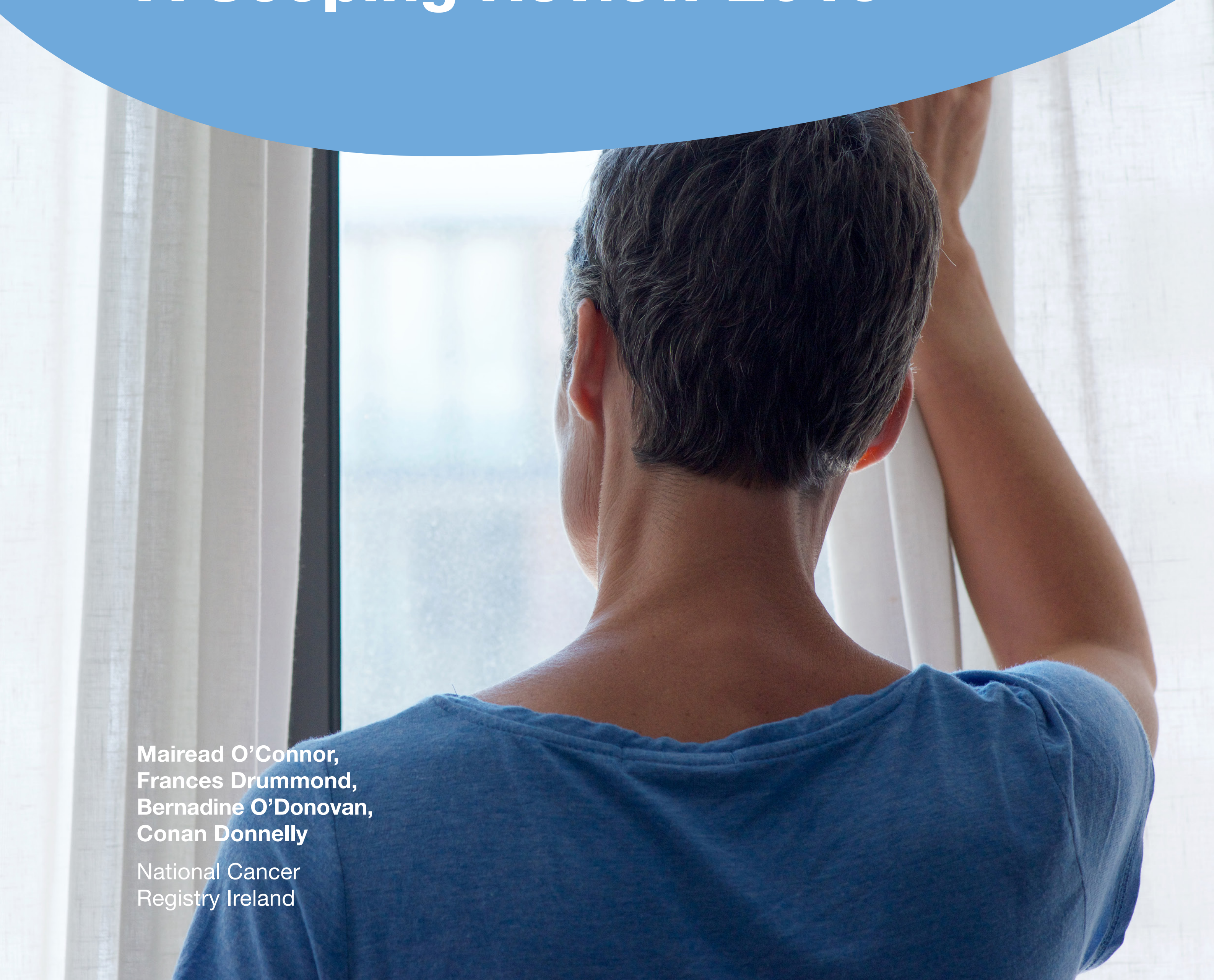
National Cancer Survivorship Needs Assessment:

The Unmet Needs of Cancer Survivors in Ireland: A Scoping Review 2019



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Foreword

For too long, the needs of people who survive cancer have not been prioritised. This is because the focus has been on survival, rather than the lives of those who have survived.

There is often an expectation cancer survivors will return to “normal life” once their treatment has stopped. However, many experience long-term side effects and other challenges for years afterwards. Others, with currently incurable cancers, may remain on treatment for the rest of their lives.

Short- and long-term effects of cancer treatment can affect every aspect of daily life. Physical issues include incontinence, bowel problems, sexual dysfunction, weight changes, sleep disturbance and fatigue. Emotional and psychological effects include shock, distress and fear of recurrence, low self-esteem and depression. Social and intimacy issues include lack of support, fear of burdening family and friends, loss of identity and altered relationships. And financial issues include increased stress due to financial difficulties, lack of or reduced household income, and an increase in costs to help manage side effects of treatment.

Understanding where support services could help address these issues is a first step in transforming the lives of the almost 200,000 people in Ireland living with or after a cancer diagnosis. To that end, this report considers the needs of survivors of adult cancers. A separate piece of work has been carried out into the needs of survivors of childhood cancers.

This research shows it is critical cancer survivors are provided with tailored support programmes specific to their cancer and treatment type, to meet their unique personal, emotional, practical and social needs. Survivorship care must be individualized and reflect our research finding that no ‘one-size fits all’.

This report also highlights that we need to learn more about what is important to cancer survivors, particularly amongst the less common cancers. However, it is important we act on what we already know and do not delay in making real changes and enhancing services.

For many years, the Irish Cancer Society has highlighted the lack of State support for cancer survivors. We were pleased the National Cancer Strategy 2017 – 2026 recommended significant improvements in this area and are currently pushing for the strategy to be delivered in full. This, together with the full implementation of the recommendations of this report, would make a big difference for cancer survivors and their families.

Cancer survivors in Ireland deserve world-class State supports and there should be no delay in making improvements that are needed right now by thousands of families all over Ireland.

The Irish Cancer Society’s own services also have a key role to play in helping people improve their quality of life. Currently, we help survivors through our Freephone Nurseline, Daffodil Centres, specialist nurses for prostate cancer survivors, counselling and patient conferences. We have also funded programmes to help people improve their quality of life after treatment through physical exercise. In addition, our peer support programme provides survivors with invaluable support from others who understand what they are going through.

This report will help us improve those services and inform the development of new ones. It should therefore help to deliver tangible improvements in supports for cancer survivors and their families.

At the same time, further research is needed, particularly into the needs of survivors of less common cancers. Otherwise, there is a risk of widening inequality between survival rates, treatment options, research investment, stage of diagnosis and socio-economic profile of different cancers. Indeed, it is the survivors of cancers not included in this report that arguably have the greatest need for support.

Advances in cancer research and services mean more people are surviving cancer than ever before. Now we must do more to ensure each and every one of them has the support they need to live life to the full. Ireland's growing community of cancer survivors, and their families, deserve nothing less.

Averil Power

Averil Power
CEO
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Contents

Accessible Summary

More than 40,000 people are diagnosed with cancer in Ireland every year. The arrival of better treatments and medicines means that more people are either being cured or living much longer after their diagnosis. The number of such survivors is growing rapidly. In 2016, the number of survivors stood at 173,000 which means that in 2019 that figure is over 200,000 people.

Cancer treatments such as surgery, radiotherapy, and chemotherapy may have a long-term impact on people's health and result in day-to-day practical difficulties. Because of this, many people who have been through a cancer diagnosis may require ongoing medical and non-medical care and support.

The National Cancer Strategy 2017-2026 was developed by the Department of Health together with a large number of stakeholders. Part of this strategy seeks to identify and address the needs of everyone who has been diagnosed with cancer in Ireland.

Some work to improve supports for cancer survivors is underway but more needs to be done. Working closely with the Irish Cancer Society and the National Cancer Control Programme (NCCP), the National Cancer Registry Ireland (NCRI) were asked to assess what is already known about the needs of adults who have been through a cancer diagnosis, with emphasis on the needs that are not being met. It should be noted that the challenges facing adolescents, young adults, and children with cancer are likely to be considerably different from adult cancer survivors. Therefore, the unmet needs of young people were examined by the NCCP as a separate piece of work, not included in this report.

By understanding the unmet needs of these cancer survivors, decisions can be made on how best to implement and deliver a model for survivorship care here in Ireland The first stage in this process and the purpose of this report is to understand what is already known from previous research regarding the unmet needs of adult cancer survivors.

The NCRI have therefore examined all available research studies that have previously reported on the needs of adult cancer survivors in Ireland.

This review showed that there has not been a lot of research in this area previously. Most of the research looked at the more common cancers in Ireland, such as prostate, colorectal, and breast. There was some research completed about the needs of people with head and neck, blood, and gynaecological cancers. Some of the unmet needs identified where specific to certain cancer types, such as swallowing difficulties in head and neck cancer survivors or erectile dysfunction in prostate cancer survivors.

The research also showed that some unmet needs are shared between different cancer types. These more shared needs included physical and psychological problems, as well as a lack of information about their healthcare. Overall, the research revealed that there are obvious gaps in what is known about survivors' care and support needs. There was a lack of research into the unmet needs of those with rarer or more aggressive types of cancer. These findings show the importance and urgency in assessing the needs of survivors with less common cancers and in developing support programmes to meet these needs. Further research is therefore needed to get a more complete picture of the care needs of everyone in Ireland living with or after a cancer diagnosis. Because of continued improvements in treatment and care, these needs are also likely to change over time. Therefore, a key recommendation from this research is to begin to regularly collect important information about the needs of cancer survivors directly from survivors. In the next phase of this research project, the NCRI, supported by the Irish Cancer Society, will kick-start this process by completing a national survey of cancer survivors. It is hoped that this survey will greatly help with motoring survivor's needs as well as planning programmes to improve cancer patient experience.

Executive Summary

Advances in cancer detection and treatment have resulted in continued improvements in life-expectancy for many. However, the ever increasing numbers of people living with a cancer diagnosis has brought about appreciation that their needs go far beyond the treatment of cancer itself. This emphasis on treating a disease, while undeniably important, can come at the expense of the person living with or beyond cancer. This time period, following a cancer diagnosis or following treatment, is described as survivorship.

Although some people diagnosed with cancer will recover substantial functional capacity and can resume their everyday activities, evidence is accumulating that others experience significant morbidity. This morbidity is associated with ongoing, and often unmet, needs for support and care.

In recognition of this, the National Cancer Strategy (2017-2026)[1] has specifically determined that addressing the unmet needs of cancer survivors should be a key area of focus. Specifically, recommendation 41 of the National Cancer Strategy charged the National Cancer Control Programme to undertake a survivorship needs assessment and subsequently develop a model of survivorship care. In advancement of this recommendation, and in support of the National Cancer Control Programme, the National Cancer Registry and the Irish Cancer Society undertook a scoping review of the available research evidence of adult cancer survivors' unmet needs in Ireland.

It is recognised that the needs of childhood, adolescent, and young adult cancer survivors can be distinct to the needs of adult cancer survivors, and therefore, a review of the available research on this specific cohort was examined by the NCCP as part of a separate report[2].

Scoping studies are a form of literature review, which examine the extent, range, and nature of research activity on a particular topic and identify gaps in the existing literature. The current review identified 34 eligible papers from 27 individual research studies from Ireland, published since 1998.

The findings can be summarised as follows:

- Evidence of unmet needs in cancer survivors were observed across a spectrum of cancer types and domains of unmet needs.
- Some unmet needs were observed across multiple cancer types, in particular:
  - physical needs (specifically, pain, fatigue, and sleep disturbances);
  - psychological needs such as the fear of recurrence;
  - need for greater access to support services;
  - sexuality related needs;
  - information deficits;

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[1] Department of Health. (2017). National Cancer Strategy (2017-2026). Department of Health; Dublin.

[2] Barrett P, Mullen L, McCarthy C. (2018). Survivorship after childhood cancer – health needs assessment 2018. National Cancer Control Programme; Dublin.

  - the need for increased information from health professionals;
  - financial hardship (actual and perceived hardship).
- However, other unmet needs were cancer-specific, for instance:
  - urinary incontinence and erectile dysfunction in men with prostate cancer;
  - bowel dysfunction in colorectal cancer survivors;
  - eating difficulties in head and neck cancer.
- Unmet needs did not exist in isolation, but were related to one another (e.g. long term psychological effects can be linked to physical needs), and commonly related to the treatment rather than the disease itself (e.g. men who received radiotherapy were likely to experience worse bowel symptoms than those who underwent surgery).

It is therefore clear that the needs of people living with and beyond cancer in Ireland are not currently being met.

While the cancer itself can lead to unmet needs, it must be also recognised that the treatment of cancer is not without its consequences. The needs of people in Ireland are multifaceted and complex; some needs are common among different cancer types, while others are cancer-specific. A model of care that truly addresses the needs of all people living with and beyond cancer in Ireland must recognise that one size does not fit all. Such a model of care must also recognise that the needs of patients are not static but fluid, and that there are significant gaps in our knowledge-base.

While some cancers and some domains of unmet needs have been relatively well studied in Ireland, others have not. Therefore, this review also identifies the considerable need for further research. Prostate cancer was the most commonly researched cancer type, followed by colorectal, breast, and head and neck cancer. However, other cancers types were underrepresented in the research literature and not all cancers could be included in this review. In particular, there was a lack of evidence on some cancers with low population numbers and high mortality rates (e.g. pancreatic cancer). The needs of survivors with these rarer types of cancers are likely to be different to those of survivors of more common cancers, and they are currently poorly understood. Focusing resource investment and research on the more common cancer types, which already have strong funding streams and often good treatment regimens, may widen the gap between cancers in terms of unmet needs and deepen the disadvantage experienced by people with less common cancers.

Additionally, little is known about the family-related, patient-clinician communication, cognitive, and spiritual needs or Irish cancer survivors, and there is a dearth of research on the specific needs of people with metastatic and hereditary cancer. Furthermore, no population-based longitudinal studies exist which would inform how the needs of survivors change over time.

Thus, the planning and design of survivorship strategies in Ireland, and in the underrepresented cancers in particular, would benefit from routine and serial collection of detailed information, with specific and standardised unmet need survey instruments. This would allow accurate, representative, and timely monitoring of the needs of cancer patients in Ireland, and should inform the model of care being developed by the NCCP.

