a cancer survivor, but not anymore. I don't think that people with terminal cancer who are linked with palliative care are cancer survivors <i>SPC, no treatment</i>
"Cancer survivor" may be used to describe certain groups	An event that is over	A "cancer survivor" should be cancer free	I don't feel like I am a cancer survivor as I'm still going through treatment. I wouldn't want to be called a survivor until I am cancer free. <i>Onc, curative</i> I think that term is for people on the other side. I will never be cured of this, I'll always be a cancer patient. <i>Onc, palliative</i> My wife had kidney cancer and had to keep going back after her surgery - so until you're totally discharged you're not yet a cancer survivor. <i>SPC, palliative treatment</i>

			I think a cancer survivor is someone who is over cancer completely. You are not a survivor unless you've beaten it. I have lived with it for 9 years and I haven't survived it. <i>SPC, no treatment</i>
		The cancer experience has been overcome	I feel being recognised as a "cancer survivor" lets others know the battle one fought and gives acknowledgment of their situation, as surviving cancer can change your outlook, opinion and the way you look at a situation. So I agree with or would agree with being called a "cancer survivor" but only after going through the process. <i>Onc, curative</i> You can't be a survivor without getting through something - there's no in between. <i>SPC, palliative treatment</i>
	Certain circumstances	It depends on certain conditions	There has to be a timeline...if it doesn't come back – then you're a cancer survivor. <i>Onc, curative</i> Depends on how long cancer has been going on for you. <i>Onc, palliative</i> Once you're in the process of treatment then I guess you can be called a survivor. <i>SPC, palliative treatment</i>
"Cancer survivor" often evokes negative feelings, but can also be viewed positively	"Cancer survivor" can evoke negative feelings	Negative emotional responses	If you're a survivor, you have to be a victim first - I'm not a victim. <i>Onc, curative</i> To call someone who is end of life a cancer survivor is an insult. <i>Onc, palliative</i>

			Someone in active treatment with cancer will be resentful of me living well with cancer. Not everyone will survive - it's human nature to be resentful of those who have survived. <i>Onc, palliative</i> For me personally I think the term is patronising. <i>SPC, palliative treatment</i> There is no doubt that I have cancer and that it's working its way through me, so to call me a cancer survivor is dismissive. It might not be important to someone else, but it's important to me. <i>SPC, no treatment</i>
		"Cancer survivor" is disagreeable	Cancer isn't a war zone. It doesn't have to be that scary. <i>Onc, curative</i> It's ridiculous – it's actually outrageous. <i>Onc, palliative</i> It's too dramatic a term; it's too extreme. <i>Onc, palliative</i> It is bloody stupid to define it this way <i>SPC, no treatment</i> It's encompassing too many groups of people - it's not appropriate. <i>SPC, no treatment</i>

	"Cancer survivor" can evoke positive feelings	Positive emotional responses	I think it's a positive term that gives hope to both the patient and their family. <i>Onc, palliative</i> A lot of people would feel proud of the term, self-included. And proud of the medical staff involved in the treatment process. <i>Onc, palliative</i> The term to me describes someone who is brave and strong. It's a positive term. <i>Onc, palliative</i>
		"Cancer survivor" is agreeable	We're all survivors these days. <i>Onc, palliative</i> Anybody with cancer who keeps going <i>Onc, palliative</i> I strongly feel that "cancer survivor" should be used for a person who is cancer free but also even with cancer and no treatment options, as there is still hope! <i>SPC, no treatment</i>
Different wording may be preferable	Alternative terminology	Accurate descriptions	I don't think it's accurate. There's a lot of woolly stuff in there - get to the point. <i>Onc, curative</i> I'm not interested in those convoluted descriptions – stay factual and simple. <i>Onc, palliative</i>
		Other terms are proposed	When you're going through treatment, you're not a survivor yet - you're only surviving the treatment. <i>Onc, curative</i>

			I prefer patient to cover everything, why add in more "categories"?? <i>Onc, palliative</i> I prefer to say I'm a person who currently has cancer. And just call me by my name. <i>SPC, palliative treatment</i> If you're free of cancer you're free of cancer, but if you're not free of cancer, you're living with cancer, and you're not a cancer survivor. <i>SPC, no treatment</i>
	Limited alternatives	Limited options	It's a bit presumptuous I guess, but can't think of another way of saying it succinctly. <i>Onc, curative</i> Can be perceived by some people as unacceptable, alternatively what else could be used? <i>Onc, palliative</i>

Key: SPC, no treatment = participant known to specialist palliative care services, not on anticancer treatment; SPC, palliative treatment = participant known to specialist palliative care services, and on anticancer treatment with palliative intent; Onc, curative = participant known to oncology services, and on anticancer treatment with curative intent; Onc, palliative = participant known to oncology services, and on anticancer treatment with palliative intent.