As a result of this scoping review, the following recommendations have been made in addressing the unmet needs of people with and beyond cancer in Ireland:

1. Survivorship care programmes should be tailored to address the specific needs (physical, psychosocial, practical, and spiritual) of individual cancer survivors as 'one size does not fit all.'
2. Specific survivorship care services are required to address unmet physical, practical and psychological needs across most cancers. These include: social, sexual, practical, quality of life, information, communication, family and spiritual needs.
3. Research on specific aspects of cancer survivors' unmet needs is lacking. These include: particular cancer types (e.g. rarer cancers) which are under-represented in the existing literature, hereditary and genetic cancers, metastatic cancers; the impact of treatment side-effects on survivors, longitudinal data on unmet needs, financial needs of cancer survivors and relationships between unmet needs and socio-economic status. Prioritisation of research in these areas is required by relevant organisations.
4. Survivorship care evidence is required for the acute care phase as well as beyond treatment.
5. Survivorship care services should be evaluated at population level to measure progress in quality of life outcomes and routine monitoring tools are required.
6. Service performance monitoring is required to provide evidence of deficits in services for population subgroups (e.g. geography, deprivation levels, comorbidity, or sexual orientation).
7. Health economic research will be valuable to assess the cost of survivorship services and the quality of life benefits for patients.
8. A comprehensive unmet needs work programme (incorporating a national survey of cancer survivors) is required to address the gaps in evidence on cancer survivor's unmet needs identified in this review and support the implementation of national cancer survivorship care strategies. Such work programmes should be undertaken on an ongoing basis in order to continually and consistently monitor progress and success of these survivorship strategies.

Introduction

The global cancer survivor population is growing steadily due to increasing incidence as a consequence of population ageing and improving survival which is in part due to earlier cancer detection and therapeutic advances. The International Agency for Research on Cancer estimated that, in 2018, the total number of people who are alive within 5 years of a cancer diagnosis, called the 5-year prevalence, is estimated to be 43.8 million compared to 2012 figures of 32.6 million [1].

In Ireland, the Annual Report of the National Cancer Registry Ireland published in November 2018 [2] reported rising annual incidence, with the total numbers of cancers diagnosed annually having increased by about 85% since the mid-1990s mainly due to population growth and ageing. Although cancer is now the most common cause of death in Ireland with an average of 8,875 deaths from invasive cancer occurring annually between 2013 and 2015, survival has increased significantly since the mid-1990s. Over 62% of patients diagnosed with cancer (excluding non-melanoma skin cancer) between 2010 and 2014 survived at least 5 years compared to less than 45% of patients diagnosed between 1994 and 1998. These patterns have contributed significantly to cancer prevalence. In survivors, the most prevalent cancers (excluding non-melanoma skin) were: breast cancer (23% of all cancer survivors), prostate cancer (20%), colorectal cancer (12%) and skin melanoma (7%). In contrast, lung cancer, a common but high-fatality cancer, accounted for only 3% of survivors while less common, high-fatality cancers such as liver, pancreatic, oesophageal and stomach cancers combined comprise less than 3% of total cancer survivors. Figure 1 presents the number of cancer survivors in Ireland alive at the end of 2016 by cancer type and gender. A total of 173,000 cancer survivors (including those still undergoing active treatment or palliative treatment in addition to longer-term survivors) were estimated to be alive at the end of 2016; this number is estimated to have increased to over 200,000 by the end of 2019. The National Cancer Registry also forecasts a potential doubling of annual cancer incidence between 2015 and 2045 assuming that 2011-2015 cancer incidence rates persist over the next 30 years. Even if we assume a decreasing incidence rate to reflect the recent pattern for some cancers, the overall increase by 2045 could still be approximately 50% [2]. Appendix 1 presents a projection applying the average annual age-specific cancer incidence rates for 2011-2015 to the estimated population in Ireland to 2045. Such an increase in incidence will bring with it an increasing burden of prevalent disease in Ireland for patients, their families and the Irish healthcare system [2].

While many people diagnosed with cancer can expect to regain their health-related quality-of-life [3] and return to ‘normal life’ [4-6], survivors often experience problems resulting from the cancer and its treatment. This may include functional and psychological issues, social, sexual and relationship difficulties, and financial problems [4-10]. Consequently, they may need medical and non-medical support and care, but these needs often go unmet [11, 12]. Quantifying how many survivors have poor outcomes, experience difficulties, limitations, or unmet needs, and which subgroups are at greatest risk, is a first step in developing supportive interventions and services.

Unmet needs of cancer survivors are needs which are currently lacking the level of support required for an individual to achieve optimal wellbeing [13]. These needs can occur in a range of areas (e.g. physical, financial, psychological, social, health system/information needs). They can also occur throughout the patient journey before, during, and well beyond treatment. International research across cancer types has identified common unmet needs in cancer survivors related to intimacy, physical, psychological/emotional, social needs, information sharing, and communication needs [14,15].

However, the supportive care needs of international survivors may differ from those of cancer survivors in the Irish healthcare system.

Research has examined unmet needs of cancer survivors in Ireland. However, the breadth and depth of this research, in terms of the cancer types investigated, as well as the type and extent of unmet need of cancer survivors in Ireland has not been assessed. Furthermore, the extent to which there are gaps in the evidence base for specific unmet needs is also unclear.

To address the challenge of managing the growing needs of those living with and beyond cancer, the recent Irish National Cancer Strategy (2017-2026) [16] recommended that designated cancer centres working with the National Cancer Control Programme, the Irish College of General Practitioners, primary care services, patients, and voluntary organisations should develop and implement cancer survivorship programmes [16]. These programmes will emphasise physical, psychological, and social factors that affect health and wellbeing, while being adaptable to patients with specific survivorship needs following their treatment. In order to achieve this recommendation, it is important to establish what the major needs in cancer survivorship care are in Ireland. A ‘needs assessment’ of those living with and beyond cancer in Ireland is required.

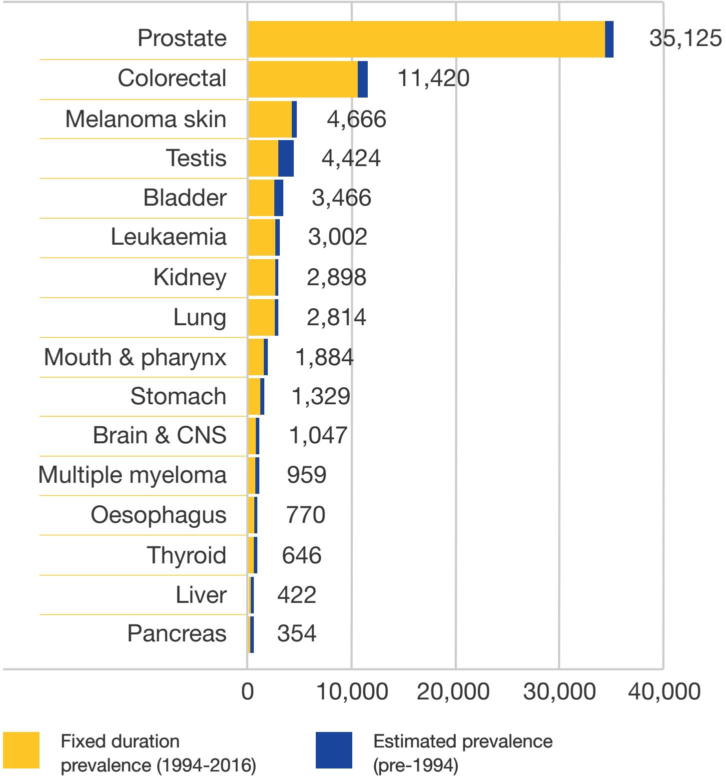
The National Cancer Registry have been commissioned by the Irish Cancer Society to undertake a scoping review of the current literature on the unmet needs of Irish cancer survivors. This was undertaken in collaboration with the National Cancer Control Programme (NCCP). The overall aim of this review was to establish an understanding of the unmet needs for those living with and beyond cancer in Ireland.

The specific objectives of the review are to:

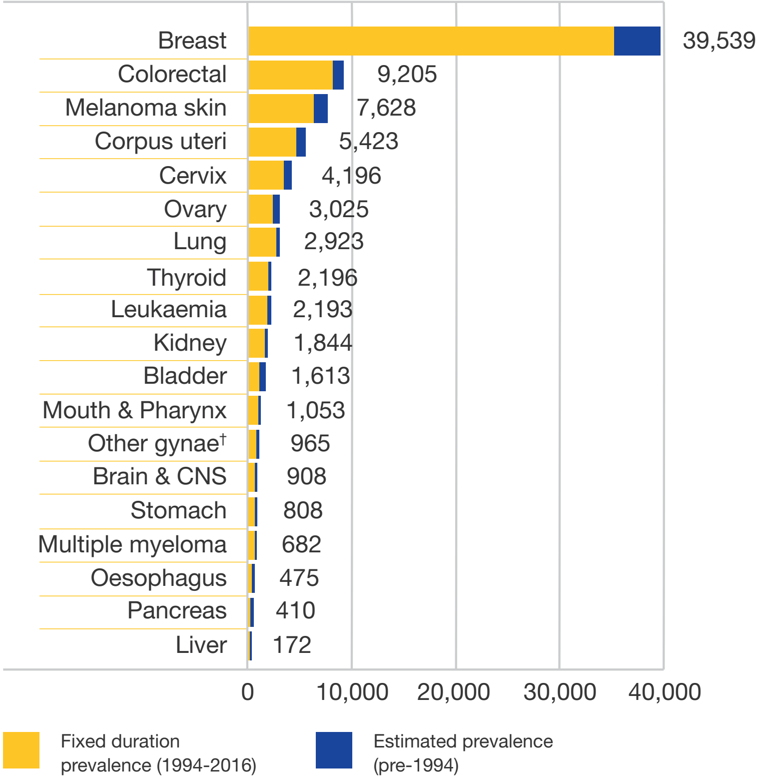
- Undertake a scoping review of the current evidence on the unmet physical, emotional, practical and social needs of those living with and beyond cancer in Ireland.
- Develop a comprehensive evidence base for future phases of research around unmet needs; specifically focus groups and patient surveys among cancer survivors exploring their unmet needs.
- Facilitate the identification of future research priorities in the area of cancer survivorship in Ireland.

Figure 1: Number of cancer survivors: prevalence by cancer type and gender

Male



Female



Only the most common cancers are shown. The numbers reflect the combined height of the stacked bars (complete prevalence), i.e. the number surviving with a particular cancer on 31/12/2016. The higher the stacked bar, the greater the number of survivors with that cancer type.

† Other gynaecological: vulva, vagina, uterus and placenta

Research Methodology

Scoping studies represent an increasingly popular approach to reviewing health research evidence [17]. They are used to examine the extent, range, and nature of research activity, determine the value of undertaking a full systematic review, summarise and disseminate research findings and identify gaps in the existing literature [18]. As such, this method is appropriate for the aims and objectives of this research. For this study, we adhered to the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) [19] reporting guidelines (Appendix 2). The scoping review is registered on the Open Science Framework (OSF; an open source software project that facilitates open collaboration in science research). Specific aims of the scoping review and the accessible summary are available to view at: https://osf.io/ax7r2/. Appendices contain review materials with additional information such as detailed tables and figures.

Search strategy

Database search strategies were defined by Conan Donnelly (CD), Mairead O'Connor (MO'C) and Bernadine O'Donovan (BO'D) (see Appendix 3). We searched five databases (Embase, PubMed, PsychINFO, CINAHL Complete and Cochrane Library) to identify studies, published between January 1998 and September 2018, which were conducted in Ireland. Search terms were developed by the research team in consultation with a specialist librarian. Combinations of disease terms, survivorship terms and terms related to care needs were adapted from previous research and in consultation with a specialist librarian (See Appendix 3). These included the National Cancer Survivorship Needs Assessment [20] and an earlier systematic review [15].

Reference lists from papers of eligible studies and relevant journals were checked to identify any potentially eligible articles that might have been missed by the electronic searches. The search was restricted to English language papers only.

Eligibility criteria

The specific scope of this review is to examine the care needs of patients who were diagnosed with adult cancer (18 years or over) and are currently post-treatment (e.g. finished chemotherapy, radiotherapy, surgery, hormonal therapy). Full details of inclusion and exclusion criteria are presented in Table 1. To be included, studies had to report on one or more patient outcomes related to cancer survivorship in the Irish context (Table 2 presents examples of outcomes). Studies reporting on adult survivors of childhood cancer, those including participants aged ≤17 years, and those which reported on palliative care services were excluded. Studies on the care needs of patients living with metastatic cancer (cancer which has spread from where it started to another body organ) were not specifically evaluated in isolation for this review; however, information on the unmet needs within this cohort were included as part of overall larger studies. Individual case studies, intervention studies, randomised controlled trials, pilot studies, opinion pieces, editorials, commentaries and narrative literature reviews (reviews that are not done in a systematic way) were not eligible.

Table 1: Details of inclusion/exclusion criteria

Criteria	Inclusion	Exclusion
Population	Age 18 years or older Any cancer type Any cancer stage (e.g. early/advanced stage - Stage 3 or 4)^ Cancer treatment completed (e.g. finished chemotherapy, radiotherapy, surgery) Cancer survivors in the Republic of Ireland	Age 17 years or younger Survivor of childhood cancer Awaiting/currently receiving treatment ^^ Palliative care services Cancer survivors in Northern Ireland **
Intervention	Survivorship care services	
Outcomes	Any patient outcomes related to survivorship care Any patient outcomes related to ongoing/unmet needs of cancer survivors Patient health outcomes Late effects/consequences which are result of cancer treatment Quality of life/patient wellbeing Physical needs/concerns e.g. symptom burden, fatigue Psychosocial needs/concerns e.g. anxiety, depression Socioeconomic needs/concerns e.g. financial burden, return to work issues Fear of recurrence Survivor information needs e.g. health utilisation needs	Studies testing the psychometric properties of patient health measures Views of survivorship care Healthcare professional (HCP) experience and views of survivorship care Carers' experience and views of survivorship care
Study Design	Systematic reviews Qualitative & Quantitative studies Mixed methods studies Population based studies Prospective & retrospective studies Cross-sectional studies Longitudinal studies Thesis/dissertations Grey literature e.g. conference abstracts, reports etc.	Individual case studies Intervention studies RCTs Pilot studies Opinion pieces Editorials Commentaries Narrative literature review
Reporting	English language Sufficient detail on supportive/unmet care needs Sufficient detail on results*	Not Applicable

^ metastatic cancer patients were not specifically evaluated in isolation for this review but were assessed as part of larger studies; ^^ Data were reported for whole study populations when it could not be extracted separately by treatment status (e.g. metastatic cancer patients in receipt of ongoing treatment); *enough data reported in the results to be extracted from the paper and reported on in a meaningful manner according to our specified data extraction format; **PiCTure whole Ireland study (70% of respondents from Republic of Ireland, 30% from Northern Ireland). Seven papers report on data from this study. Of the seven papers, four of these present data separately for ROI and NI [21-23, 42]. For these papers only Republic of Ireland data are reported in this review. For the remaining three PICTure papers, all Ireland (Republic of Ireland and Northern Ireland) data are reported.

Supportive care needs were classified into eleven primary domains, which included physical; psychosocial/emotional; cognitive; family-related; social; intimacy/interpersonal; practical; quality of life/needs related to daily living; spiritual/existential; health system/information and patient-clinician communication needs. See Table 2 for the supportive care domains.

Table 2: Eleven domains of supportive care needs*

Primary domains	Definition	Examples
Physical needs	Experience of physical symptoms	Pain, fatigue
Psychosocial/emotional needs	Experience of psychosocial/ emotional symptoms	Anxiety, depression, fear of recurrence
Cognitive needs	Experience of cognitive impairments; cognitive distortions	Difficulties in concentration, memory loss, catastrophizing, emotional reasoning
Family-related needs	Experience of fears/concerns for the family	Dysfunctional/negative family relationships
Social needs	Experience of reduced social support	Loneliness, isolation
Intimacy/interpersonal needs	Experience of difficulties with self-image and gender roles	Fertility, reduced libido, compromised intimacy with partner
Practical needs	Experience of difficulties with practical issues	Access to HCPs (and/or out of hours access to HCPs), sufficient time with HCPs during consultations, financial difficulties/financial support
Quality of life/needs related to daily living	Experience of difficulties with active daily living (ADLs) or instrumental activities of daily living (IADLs)	Work related issues, problems with exercise/housekeeping
Spiritual/existential needs	Existential concerns/issues	Spiritual questioning, fear of death
Health system/information needs	Experience of health information deficits	Lack of information or uncertainty about treatment effects/follow-up care e.g. treatment summaries
Patient-clinician communication needs	Quality of communication between patients and HCPs	Shared decision making, satisfaction with care

*adapted from Paterson et al., 2015 [15]

Quality appraisal

The papers were critically appraised using one of two checklists depending on study design. The 14-item National Institutes of Health Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies was used to appraise the quality of quantitative studies [25]. See Appendix 4. There are three response options for each question – “Yes = 1”, “No = 0” and “other (cannot determine, not reported, not applicable) = 0” – which were then summed to get an overall score. Thus, a paper was scored between 0 and 14 with a score of ≤4 classified as ‘Poor’, 5-9 as ‘Fair’ and ≥10 as ‘Good’. Qualitative studies were assessed using the 10-item Critical Appraisal Skills Programme (CASP) Qualitative Checklist [26]. See Appendix 5. This tool also has three response options for each question – “Yes = 1”, “Can’t Tell = 0” and “No = 0” which are then summed giving a score of 0-10 with a score ≤ 3 being ‘Poor’, 4-6 ‘Fair’, and ≥ 7 ‘Good’. The methodological quality of the papers was appraised independently by three reviewers (BO’D and Francis Drummond (FD) assessed 27 papers). FD is an author on seven papers included in this scoping review – therefore BO’D and MO’C assessed the remaining seven papers). Any differences were resolved through discussion.

Data extraction and synthesis

Two reviewers (MO’C, BO’D) independently screened titles and abstracts of records. Full text versions of papers considered potentially eligible for inclusion were read by both reviewers and their suitability for inclusion independently assessed. The reviewers then compared results and resolved any discrepancies. Data were extracted from each eligible paper on: (a) authors and year of study, data collection time period; (b) study population; (c) unmet need investigated; (d) data collection method and instruments used, and (e) main results.

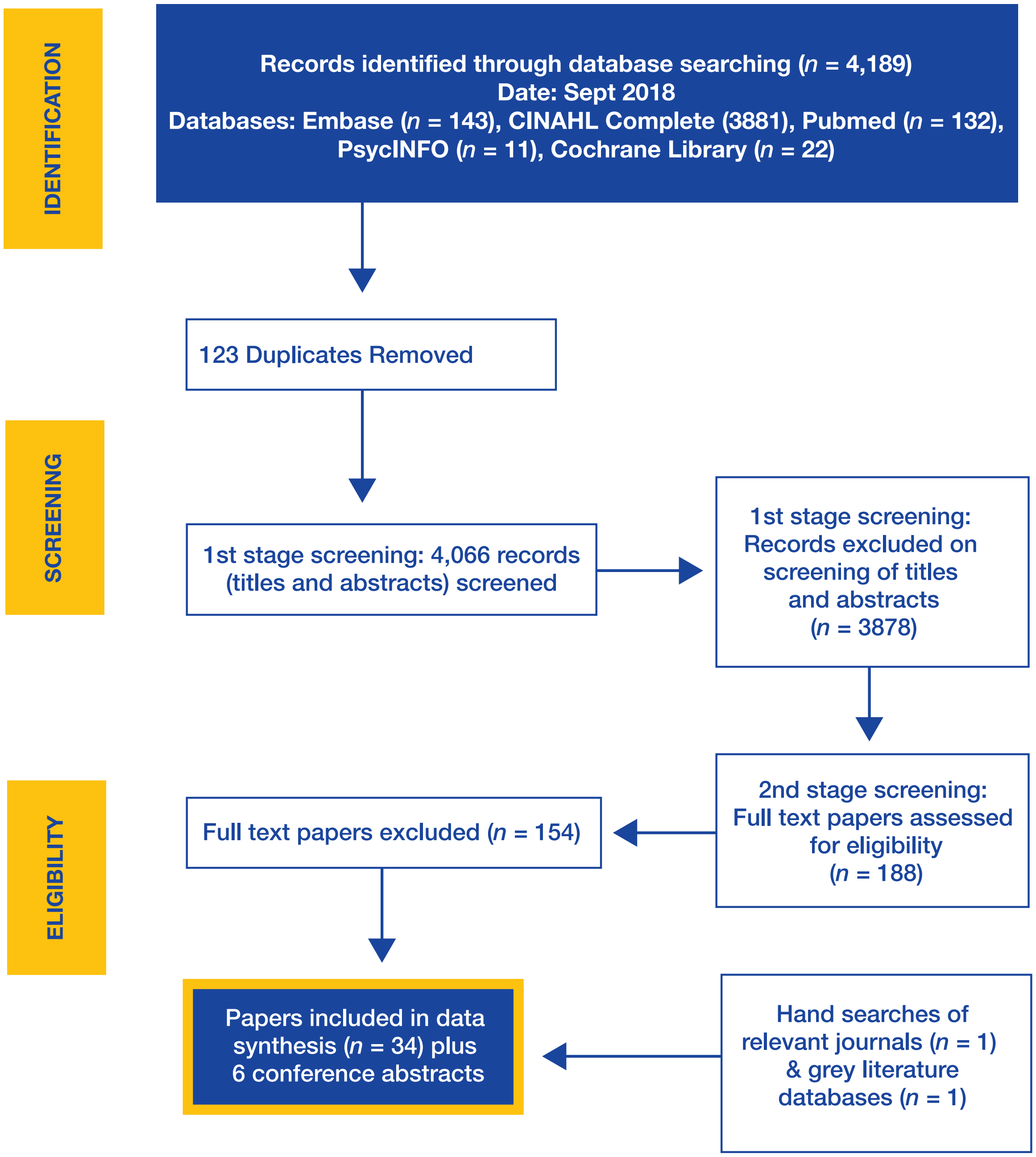
In the few papers which contained results for populations from different countries (including Ireland), every effort was made to extract Irish data only where available. However where it was not possible to extract the data separately for Republic of Ireland and Northern Ireland, all Ireland data (i.e. the Republic and Northern Ireland combined) was reported. Some eligible papers reported data from patients that were still undergoing treatment (e.g. metastatic patients in receipt of treatment) and patients who had finished their treatment. In such cases, it was not possible to extract the data separately for the different treatment groups. In order not to exclude valuable data from the limited research available among Irish populations, we reported data from these mixed papers, for the whole study population, regardless of patients’ treatment status. Appendix 6 provides an overview of the characteristics of eligible studies.

A narrative synthesis of the data was undertaken, with a structure based on (i) the overall needs of cancer survivors in Ireland and (ii) evidence of unmet supportive care needs by domain (11 domains of supportive care needs [see table 2]). Where appropriate, illustrative quotes from study participants are included in the results section.

Results

A total of 4,189 records were attained from databases and hand searches. Of these, 4,066 remained following removal of duplicates. Once abstracts and titles were reviewed, 188 records were selected for full text review. An additional paper was identified through hand searches of relevant journals. This resulted in 34 papers and six conference abstracts that met the inclusion criteria. Figure 2 shows the number of papers identified, screened and included.

Figure 2: PRISMA flowchart



Characteristics of Studies

34 papers (26 quantitative and eight qualitative papers) reporting 27 individual studies were included. In addition to the eligible studies, six conference abstracts were also reviewed (see Appendix 8 for the main findings). There were no population-based longitudinal studies. The research was conducted in Ireland from 2008 to the most recent study in 2018. Sample sizes varied across studies ranging from eight to 2,567 participants. Recruitment details were not reported in all papers but nine studies recruited participants through the National Cancer Registry. Some studies recruited in outpatient clinics/hospitals (*n* = 10), with cancer support groups/organisations (*n* = 4), and from hospital databases (*n* = 2). Most of the research conducted at clinical sites were single-centre studies (*n* = 6). There were a range of clinical and demographic characteristics across the studies. Most of the studies were in mixed gender populations (*n* = 15); five studies with males only and seven with females only. A variety of cancer types were investigated: prostate cancer (*n* = 11 papers); colorectal cancers (*n* = 6); breast cancer (*n* = 5); head and neck cancers (*n* = 4); mixed cancer populations (*n* = 2; cancers investigated in mixed cancer populations included breast, prostate, lung, gastric, sarcoma, lymphoma and leukaemia); gynaecological cancer (*n* = 2); oesophageal cancer (*n* = 1); myeloma (*n* = 1); lymphoma (*n* = 1); and ostomates (*n* = 1). Nine studies were nationwide (National Cancer Registry/ the PiCTure study); ten in hospitals/centres in Southern Ireland, one in the Midlands, and one in the Southeast. See Table 3 for a summary of demographic and study characteristics.

Needs of cancer survivors in Ireland

Unmet needs across a range of domains including physical, emotional, practical, social, or information were extensively reported across the included studies. See Appendix 7 for summary of supportive care needs reported in eligible studies.

Supportive care needs were not ranked or assessed for importance by survivors in these studies i.e. number of responses on supportive care needs does not reflect importance of these needs. Research focused on the following areas: physical needs (*n* = 25 papers; 74%); psychosocial/ emotional (*n* = 17 papers; 50%); quality of life (*n* = 14 papers; 41%); intimacy/ interpersonal (*n* = 12 papers; 35%); practical (*n* = 11 papers; 32%); social (*n* = 10 papers; 29%); health system/information (*n* = 11 papers; 32%); family-related (*n* = 1 paper; 3%); patient-clinician communication (*n* = 2 papers; 6%); cognitive (*n* = 2 papers; 6%); and spiritual (*n* = 1 paper; 3%).

Table 3: Demographic summary and characteristics of study participants

Authors	No of participants	Cancer type	Gender	Study design	Quality rating	Treatment status	Sampling frame (recruitment location)[¥]
Cleary et al., 2011 [27]	106	Gynaecological	Female	Quantitative	Poor	Mixed treatment population^	1 hospital (Cork)
Cleary et al., 2013 [28]	8	Gynaecological	Female	Qualitative	Poor	Mixed treatment population^	1 hospital (Cork)
Cockle-Hearne et al., 2013 [29]	53*	Prostate	Male	Quantitative	Poor	Mixed treatment population^	7 European countries
Davidson, 2016 [30]	55**	Ostomates~	Mixed	Quantitative	Fair	Post-treatment^^	Ileostomy Association Ireland (nationwide
Droog et al., 2014 [31]	302	Breast	Female	Quantitative	Poor	Post-treatment	3 hospital review clinics (unknown)
Drummond et al., 2015[a] (PROMS)[#] [21]	2338	Prostate	Male	Quantitative	Good	Post-treatment^^^	NCRI & NICR (Island of Ireland)
Drummond et al., 2015[b#] [32]	2338	Prostate	Male	Quantitative	Fair	Post-treatment^^^	NCRI & NICR (Island of Ireland)
Drury et al., 2017 [33]	252	Colorectal	Mixed	Quantitative	Fair	Post-treatment^^^	3 hospital & 21 cancer support centres (across Ireland)
Dunne et al., 2017 [34]	27	Head and Neck	Mixed	Qualitative	Fair	Post-treatment^^^	4 hospital cancer centres (across Ireland
Gannon et al., 2017[##] [35]	25	Ooesophageal	Male	Quantitative	Fair	Post-treatment^^^	1 hospital database (Dublin)
Gavin et al., 2015[#] [36]	3348	Prostate	Male	Quantitative	Fair	Post-treatment^^^	NCRI & NICR (Island of Ireland)
Gavin et al., 2016[#] [22]	2567	Prostate	Male	Quantitative	Fair	Post-treatment^^^	NCRI & NICR (Island of Ireland)
Hackett et al., 2018 [37]	14	Lymphoma	Mixed	Qualitative	Poor	Post-treatment	1 hospital database (Limerick)
Hanly et al., 2013 [38]	159	Colorectal	Mixed	Quantitative	Fair	Post-treatment[†]	NCRI (nationwide)

Authors	No of participants	Cancer type	Gender	Study design	Quality rating	Treatment status	Sampling frame (recruitment location)$^{¥}$
Hanly et al., 2018 [39]	496	Colorectal	Mixed	Quantitative	Fair	Post-treatment†	NCRI (nationwide)
Kelly & Dowling, 2011 [40]	11	Myeloma	Mixed	Qualitative	Poor	Post-treatment	Haematology Oncology centre (Tullamore)
Landers et al., 2014 [41]	143	Rectal cancer	Mixed	Quantitative	Poor	Post-treatment^^	10 clinical sites (across 5 geographical areas in Ireland)
Maguire et al., 2017$^{\#}$ [23]	817	Prostate	Male	Quantitative	Fair	Post-treatment^^^	NCRI & NICR (Island of Ireland)
Maguire et al., 2018$^{a\#}$ [42]	817	Prostate	Male	Quantitative	Fair	Post-treatment^^^	NCRI & NICR (Island of Ireland)
Maguire et al., 2018^{b} [24]	141	Colorectal cancer	Mixed	Quantitative	Fair	Post-treatment	NCRI (nationwide)
Meade et al., 2017 [43]	51	Breast	Female	Qualitative	Good	Post-treatment††	2 clinical cancer centres; 1 urban & 1 rural (unknown)
Naidoo et al., 2013 [44]	39	Breast	Female	Quantitative	Poor	Post-treatment††	1 cancer centre (South East of Ireland)
O'Brien et al., 2017 [45]	583	Head and Neck	Mixed	Quantitative	Fair	Post-treatment	NCRI (nationwide)
O'Shaughnessy et al., 2013 [46]	11*	Prostate	Male	Quantitative	Poor	Post-treatment†	Australia with Irish participants
O'Shaughnessy et al., 2015$^{\sim\sim}$ [47]	15*	Prostate	Male	Quantitative	Poor	Post-treatment†	Australia with Irish participants
Pearce et al., 2015 [48]	264	Head and Neck	Mixed	Quantitative	Fair	Post-treatment†	NCRI nationwide

Authors	No of participants	Cancer type	Gender	Study design	Quality rating	Treatment status	Sampling frame (recruitment location)¥
Pertl et al., 2014 [49]	73	Cancer survivors	Mixed	Qualitative	Poor	Post-treatment†	Cancer support groups/associations (nationwide)
Power & Hegarty, 2010 [50]	8	Breast	Female	Qualitative	Fair	Post-treatment^^^	1 cancer support centre (Cork)
Sharp et al., 2013 [51]	654	Breast, Prostate & Lung	Mixed	Quantitative	Good	Post-treatment†	NCRI (nationwide)
Sheehy et al., 2018 [52]	105	Breast	Female	Quantitative	Poor	Mixed treatment population^	1 hospital (Cork)
Steentjes et al., 2018# [53]	2567	Prostate	Male	Quantitative	Fair	Post-treatment^^^	NCRI & NICR (Island of Ireland)
Thomas et al., 2014 [54]	583	Head and Neck	Mixed	Quantitative	Fair	Post-treatment†	NCRI (nationwide)
Thomas et al., 2015 [55]	496	Colorectal	Mixed	Quantitative	Fair	Post-treatment†	NCRI (nationwide)
Walsh & Hegarty, 2010 [56]	8	Prostate	Male	Qualitative	Poor	Post-treatment^^	Prostate cancer support group (Cork)

¥ Sampling frames and recruitment locations are based on what is reported in individual papers; ^Mixed treatment populations include some patients undergoing treatment and those that have completed treatment - data reported for whole study populations in ‘mixed treatment population’ studies as data could not be extracted separately for patients undergoing treatment and post-treatment patients; ^^ post-surgical treatment; ^^^ reported that primary treatment completed; † reported that treatment received; †† reported that adjuvant breast cancer treatment completed; *number of Irish respondents the study; ** number of respondents with cancer diagnosis; # PiCTure whole Ireland study (70% of respondents from Republic of Ireland, 30% from Northern Ireland). Seven papers report on data from this study. Of the seven papers, four of these present data separately for ROI and NI [21-23, 42]. For these papers only Republic of Ireland data are reported in this review. For the remaining three PICTure papers, all Ireland (Republic of Ireland and Northern Ireland) data are reported. ## matched control study with non-cancer control group; ~Ostomates – individuals who have undergone a surgical operation to create an opening in the body for the discharge of body wastes of which 22% were colorectal survivors; metastatic cancer patients not specifically assessed in isolation for this study.

Abbreviations: NCRI=National Cancer Registry Ireland; NICR = Northern Ireland Cancer Registry.

Evidence of unmet supportive care needs by domain

Physical needs

Survivors reported considerable physical effects as a result of their cancer and its treatment. Nine papers from three studies described physical needs in cancer survivors affected by prostate cancer [21-23, 32, 36, 42, 47, 53, 56]; four studies of breast cancer [31, 43, 44, 50]; three studies with head and neck cancer [34, 45, 54]; four studies with colorectal cancer [24, 33, 41]; one study of myeloma [40] ; one study of oesophageal [35]; one study of lymphoma [37]; one study with ostomates [30], and one study with mixed cancer survivors [49].

As expected, symptom burden was cancer specific with long term effects frequently linked to treatment. Symptoms particular to prostate cancer survivors were reported such as urinary incontinence (ranging from 14.3% among men with early stage disease symptoms to 22.2% among men with late stage disease symptoms), erectile dysfunction (56.1 – 66.9% of men), loss of libido (41.3 – 51.6% of men), bowel problems (11.5 – 14.2% of men) and hot flushes (9 – 18.8% of men) [21, 22, 32, 36, 47, 53, 56] Many of the physical effects experienced by prostate cancer survivors were linked to treatment [21, 32, 53]. Survivors who received radiotherapy experienced worse bowel symptoms than those who had surgical treatment [32]; while survivors who underwent radical prostatectomy (removal of prostate) were at a higher risk of incontinence, libido loss and impotence, regardless of disease stage [53]. However, less well known physical changes were also reported by prostate cancer survivors such as loss of body hair, penile shrinkage and muscle wastage [47]. Prostate cancer survivors reported that these 'lesser' treatment effects could have significant psychological impact [47].

Many breast cancer survivors experienced distressing physical symptoms such as pain (38% of survivors), sleep disturbance (44%), and fatigue (51%) [44]; weight changes and hair loss [43, 50]. They reported that management of these chronic symptoms was an important aspect of their survivorship [43]. One small study of breast cancer survivors identified the significant psychological impact of treatment induced hair loss [50]:

> "I can't say that losing the breast affected me…because there were other issues going on at the time. I think my hair was worse. I think that's more visible you know… it's more in your face, and you're just like "Oh my God…YEUCH!' (laughs) (pause) ...It's like, oh here comes the cancer patient!"

Postmenopausal breast cancer survivors reported treatment effects such as weight gain and arthritis which limited their mobility [43]:

> "I found when I was put on my tablet my arthritis went very, very bad and my weight started to go on. I have 4 stone on now at the minute which I don't want because it's bad, my knees are gone, my back, I have problems with my back and I'm trying to lose get this weight off now."

Head and neck cancer survivors also have specific treatment effects which can persist, such as dry mouth, pain, lack of energy, communication problems or eating difficulties. Two studies found that half of head and neck cancer survivors reported at least one unmet need, with many reporting unmet physical needs [45, 54]; across the two studies, 20 to 29% of head and neck cancer survivors experienced a lack of energy. In one of these studies 38% experienced dry mouth, 28% had difficulties with swallowing and 24% had eating difficulties [54]. Survivors who experienced financial hardship were at increased risk of unmet physical needs; almost twice as many patients with financial difficulties reported higher levels of unmet physical needs compared to those without financial issues: 48% compared to 25% [45]. One study found that when head and neck cancer survivors experienced persistent physical effects, they frequently used adaptive strategies - such as adapting their diet or carrying a water bottle [34]. Common symptoms reported by colorectal cancer survivors included bowel dysfunction (74% of survivors), gastrointestinal problems (29% experienced nausea/vomiting), and appetite loss (38% of female colorectal survivors; 26.9% of male colorectal cancer survivors) [33, 41, 55]. Research which focused on bowel symptoms after surgery found that many survivors reported an average of four such symptoms [41]. A later study of acute stage colorectal cancer survivors found the most common symptoms were fatigue (81%), insomnia (56%) and pain (48%) [55]. Some colorectal cancer survivors (18%) experienced long term treatment effects with persistent bowel symptoms beyond the two year post-operative period [41]. While the majority of ostomates who had colorectal cancer reported no/minor problems, just under 10% of ostomates reported severe physical issues. These included treatment effects such as skin problems, leakage, and gas/wind problems [30].

Some common physical needs were identified across cancer types which included pain (ranging from 31% to 91% of survivors across cancer types), fatigue (ranging from 17% to 81%), and sleep disturbances (ranging from 44% to 76%) [33, 43-45, 49, 50, 54, 55] A mixed population of cancer survivors reported unmet needs with lack of support regarding cancer-related fatigue [49]. Gaps in communication and understanding of this type of fatigue were identified; among survivors' family/friends as well as their healthcare professionals (HCPs) [49]:

> "People often say to me 'We all get tired'. This really annoys me, because I know what the difference [sic] between a long day at work and THIS feels like! And they (thankfully) DON'T."

Psychosocial/emotional needs

Survivors reported considerable psychological effects as a result of their cancer and its treatment. Eight studies described psychosocial needs in cancer survivors affected by prostate cancer [21-23, 29, 32, 42, 47, 56]; breast cancer [31, 43, 44, 50]; head and neck cancer [45, 54, 56]; lymphoma [37]; and ostomates [30]. Reported psychological effects across cancer types included fear; shock; distress (10% to 29% of survivors); a feeling of loss, regret, or anxiety (16.1% to 29%); and low self-esteem and depression (16.3% to 36%) [29, 40, 45, 47, 56].

For many survivors, fear of recurrence was the most common psychological issue [40, 43, 44]. For example, fear of recurrence was experienced by approximately 70% of breast cancer survivors in one study [44]. Factors that acted as psychological triggers for fear of recurrence included: attendance at review clinics and hearing about disease progression in other patients [40]:

> "That [fear of recurrence] worries me when the time is coming near for going back to the hospital. I would be wondering what the cancer was doing. Was it coming back?"

Survivors reported vigilance for physical symptoms which could indicate recurrence [56]:

> "Every time you get a pain in your tummy or whatever you're wondering is that the prostate cancer coming around again."

Survivors identified an unmet need that they felt should be prioritised in survivor care – the need to have a contact person if they had a worrying symptom, or were experiencing pain/discomfort between their review visits [43]. A direct contact route was described as a valuable and reassuring aspect of survivor care [37]:

> "Like having an alarm in your house."

A study with a mixed cancer population also found that fear of recurrence was linked to persistent cancer related fatigue [49]. Survivors reported a perceived lack of support, interest and/or knowledge from HCPs about how cancer related fatigue contributed to their distress and often resulted in maladaptive health behaviours such as catastrophizing [49].

Breast cancer survivors reported high levels of satisfaction (75%) with the emotional support they received during care [31]. However the same survivors identified an information gap in their care. Information was not provided about psychological treatment effects that they might experience [31]:

> "I felt that I didn't get enough information about possible changes in my emotions. Chemo affects the brain, your whole personality. I lost my confidence."

An earlier breast cancer study also reported that the emotional effects of treatment induced hair loss were not addressed by HCPs [50]. Survivors felt that the psychological impact of their hair loss was not being highlighted and emotional support was lacking from their HCPs [50]:

> "I think with the hair. Yes…I think there is really a need for somebody to be involved when you lose your hair, it [is] growing back and just dealing with it. At the hospital maybe, because at the time I feel. You know, you're in shock…you don't feel up to going places… It should be something that's brought to you in the hospital…I feel that there is a big gap there you know…for hair loss."

While many survivors reported sufficient emotional support, some prostate cancer survivors reported high levels of unmet needs and the need for further psychological support [47]:

> "I seem to go from numb to feeling emotional about my body image and lack of sexuality all the time, so I would like to change that."

As expected, long term psychological effects could be linked to symptoms [41] or treatment [30]. Many rectal cancer survivors were worried (45%), anxious (41%), or embarrassed (45%) about their symptoms [41]. Ostomates - of whom 22% were colorectal cancer survivors - reported being somewhat/very depressed six months post-stoma. Nearly half reported that it took an extended time period - over 6 months - for them to feel comfortable with their stoma care with under 10% reporting they never felt comfortable [30].

Social needs

The most common support that survivors received came from family/friends and extended social networks [30, 34, 37, 40, 47, 50, 56]. One study of ostomates, which included 55 colorectal cancer survivors, reported that more than half (59%) belonged to a support group [30]. A small study among head and neck cancer survivors also found that many used social support (*n* = 24) and most received support from family/friends (*n* = 20) [34]. The importance of social support and strong supportive relationships were commonly identified across cancer types [30, 34, 37, 40]. Prostate cancer survivors in one study reported that all survivors needed social support with peer support considered by all participants to be the most important type of support [56]:

> "I mean tis the personal experience of the thing that would be beneficial to know that maybe ya know you're going to be sore here…"

Some survivors reported their partners as their best support; survivors with partners were less likely to experience distress or issues related to their masculinity [47]. Breast cancer survivors identified participation in peer support programmes as greatly beneficial in terms of emotional and appraisal support [50]:

> "It's like a jigsaw….you know you go to the support group and everything comes together…the penny drops!"

A majority of ostomates - 22% were colorectal cancer survivors - had the opportunity to talk to someone with a stoma; while over half belonged to a support group [30]. Self-care strategies were commonly used by mixed cancer populations and included seeking social support and managing social activities [34, 41].

Unmet social needs were reported in a number of studies; with over half of breast cancer survivors (55%) reporting inadequate support group services [44].

While survivors valued social support and reported its importance, they also felt the conflicting need to protect/not burden their loved ones [34, 40, 56]. This desire to protect others could often lead to distress and anxiety [40]:

> "I used to cry and a lot…on my own. I wouldn't tell them bad news if I could help it. I wouldn't like to upset them."

Less social support was identified as a significant factor for head and neck cancer survivors and associated with an increased risk of unmet needs across the following domains: physical/daily living, psychological, and health system/information [45]. Prostate cancer survivors' experiences of peer and HCP support also varied; some had positive interactions, while others described a lack of information on support groups and lack of support from HCPs [56]:

> "There was nobody here that I could talk to about it."

Intimacy/interpersonal needs

Sexuality-related needs were investigated in a number of studies [21, 22, 27-30, 32, 45-47, 56]. Both male and female survivors reported distressing alterations in their sexuality, and adverse effects in their sexual relationships [27-29, 46, 47, 56]. In one study among gynaecological cancer survivors, over half (54%) reported negative changes in their sexual relationships [27]. Overall survivors reported that long term treatment effects had a significant impact on intimacy and altered relationships [28, 30, 47, 56]. Sexual dysfunction associated with prostate cancer treatment was reported by many survivors and identified as a key area of concern [21, 22, 32, 53]. Impaired sexual functioning could be associated with a loss of masculine identity [56]:

> "I mean well I felt anyway I'm going in a whole man and not coming out a whole man"

Sexuality issues may have not have seemed important at diagnosis [28]:

> "…at diagnosis, your head is spinning and I think any other information would probably be too much to take on board."

However issues related to intimacy increased in significance for survivors as they progressed through treatment [27, 28]. It is noteworthy that many female survivors experienced decreased confidence as a result of alterations in their sexual self-concept, functioning, or fertility after treatment [27, 28]:

> "The fact that I couldn't have kids, I thought I wasn't normal."

Negative changes in sexual functioning were an area of concern for many survivors [28, 29, 46, 47, 56]. However, unmet intimacy needs did not feature in the top ten unmet needs reported by head and neck cancer survivors [45]. Survivors reported varied experiences of addressing sexuality concerns with HCPs [27, 56]. Negative interactions were reported, with survivors believing barriers to addressing their intimacy issues with HCPs existed. These included survivors' perceptions that HCPs were reluctant to talk about sexuality [27] or had negative attitudes towards intimacy-related discussions with their patients [56]:

> "ED [erectile dysfunction] is something that no one not even the consultants want to talk about… Of course I wanted to but it didn't happen and no one ever said to me there's medication there, there's counselling there."

Practical needs

Survivors reported unmet practical needs which included loss of income/lack of financial independence/support [37, 39, 40, 45, 51, 55] and issues such as access to HCPs (and/or out of hours access to HCPs) and sufficient time with HCPs during consultations [24, 31, 40, 43]. Financial hardship was reported across cancer types. In particular cancer-related financial stress and strain were measured. Financial strain reflects an individual's subjective perception of financial hardship (which may be unrelated to their income) while financial stress is a measure of the financial burden on an individual or household (incorporating illness-related financial costs) [51]. A study among mixed cancer survivors found increased financial stress (49%) and increased financial strain (32%) associated with cancer [51].

Head and neck cancer survivors (47%) also reported financial stress and increased concerns about finances (49%) due to cancer [45]. Similarly, large studies among colorectal cancer survivors have found financial difficulties (36%) [55]; financial stress (40.9%) or strain (39.4%) [39]. Survivors experiencing financial stress/strain were more likely to experience adverse psychological outcomes such as depression (36%) and/or anxiety (29%) [51]. Among prostate cancer survivors, those who were treated by radical prostatectomy reported a significantly higher financial difficulty score than those who were treated by brachytherapy [32]. Many survivors reported satisfaction with their general healthcare [40, 43] and considered they received high quality care during their treatment [31]:

> "The team was exceptional! They made the journey as easy as possible."

However some specific issues for survivors were also identified - these included lack of consistent contact between patient and HCPs and no specific contact details if assistance is required between visits [43]:

> "Somebody that we can ring or phone or follow up …"

Survivors' perception that HCPs were too busy had adverse outcomes for instance, important health issues/questions were not addressed [40]:

> "Well, I would love to have asked if I had enough time with the doctor… even the nurses… they are just so busy… but they haven't got time and I think that's a huge minus."

Quality of life/Daily living needs

There was variation in quality of life scores for survivors, suggesting difficulties with daily tasks [21, 24, 32, 33, 54]. In one study of ostomates, of whom 22% were colorectal cancer survivors, 69% reported good to excellent quality of life [30]. However a study of colorectal cancer survivors found that 76% of survivors with pain had poor quality of life [33]. Global health status (self-reported health-related quality of life) scores ranged from 67.2 in colorectal cancer survivors to 71.15 in prostate cancer survivors [21, 24] and across prostate cancer treatment groups from 64.1 - 79.4 [32]. This variation in global health status scores was also reflected in variation among survivors in general functioning across domains. These included low emotional functioning for oesophageal cancer survivors [35]; low cognitive functioning and low role functioning (i.e. ability to work) for prostate cancer survivors [21, 22]. Quality of life varied greatly across prostate cancer survivors and was often associated with symptom burden, treatment effects as well disease stage [22, 32, 35]. Breast cancer survivors also experienced unmet daily living needs in the areas of exercise and diet [43]:

> "Nobody in the clinic wants to give you advice [on diet or exercise]. I don't know, I get the impression that either they are not convinced themselves that diet makes any difference or it's not conclusively researched so they are not sure … but it's [diet] probably one of the things when I do come off the treatment, it's one of things I'd like advice on."

Many colorectal cancer survivors reported significant disruption to their quality of life which was linked to pain [33]. A study of urban and rural head and neck cancer survivors found many common quality of life issues such as communication difficulties, lack of energy and difficulties eating across the urban/rural divide. However, the study also found poorer quality of life scores in urban survivors compared to rural survivors [54].

Studies with colorectal cancer, head and neck cancer, and lymphoma survivors reported work related issues with many taking time off work or reducing their working hours [37, 38, 48]. Male colorectal cancer survivors were more likely to return to work on reduced hours than female survivors; average weekly reduction in hours following a return to work of 22.1 hours for males versus 12.4 hours for females. This higher reduction in hours for males may be a result of their higher working hours before diagnosis and/or less opportunities for females to reduce their hours as a result of their lower income before diagnosis [38]. Survivors reported difficulties adjusting to the loss of their work identity [37]:

> "When I was working I was a very good worker, I really loved my job […] There's a big gap there."

An important finding was the extended period before returning to work – greater than 12 months - experienced by 15% of head and neck cancer survivors [48]. Head and neck cancer survivors can experience specific challenges with daily activities, which can lead to decreased quality of life. These challenges include difficulties in communication/eating which can be persistent/long-term. Many head and neck survivors (over 90%) reported self-sustaining strategies - such as customising dietary practices - as their most common self-management strategy [34]. In addition, difficulties with daily activities could be overcome with social support - myeloma survivors described the assistance they relied on from family members to perform household tasks [40].

Health system/information needs

Several information needs were identified across studies [23, 31, 37, 40, 43-45, 49, 50, 52, 56]. One study among head and neck cancer survivors found that 21% of respondents reported at least one unmet need in the health system domain [45]. Survivors identified information deficits, with a lack of readily available information as well as the necessity of increased information from HCPs [37, 56]. Some survivors reported the need for HCPs to recap information [56]:

> “When I was being told about the side-effects all I wanted to be was above ground so I didn’t take much of what he said away with me.”

This information ranged from treatment summaries - with 59% of Irish breast cancer survivors reporting that a treatment summary would be useful [44] - to details of treatment options to physical, psychological, and social information [37, 44, 50, 56]. Breast cancer survivors specifically identified gaps in terms of continuity and co-ordination of their care. These included lack of information about possible emotional effects related to treatment [50] and lack of nutritional information.

Other issues included lack of practical information on managing treatment effects [50]. Unmet information needs were reported – low levels of breast cancer survivors (59%) received adequate information about their nutritional needs [31]. This study also identified a lack of personal contact or a patient-nurse relationship in their oncology care [31]:

> “You think at times that you’re the only one experiencing such symptoms! I couldn’t call my breast care nurse as her job is to look after patients before and after surgery. You’re kind of left to learn as you go along.”

A recent study with breast cancer survivors highlighted the change in information needs that occurs over time for survivors and the importance of addressing these evolving needs [52]. These survivors preferred HCPs as information sources (66%), followed by leaflets (18%) and the Internet (6%) [52]. Some prostate cancer survivors addressed their unmet information needs by using a variety of information sources. These information sources included peers, GPs, specialised HCPs, leaflets, urologist, the Irish Cancer Society, internet, books, newspapers, and alternative therapists [56]. The value of peer support programmes as a method of consolidating relevant and useful health information was also reported by survivors [50]:

> “You know I found by being in the group that there were major gaps in the information people were given…you know I was told one thing, and XXX would be told another…yeah…gaps in information. The group…it filled in a lot of the gaps.”

Patient-clinician communication needs

Many survivors reported unmet communication needs which included negative HCP interactions with time constraints; and insufficient/inadequate information about important aspects of treatment, such as emotional changes, and long term/persistent effects, such as cancer related fatigue [49, 56]. Survivors' perceptions were that HCPs frequently displayed inadequate communication which could be a result of a lack of knowledge [49].

Prostate cancer survivors also identified the attributes/characteristics of a HCP who could communicate effectively. Meeting patient-clinician communication needs were linked to HCP knowledge and attitudes [56]:

> "The GP has no idea how to respond and is offering no aftercare… There seems to be a complete lack of understanding of fatigue by the medical professionals and by other health related folks/voluntary organisations."

> "I think it would have to be a very special person to talk about these things. They'd have to have a great understanding themselves and none of that word taboo or any of these things. Twould be quite normal like."

Cognitive needs

There was a lack of information on survivors' cognitive functioning as cognitive impairments were generally not reported. The themes of distorted cognition and cognitive avoidance were reported as salient to cognitive needs. Survivors with cancer-related fatigue linked their persistent/unexplained fatigue to catastrophizing about cancer recurrence [49]:

> "Sometimes fear would take over me with the fatigue as the only symptom I had of breast cancer originally was fatigue. This fear is that the cancer has returned."

Adaptive strategies such as cognitive avoidance were frequently used by head and neck cancer survivors to cope with the specific challenges and long term effects associated with head and neck cancer [34]. In one study, head and neck cancer survivors (*n* = 16) used the specific cognitive strategy of avoiding thinking about cancer and its consequences [34].

Family-related needs

One study described family-related issues for prostate cancer [56]. The key focus for many survivors was to maintain normal life by preserving family relationships as they were before diagnosis:

> "…by the time I got into hospital. I still hadn't told my wife or children. I just didn't want to worry them about something that no one could put a name to."

Support from the family was reported as essential by some survivors; however, survivors also wanted to protect their family members and were reluctant to cause them distress [56].

Spiritual/existential needs

Limited research has been conducted in this area and just one Irish study with breast cancer survivors, which investigated spiritual needs, was identified by this review. A majority of breast cancer survivors reported no concerns about loss of faith (89%) and felt they did not need religious support (84%) [44]. However, 34% of participants in this study felt that they required additional spiritual information. This may reflect a desire among these participants for information about informal spiritual support options rather than formal pastoral care.

Discussion

This scoping review, the first of its kind conducted among Irish studies, investigated the unmet needs of cancer survivors following recommendation by the National Cancer Strategy 2017-2026 [16]. A total of 27 studies (34 papers) were included in the review. Quality appraisal of included studies can be found in Box 1. The majority of studies looked at unmet needs between 1-3 years post-treatment (*n* = 9), while, prostate, colorectal, and breast cancer survivors were the most frequently studied populations (prostate cancer survivors = 11 papers (from four studies), colorectal = 7 papers, and breast = 5 papers). This distribution reflects the burden of prevalent disease in the Irish population with breast, prostate, and colorectal cancer accounting for over 55% of total cancer prevalence. Head and neck cancer, blood and gynaecological malignancies were also represented in the literature. Although testicular cancer, melanoma, bladder, and kidney cancers contribute significantly to total cancer prevalence, these cancers have received little attention in the Irish survivorship literature. In addition, lung cancer has also received relatively little attention (though survival is poor); given its high incidence and physical challenges associated with treatment and the disease itself, it ought to receive more attention in unmet need research. This is also true for less common cancers and those with poor survival - the review found a striking lack of evidence on some cancers with low population numbers and high mortality rates (e.g. pancreatic cancer, gynaecological cancers, head, mouth and neck cancers, oesophageal and stomach cancers). Survivors of some of the cancers for which the evidence is lacking may have particular unmet needs which have not being identified in this review. The absence of some cancers in this scoping review does not detract from the urgent needs of many cancer survivors about which we know little about. Arguably, there is a case to be made for prioritising these groups which suffer acute physical, social and emotional consequences of surviving cancer.

As part of this scoping review, the survivorship needs of metastatic cancer patients (cancer which has spread from where it started to another body organ) were not looked at specifically in isolation. However, studies that had patients with advanced stages of disease (Stage 3 or 4) were examined as part of the overall picture of cancer survivors in Ireland. It is likely that the needs of those with metastatic cancer differ to those who have finished their cancer treatment(s) and are in the survivorship phase. A cursory look at the available literature on the needs of those living with metastatic cancer in Ireland highlights that there is a significant dearth of evidence available. One recent report described findings from a study on quality of life, fatigue, and cognitive concerns in twelve women with metastatic breast cancer in Ireland [57]. This study found that the physical and psychosocial needs of these women were not being meet by existing services. The data on the numbers of people living with metastatic cancer in Ireland have only begun to be looked at by the National Cancer Registry. Establishing a broad picture of the burden of metastatic cancer in Ireland is needed – this will help inform research around the patient experience and unmet needs of those living with metastatic cancer. Investigation into this area is urgently required to help inform the development of metastatic cancer specific support services.

The following unmet needs were common across cancer types: physical symptoms (in particular pain, fatigue, and sleep disturbances); psychological needs; information deficits and need for increased information from health professionals; recognition among cancer survivors of the importance of social support; conflicting desire to shield family/friends; and financial hardship (financial stress linked to depression/anxiety). The review also found clear evidence of inter-relationships between various unmet needs. For example, in the case of physical and psychosocial/emotional needs, long term psychological effects could be linked to physical symptoms [41] or treatment [30].

There was also evidence of a link between social needs (particularly social support) and health system/information needs, while cancer survivors experiencing financial stress (a common practical unmet need) were more likely to experience adverse psychological outcomes such as depression and/or anxiety. While the evidence in this review was limited, there may be specific need profiles associated with specific diseases and treatments. Therefore, the planning and design of survivorship services will benefit from additional research which gathers detailed information across multiple diseases. Unmet needs were not ranked or assessed for importance by survivors in the studies reported on for this review. Future research is required to determine if survivor's rank particular supportive care needs as more important than others and if these rankings change over time. Some evidence on the impact of cancer treatment side-effects on survivors was available in this review. However, the available research suggests that the impact of side-effects have been primarily investigated among prostate cancer survivors in Ireland (see results reported from the PiCTure study e.g. [21-24]. The impact of side-effects on survivors' quality of life, requires fuller investigation, across cancer types, in future research on unmet needs.

In addition to gaps in the literature related to specific cancer types, there is also a lack of information on variation in unmet needs depending on socio-demographic characteristics. Only one study included in the review specifically investigated unmet need differences in urban and rural cancer survivor populations [54] and no studies investigated unmet needs related to deprivation status. Cancer incidence is higher in the most deprived 20% of the population compared with the least deprived 20% of the population. In addition, survival rates are also poorer in the most deprived populations, and treatment patterns may also vary [58]. Consequently, unmet needs and the burden of unmet needs are likely influenced by deprivation status. Further work should focus on investigating differences in unmet needs by deprivation status.

With the exception of one study which reported that feeling pain after treatment for colorectal cancer was associated with younger age [33], no other studies examined the extent to which age impacts on unmet needs or whether unmet needs differ by age. While cancer is in many respects a disease of older age, one in seven cancer survivors alive at the end of 2016 were under 50 years of age [2] and many more would be of working age. With working age increasing and cancer incidence increasing in younger populations, examining care needs of people at working age will be of particular importance [2].

Another major limitation of the evidence-base identified in the scoping review is the fact that almost all of the quantitative studies included were cross-sectional in design. There is a lack of longitudinal data on the unmet needs of cancer survivors following treatment and how these needs may vary over time. However, the studies that have been included in this report do vary by time since diagnosis. Although these do not facilitate a meaningful comparison of health and quality of life in individual patients over time, they do allow a certain understanding of the burden of disease in the population and the services required to support them. These studies are particularly important for prostate and breast cancers where a large proportion of patients survive over 10 years after diagnosis and beyond. Seven studies (*n* = 11 papers) investigated physical effects which included long term treatment effects [21-23, 32, 36, 41-45, 55]. Long term effects were linked to adverse psychological outcomes and poor quality of life. Cancer survivors were not prepared by their health professionals for the psychological impact of treatment effects. In addition, it is also important to monitor unmet need during the acute treatment phase when physical, psychological, and information needs may be at their greatest. Studies investigating need during the acute treatment phase of the patient experience were excluded from this review, as acute survivorship has very specific patient needs which are often specific to the cancer treatment and considered distinct from extended or permanent survivorship needs.

However, acute care needs represent an important phase of the survivorship pathway for support services and the first opportunity to address health and quality of life deficits in cancer patients. While it is likely that there are specific physical, psychological and social needs particularly after surgery relating to pain, wound management, and information, this is not available in the literature. All of the large population-based studies focused on patients diagnosed at least two years after diagnosis. This is largely due to the timeliness of cancer registry data which is only considered complete around 18 months after the end of the year of diagnosis. The timeliness of registry data presents a significant challenge in terms of capturing routine data on unmet need and patient reported outcomes generally during the acute phase of patient care. Future studies should aim to collect information on the patient care experience and increase understanding of unmet need at the acute phase of care. Increased information on this particular aspect of patient care could lead to the development of targeted interventions that address survivors' needs and lead to downstream improvements in health and quality of life.

A key observation in this review was that most of the quantitative studies (survey-based) which were eligible for inclusion in this scoping review did not use standardised cancer unmet need instruments to assess outcomes. With the exception of two studies [29, 45], which used the Supportive Care Needs Survey, studies either used cancer-related quality of life measures (e.g. the EORTC QLQ instrument) and/or authors of studies developed their own measures for assessing outcomes. Quality of life instruments while useful for assessing quality of life are not designed to capture specific unmet needs of cancer patients. While these instruments provide useful insights into the needs of patients, they restrict the extent to which explicit statements can be made about the volume of unmet need that exists in the Irish population. Future studies should specifically include standardised unmet need survey instruments and ensure that meaningful meta-analysis of the data can be conducted.

It is unlikely that the unmet needs of patients diagnosed in 2018 would be comparable to those of patients diagnosed 20 years previously. Not only has the demography of cancer survivors changed over that period, but surgical and oncological treatments for most diseases have also changed considerably, with an increased emphasis on quality of life. In addition, cancer services have become increasingly centralised and screening programmes have been introduced for breast, bowel, and cervical cancer. These changes may have significantly impacted on supportive care needs at a population level. Of the 27 studies included in this review, the majority were published after 2010; however, they often relate to patients diagnosed earlier and may not provide the most up to date evidence to support development of cancer support services in Ireland. This suggests a requirement to routinely monitor the care needs of cancer patients in Ireland, both to design and evaluate cancer survivorship strategies in Ireland.

With an ageing population and increasing numbers of patients diagnosed with cancer, comorbidity management is set to play an increasing role in modern health services in Ireland. Comorbidity is a disease or illness affecting a cancer patient in addition to, but not as a result of, their current cancer. Comorbidity potentially affects the development, stage at diagnosis, treatment, and outcomes of people with cancer. Despite the intimate relationship between comorbidity and cancer, there is limited consensus on how to record, interpret, or manage comorbidity in the context of cancer, resulting in patients with comorbidity being less likely to receive treatment with curative intent.

Evidence in this area is lacking because of the frequent exclusion of patients with comorbidity from randomised controlled trials [59]. Few studies included in this review reported the impact of comorbidities on cancer survivors ($n = 3$) [59]. In one study [53] of prostate cancer survivors, the presence of comorbidities was associated with a higher risk of four “current” side-effects (incontinence, libido loss, bowel problems, and fatigue) of cancer treatment.

Collecting patient-reported data on comorbidity among the growing Irish cancer survivor population is important.

Such data can not only help support treatment decisions but it can also facilitate the monitoring and management of comorbidity as a consequence of cancer and its treatment.

Box 1 Quality appraisal of data available on cancer unmet needs and potential sources of bias

The National Institutes of Health Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies was used to appraise the quality of quantitative studies [25]. Qualitative studies were assessed using the 10-item CASP (Critical Appraisals Skills Programme) Qualitative Checklist [26]. The methodological quality of the majority of studies was rated as fair ($n = 18$). Thirteen papers were rated poor and three assessed as good. The majority of quantitative studies were rated as fair ($n = 16$), poor ($n = 8$), or good ($n = 2$). Many of these papers had a high risk of potential bias and did not control for confounding variables. Diverse instruments were used to assess survivor needs and some papers did not use validated measures. In addition, there are multiple papers reporting on data from the same populations (e.g. the PICTure study; $n = 7$ papers) consideration must be given to this in the overall interpretation of the results. The majority of qualitative studies were rated as poor ($n = 5$) or fair ($n = 2$), with one study rated as good. Many of the qualitative papers had a high risk of bias and problems with generalisability due to small sample sizes. Poor reporting of results and limited descriptions of analysis were also common across these studies. Future studies in the Irish setting should focus on consistent measurement of unmet needs, with validated measures and robust methodologies.

Conclusions and Recommendations

The overarching aim of this research was to inform survivorship healthcare by assessing the available research on unmet needs of cancer survivors in Ireland. The results from this review indicate current research in this area is limited and that more detailed information is required for strategic development. Overall the available research indicates that survivors' needs are frequently complex, with multidimensional relationships and affected by both intrinsic and extrinsic factors. It is clear that appropriate survivorship care programmes need to be adaptable and assist survivors with a range of both short-term and long-term effects which can be related to cancer and its treatments. These effects relate to physical, psychological, social, and financial issues.

Cancer prevalence is rising with increasing incidence and improving survival rates, and as a result, survivorship care in Ireland requires a fundamental review. Traditional perceptions of cancer as a life-threatening condition have changed to the current awareness that cancer can be considered a chronic illness, with attendant implications for healthcare services. The National Cancer Strategy has identified survivorship care as a key challenge until 2026 and beyond. This report further reinforces the importance of enhancing survivorship services to address the unmet needs of cancer survivors. Survivorship strategies should be focused on services that will help achieve the greatest gains in quality of life of cancer survivors. Innovative methods will be required to address the growing burden of unmet need in the Irish cancer patient population in a cost-effective way.

The results of this report highlight significant gaps in evidence in the understanding of the extent to which services are currently addressing unmet needs among cancer survivors. The unmet needs of survivors are extensive and vary by geography, socio-demographic grouping, and by cancer type.

A broad research programme around the unmet needs of Irish cancer survivors including an up to date large-scale national survey is required to help address the gaps identified in this review. As is evident from the following recommendations emerging from this scoping review, and as is highlighted within the National Cancer Strategy 2017-2026, a comprehensive approach needs to be undertaken in order to implement the following recommendations and fully address the needs of all cancer survivors within Ireland.

Summary of recommendations:

Recommendations 1-8

1. Survivorship care programmes should be tailored to address the specific needs (physical, psychosocial, practical, and spiritual) of individual cancer survivors as 'one size does not fit all.'

2. Specific survivorship care services are required to address unmet physical, practical and psychological needs across most cancers. These include: social, sexual, practical, quality of life, information, communication, family and spiritual needs.

3. Research on specific aspects of cancer survivors' unmet needs is lacking. These include: particular cancer types (e.g. rarer cancers) which are under-represented in the existing literature, hereditary and genetic cancers, in addition to metastatic cancers; the impact of treatment side-effects on survivors; longitudinal data on unmet needs; financial needs of cancer survivors; and relationships between unmet needs and socio-economic status. Prioritisation of research in these areas is required by relevant organisations.

4. Survivorship care evidence is required for the acute care phase as well as beyond treatment.

5. Survivorship care services should be evaluated at population level to measure progress in quality of life outcomes and routine monitoring tools are required.
6. Service performance monitoring is required to provide evidence of deficits in services for population subgroups (e.g. geography, deprivation levels, comorbidity, sexual orientation).
7. Health economic research will be valuable to assess the cost of survivorship services and the quality of life benefits for patients.
8. A comprehensive unmet needs work programme (incorporating a national survey of cancer survivors) is required to address the gaps in evidence on cancer survivor's unmet needs identified in this review and support the implementation of national cancer survivorship care strategies. Such work programmes should be undertaken on an ongoing basis in order to continually and consistently monitor progress and success of these survivorship strategies.

Glossary of terms

Activities of daily living: activities of daily living are basic tasks that must be accomplished for an individual to live independently. Basic activities of daily living include tasks such as personal care/hygiene, feeding, and dressing. Instrumental activities of daily living are more demanding tasks, such as managing finances, shopping, managing medications, and cooking.

Care plan: is a plan of care for survivors of cancer which should include treatment care plan, patient treatment summary and follow up plan. In 2006 the Institute of Medicine issued a report recommending that every cancer patient receive an individualised survivorship care plan that includes guidelines for monitoring and maintaining their health. In response to that report, many groups have now developed various types of "care plans" to help improve the quality of care of survivors as they move beyond their cancer treatment.

Cognition: a mental process that allows people to acquire knowledge, experience and interact with their environment, experience consciousness, etc. For example, language and memory are domains of cognition.

Comorbidity: the existence of one or more conditions in addition to the primary condition.

Disease trajectory: course of disease/illness.

Fear of recurrence: a fear that cancer may return post-treatment.

General practitioners/primary care physician: physician or medical doctor who specialises in internal medicine, paediatric medicine or family/general practice.

Healthcare professional (HCP): an individual working in a health care environment. Includes, amongst others, the disciplines of medicine, nursing, psychology, physiotherapy, speech and language therapy, dietetics, etc.

Post-treatment: the stage of cancer trajectory where a person has completed their treatment such as chemotherapy, radiotherapy, surgery, hormonal therapy or combinations of these.

PROMs (Patient-Reported Outcome Measures): PROMs are standardised questionnaires completed by patients to measure their functional and health status.

Scoping review: scoping studies are a form of literature review. They are used to examine the extent, range, and nature of research activity, determine the value of undertaking a full systematic review, summarise and disseminate research findings and identify gaps in the existing literature

Survivor: a person with any type of cancer who has undergone treatment, completed the intervention and is living. The National Cancer Institute's (NCI) Office of Cancer Survivorship states that "an individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life." For the purpose of this review, research was undertaken on any cancer survivor who was an adult (18 years or over) and currently post-treatment (e.g. finished chemotherapy, radiotherapy, surgery, hormonal therapy). Some studies included in this report also incorporated cancer survivors living with advance cancer (metastatic), who were likely in receipt of ongoing treatment.

Survivorship pathway: a depiction of the process involved in survivorship care maintaining the key principles of survivorship care which should be available to all cancer survivors

Qualitative research: qualitative research gathers data in non-numerical format e.g. interviews, focus groups. Qualitative research is concerned with words, meanings, or experiences.

Quality of life: perceived quality of an individual's everyday life, usually stratified under subdomains e.g. health-related quality of life.

Quantitative research: quantitative research gathers data in numeric format e.g. age, score on a questionnaire, counts of certain cancer types.

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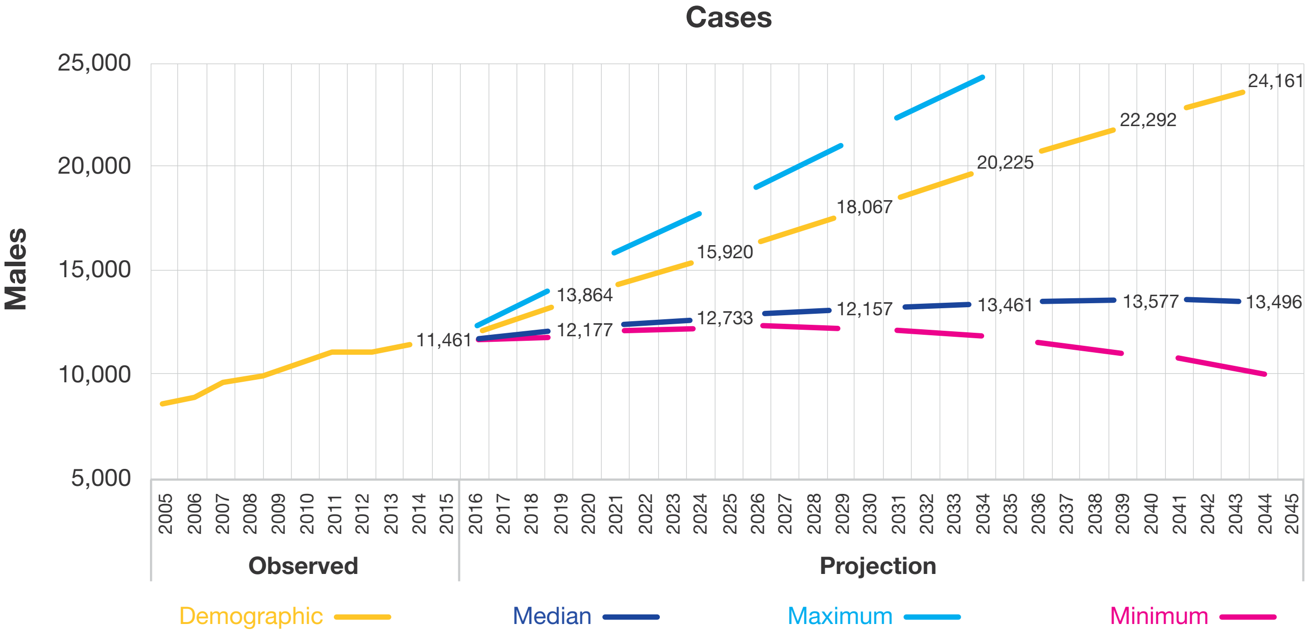
Appendices

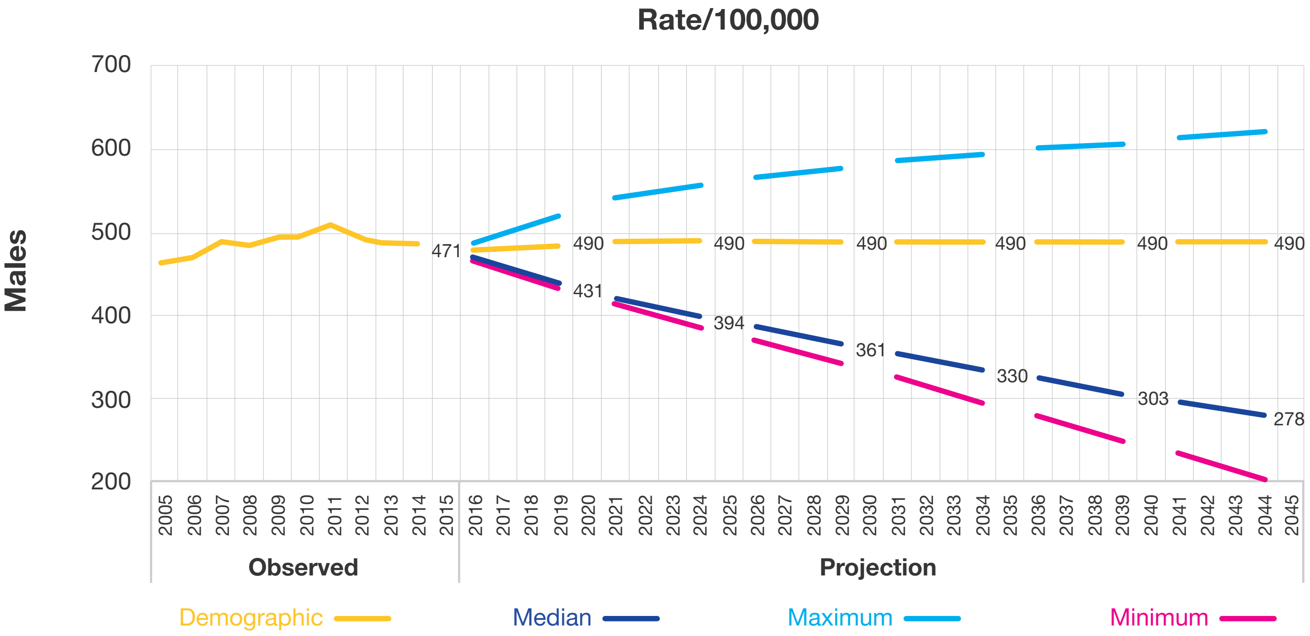
Abbreviations and symbols used in tables and figures throughout appendices

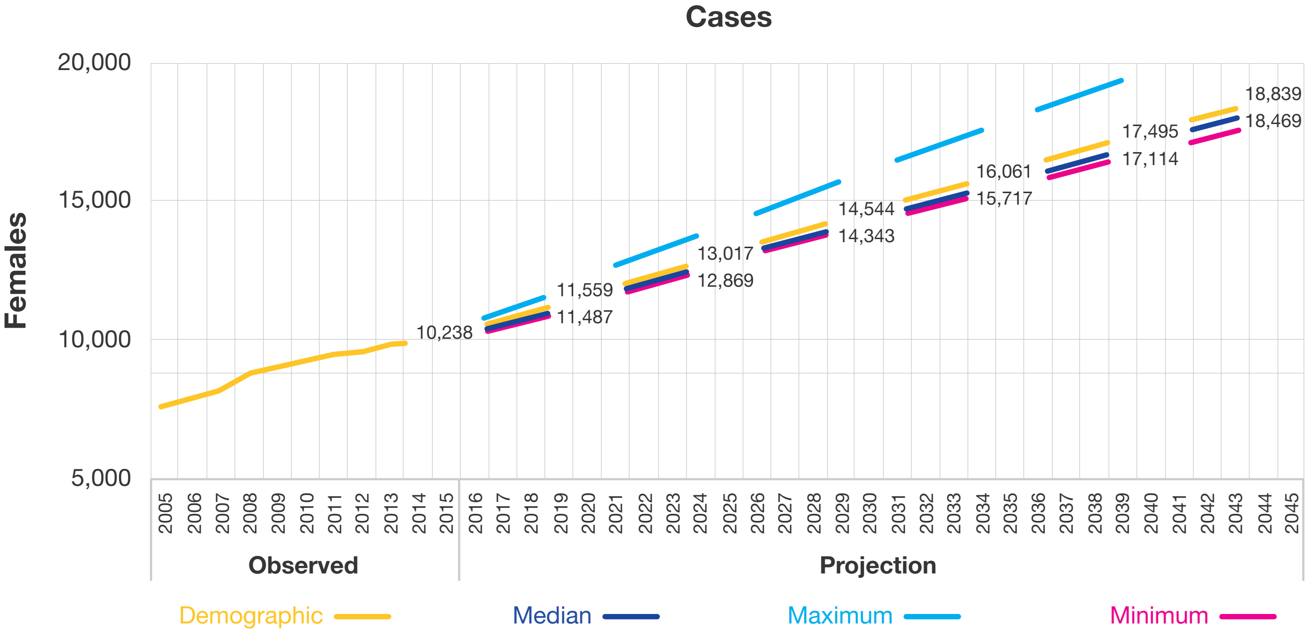
ADT	Androgen deprivation therapy
BC	Breast cancer
BT	Brachytherapy
CASP	Critical Appraisal Skills Programme
CI	Confidence intervals
CRC	Colorectal cancer
CRF	Cancer related fatigue
DASS	Depression anxiety stress scales
ED	Erectile dysfunction
ERB	External beam radiation therapy
EORTC	European organization for research and treatment of cancer
EuroQoL	European quality of life scale
FACT	Functional Assessment of Cancer Therapy
FOR	Fear of recurrence
GHS	Global health status
GP	General practitioner
GLOBOCAN	Global cancer incidence mortality and prevalence
HCP	Healthcare professional
HNC	Head and neck cancers
HRQoL	Health-related quality-of-life
HT	Hormone therapy
LRT	Likelihood ratio tests
Mdn	Median
N	Number (total sample/population)
n	Number (subsample)
NB	Important
NCRI	National Cancer Registry Ireland

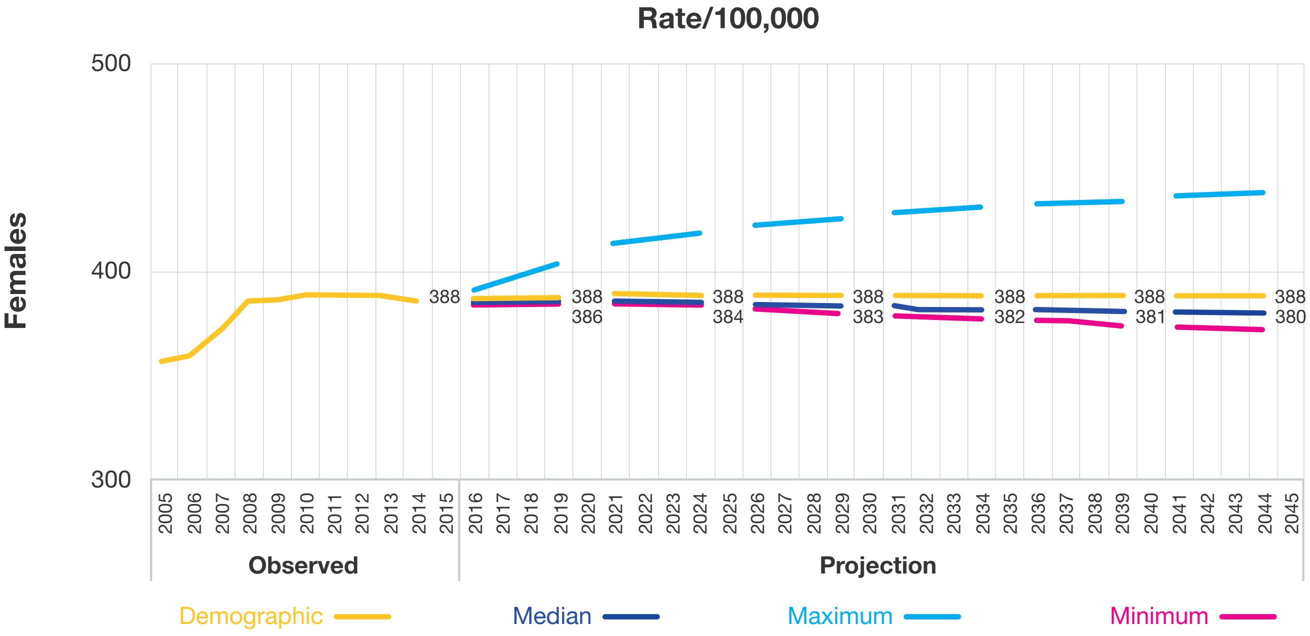
NI	Northern Ireland
NICR	Northern Ireland Cancer Registry
NR	Not reported
OR	Odds Ratio
P	Significance value
PC	Prostate cancer
PD	Permanent disability
PM	Premature mortality
PiCTure	Prostate Cancer Treatment, your experience
PROMs	Patient reported outcome measures
QoL	Quality of life
ROI	Republic of Ireland
RP	Radical prostatectomy
SCN	Supportive care need
SD	Standard deviation
SE	Side-effects
SRH	Self-rated health
TD	Temporary disability
$\bar{X}$	Mean
<	Less than
>	Greater than

Appendix 1: Projected cases and incidence rates of all invasive cancers, excluding non-melanoma skin cancer, for the estimated population in Ireland up to 2045 (Source: NCRI)









The demographic incidence projections were generated by applying the average annual incidence rate for the period 2011-2015 to the projected population up to 2045. Projections were generated using five additional models using different assumptions to project recent trends in incidence rates into the future. The median of all six models (five models and the demographic model) was then calculated. The demographic and median projections are presented here, as well as the minimum and maximum incidence projected using the other five models.

Appendix 2: PRISMA-ScR Checklist

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

Section	Item	PRISMA-ScR Checklist Item	Reported on Page #
Title			
Title	1	Identify the report as a scoping review.	Front Cover
Abstract			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	6
Introduction			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	10 to 12
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g. population or participants, concepts, and context) or other relevant key elements used to conceptualise the review questions and/or objectives.	11
Methods			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g. a Web address); and if available, provide registration information, including the registration number.	13; https://osf.io/ax7r2
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g. years considered, language, and publication status), and provide a rationale.	13 and 14
Information sources*	7	Describe all information sources in the search (e.g. databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	13
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	48
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e. screening and eligibility) included in the scoping review.	13 to 16
Data charting process	10	Describe the methods of charting data from the included sources of evidence (e.g. calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	15
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	16
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	16

Synthesis of results	13	Describe the methods of handling and summarising the data that were charted.	16
Results			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	17
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	18
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	16, 19, 20 and 33
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	59 to 77
Synthesis of results	18	Summarise and/or present the charting results as they relate to the review questions and objectives.	59 to 77
Discussion			
Summary of evidence	19	Summarise the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	30 to 33
Limitations	20	Discuss the limitations of the scoping review process.	30 to 33
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	34 and 35
Funding			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	3

* Where sources of evidence (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g. quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with information sources (see first footnote).

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g. quantitative and/or qualitative research, expert opinion, and policy document).

Table from: Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K. K., Colquhoun, H., Levac, D., ... & Hempel, S. (2018). PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. Annals of internal medicine, 169(7), 467-473.doi: 10.7326/M18-0850 [19]

Appendix 3: Search terms and strategy for databases

Databases 1998-2018	Search strategy
EMBASE **CINAHL Complete** **Pubmed** **PsychInfo** **Cochrane Library**	cancer OR neoplasm OR oncol*
	AND
	survivor* OR survivorship OR “follow up” OR follow-up
	AND
	“unmet needs” OR “care needs” OR “patient* needs” OR “needs assessment” OR “family needs” OR “supportive care needs”
	AND
	“physical needs” OR “psychosocial needs” OR “emotional needs” OR “social needs” OR “interpersonal needs” OR “intimacy needs” OR “practical needs” OR “daily living needs” OR “spiritual needs” OR “existential needs” OR “health information” OR “health system information” OR “patient clinician communication needs” OR “cognitive needs”
	AND
	‘ireland’ OR ‘irish (citizen)’
Hand searching‡	Journal of Cancer Survivorship; The Irish Medical Journal

Adapted from Paterson et al., 2015 [15] & Hegarty et al., 2018 [20]; ‡Relevant journals identified from reference lists of eligible papers.

Appendix 4: NIH Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies

NIH National Heart, Lung, and Blood Institute

Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies

Criteria	Yes	No	Other (CD, NR, NA)*
1. Was the research question or objective in this paper clearly stated?			
2. Was the study population clearly specified and defined?			
3. Was the participation rate of eligible persons at least 50%?			
4. Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?			
5. Was a sample size justification, power description, or variance and effect estimates provided?			
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?			
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?			
8. For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as continuous variable)?			
9. Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?			
10. Was the exposure(s) assessed more than once over time?			
11. Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?			
12. Were the outcome assessors blinded to the exposure status of participants?			
13. Was loss to follow-up after baseline 20% or less?			
14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?			

Quality Rating (Good, Fair, or Poor) (see guidance)
Rater #1 initials:
Rater #2 initials:
Additional Comments (If POOR, please state why):

*CD, cannot determine; NA, not applicable; NR, not reported

Guidance for Assessing the Quality of Observational Cohort and Cross-Sectional Studies

The guidance document below is organized by question number from the tool for quality assessment of observational cohort and cross-sectional studies.

Question 1. Research question

Did the authors describe their goal in conducting this research? Is it easy to understand what they were looking to find? This issue is important for any scientific paper of any type. Higher quality scientific research explicitly defines a research question.

Questions 2 and 3. Study population

Did the authors describe the group of people from which the study participants were selected or recruited, using demographics, location, and time period? If you were to conduct this study again, would you know who to recruit, from where, and from what time period? Is the cohort population free of the outcomes of interest at the time they were recruited?

An example would be men over 40 years old with type 2 diabetes who began seeking medical care at Phoenix Good Samaritan Hospital between January 1, 1990 and December 31, 1994. In this example, the population is clearly described as: (1) who (men over 40 years old with type 2 diabetes); (2) where (Phoenix Good Samaritan Hospital); and (3) when (between January 1, 1990 and December 31, 1994). Another example is women ages 34 to 59 years of age in 1980 who were in the nursing profession and had no known coronary disease, stroke, cancer, hypercholesterolemia, or diabetes, and were recruited from the 11 most populous States, with contact information obtained from State nursing boards.

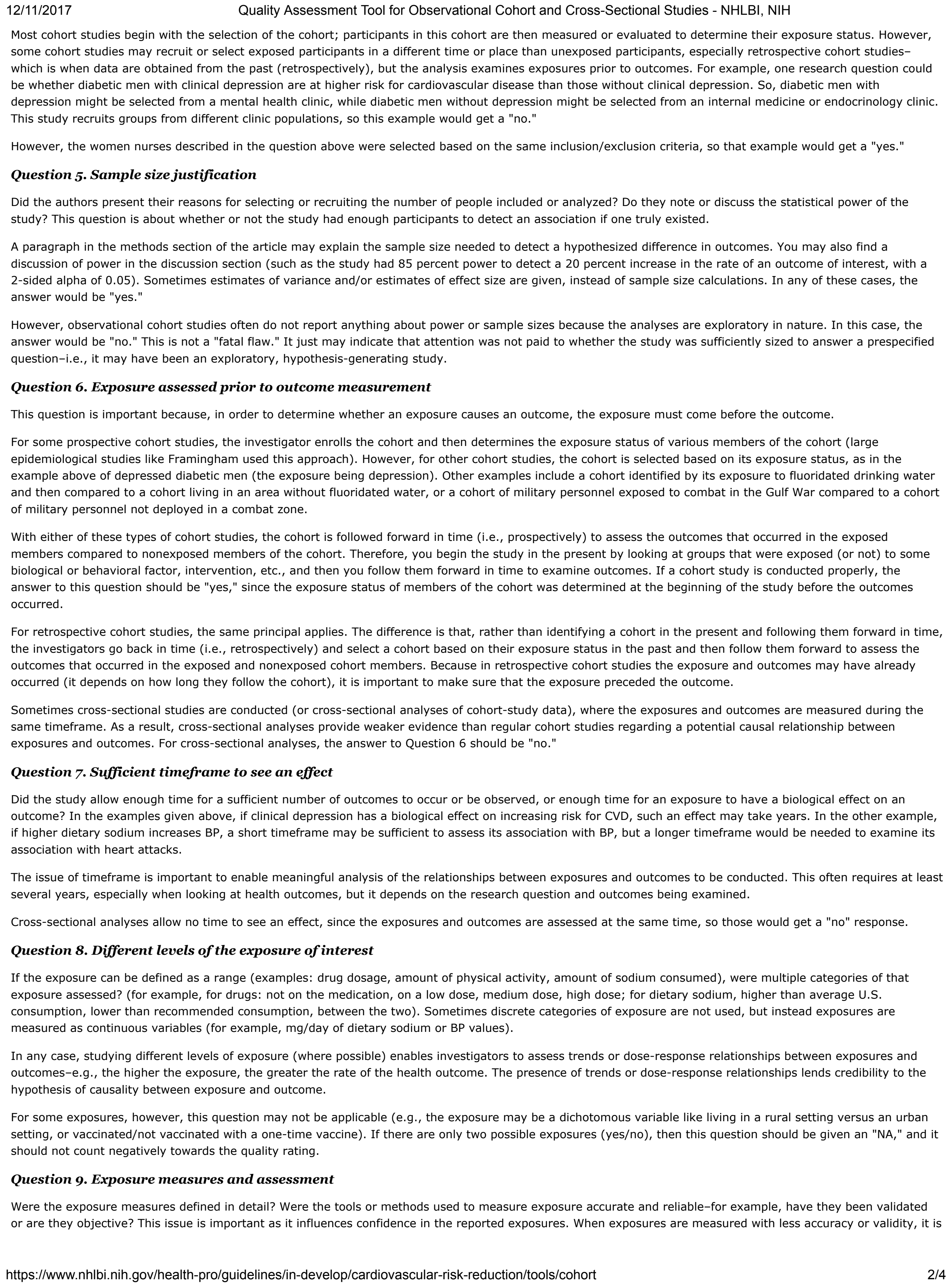
In cohort studies, it is crucial that the population at baseline is free of the outcome of interest. For example, the nurses' population above would be an appropriate group in which to study incident coronary disease. This information is usually found either in descriptions of population recruitment, definitions of variables, or inclusion/exclusion criteria.

You may need to look at prior papers on methods in order to make the assessment for this question. Those papers are usually in the reference list.

If fewer than 50% of eligible persons participated in the study, then there is concern that the study population does not adequately represent the target population. This increases the risk of bias.

Question 4. Groups recruited from the same population and uniform eligibility criteria

Were the inclusion and exclusion criteria developed prior to recruitment or selection of the study population? Were the same underlying criteria used for all of the subjects involved? This issue is related to the description of the study population, above, and you may find the information for both of these questions in the same section of the paper.



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Most cohort studies begin with the selection of the cohort; participants in this cohort are then measured or evaluated to determine their exposure status. However, some cohort studies may recruit or select exposed participants in a different time or place than unexposed participants, especially retrospective cohort studies–which is when data are obtained from the past (retrospectively), but the analysis examines exposures prior to outcomes. For example, one research question could be whether diabetic men with clinical depression are at higher risk for cardiovascular disease than those without clinical depression. So, diabetic men with depression might be selected from a mental health clinic, while diabetic men without depression might be selected from an internal medicine or endocrinology clinic. This study recruits groups from different clinic populations, so this example would get a "no."

However, the women nurses described in the question above were selected based on the same inclusion/exclusion criteria, so that example would get a "yes."

Question 5. Sample size justification

Did the authors present their reasons for selecting or recruiting the number of people included or analyzed? Do they note or discuss the statistical power of the study? This question is about whether or not the study had enough participants to detect an association if one truly existed.

A paragraph in the methods section of the article may explain the sample size needed to detect a hypothesized difference in outcomes. You may also find a discussion of power in the discussion section (such as the study had 85 percent power to detect a 20 percent increase in the rate of an outcome of interest, with a 2-sided alpha of 0.05). Sometimes estimates of variance and/or estimates of effect size are given, instead of sample size calculations. In any of these cases, the answer would be "yes."

However, observational cohort studies often do not report anything about power or sample sizes because the analyses are exploratory in nature. In this case, the answer would be "no." This is not a "fatal flaw." It just may indicate that attention was not paid to whether the study was sufficiently sized to answer a prespecified question–i.e., it may have been an exploratory, hypothesis-generating study.

Question 6. Exposure assessed prior to outcome measurement

This question is important because, in order to determine whether an exposure causes an outcome, the exposure must come before the outcome.

For some prospective cohort studies, the investigator enrolls the cohort and then determines the exposure status of various members of the cohort (large epidemiological studies like Framingham used this approach). However, for other cohort studies, the cohort is selected based on its exposure status, as in the example above of depressed diabetic men (the exposure being depression). Other examples include a cohort identified by its exposure to fluoridated drinking water and then compared to a cohort living in an area without fluoridated water, or a cohort of military personnel exposed to combat in the Gulf War compared to a cohort of military personnel not deployed in a combat zone.

With either of these types of cohort studies, the cohort is followed forward in time (i.e., prospectively) to assess the outcomes that occurred in the exposed members compared to nonexposed members of the cohort. Therefore, you begin the study in the present by looking at groups that were exposed (or not) to some biological or behavioral factor, intervention, etc., and then you follow them forward in time to examine outcomes. If a cohort study is conducted properly, the answer to this question should be "yes," since the exposure status of members of the cohort was determined at the beginning of the study before the outcomes occurred.

For retrospective cohort studies, the same principal applies. The difference is that, rather than identifying a cohort in the present and following them forward in time, the investigators go back in time (i.e., retrospectively) and select a cohort based on their exposure status in the past and then follow them forward to assess the outcomes that occurred in the exposed and nonexposed cohort members. Because in retrospective cohort studies the exposure and outcomes may have already occurred (it depends on how long they follow the cohort), it is important to make sure that the exposure preceded the outcome.

Sometimes cross-sectional studies are conducted (or cross-sectional analyses of cohort-study data), where the exposures and outcomes are measured during the same timeframe. As a result, cross-sectional analyses provide weaker evidence than regular cohort studies regarding a potential causal relationship between exposures and outcomes. For cross-sectional analyses, the answer to Question 6 should be "no."

Question 7. Sufficient timeframe to see an effect

Did the study allow enough time for a sufficient number of outcomes to occur or be observed, or enough time for an exposure to have a biological effect on an outcome? In the examples given above, if clinical depression has a biological effect on increasing risk for CVD, such an effect may take years. In the other example, if higher dietary sodium increases BP, a short timeframe may be sufficient to assess its association with BP, but a longer timeframe would be needed to examine its association with heart attacks.

The issue of timeframe is important to enable meaningful analysis of the relationships between exposures and outcomes to be conducted. This often requires at least several years, especially when looking at health outcomes, but it depends on the research question and outcomes being examined.

Cross-sectional analyses allow no time to see an effect, since the exposures and outcomes are assessed at the same time, so those would get a "no" response.

Question 8. Different levels of the exposure of interest

If the exposure can be defined as a range (examples: drug dosage, amount of physical activity, amount of sodium consumed), were multiple categories of that exposure assessed? (for example, for drugs: not on the medication, on a low dose, medium dose, high dose; for dietary sodium, higher than average U.S. consumption, lower than recommended consumption, between the two). Sometimes discrete categories of exposure are not used, but instead exposures are measured as continuous variables (for example, mg/day of dietary sodium or BP values).

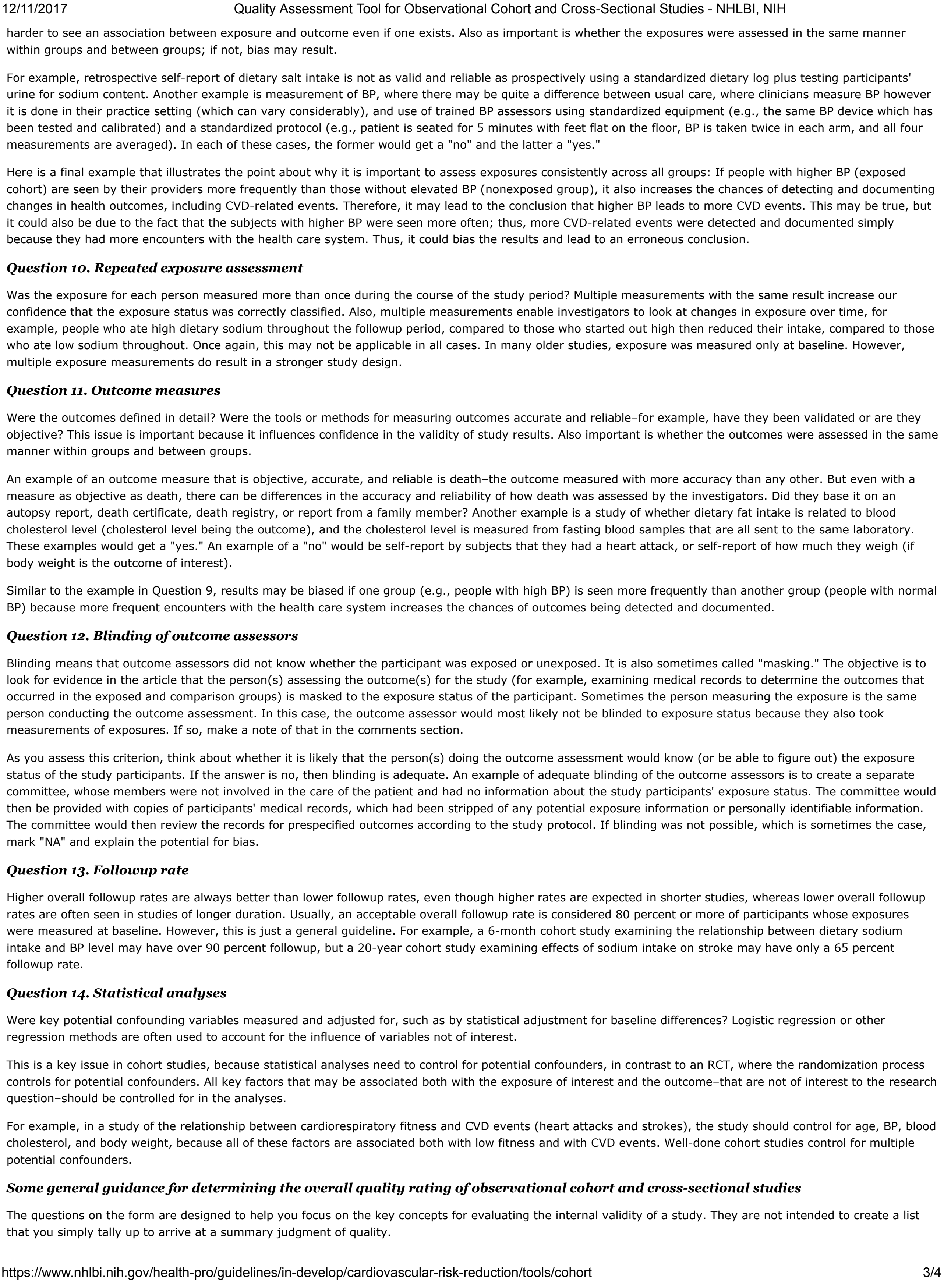
In any case, studying different levels of exposure (where possible) enables investigators to assess trends or dose-response relationships between exposures and outcomes–e.g., the higher the exposure, the greater the rate of the health outcome. The presence of trends or dose-response relationships lends credibility to the hypothesis of causality between exposure and outcome.

For some exposures, however, this question may not be applicable (e.g., the exposure may be a dichotomous variable like living in a rural setting versus an urban setting, or vaccinated/not vaccinated with a one-time vaccine). If there are only two possible exposures (yes/no), then this question should be given an "NA," and it should not count negatively towards the quality rating.

Question 9. Exposure measures and assessment

Were the exposure measures defined in detail? Were the tools or methods used to measure exposure accurate and reliable–for example, have they been validated or are they objective? This issue is important as it influences confidence in the reported exposures. When exposures are measured with less accuracy or validity, it is

https://www.nhlbi.nih.gov/health-pro/guidelines/in-develop/cardiovascular-risk-reduction/tools/cohort 2/4



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harder to see an association between exposure and outcome even if one exists. Also as important is whether the exposures were assessed in the same manner within groups and between groups; if not, bias may result.

For example, retrospective self-report of dietary salt intake is not as valid and reliable as prospectively using a standardized dietary log plus testing participants' urine for sodium content. Another example is measurement of BP, where there may be quite a difference between usual care, where clinicians measure BP however it is done in their practice setting (which can vary considerably), and use of trained BP assessors using standardized equipment (e.g., the same BP device which has been tested and calibrated) and a standardized protocol (e.g., patient is seated for 5 minutes with feet flat on the floor, BP is taken twice in each arm, and all four measurements are averaged). In each of these cases, the former would get a "no" and the latter a "yes."

Here is a final example that illustrates the point about why it is important to assess exposures consistently across all groups: If people with higher BP (exposed cohort) are seen by their providers more frequently than those without elevated BP (nonexposed group), it also increases the chances of detecting and documenting changes in health outcomes, including CVD-related events. Therefore, it may lead to the conclusion that higher BP leads to more CVD events. This may be true, but it could also be due to the fact that the subjects with higher BP were seen more often; thus, more CVD-related events were detected and documented simply because they had more encounters with the health care system. Thus, it could bias the results and lead to an erroneous conclusion.

Question 10. Repeated exposure assessment

Was the exposure for each person measured more than once during the course of the study period? Multiple measurements with the same result increase our confidence that the exposure status was correctly classified. Also, multiple measurements enable investigators to look at changes in exposure over time, for example, people who ate high dietary sodium throughout the followup period, compared to those who started out high then reduced their intake, compared to those who ate low sodium throughout. Once again, this may not be applicable in all cases. In many older studies, exposure was measured only at baseline. However, multiple exposure measurements do result in a stronger study design.

Question 11. Outcome measures

Were the outcomes defined in detail? Were the tools or methods for measuring outcomes accurate and reliable–for example, have they been validated or are they objective? This issue is important because it influences confidence in the validity of study results. Also important is whether the outcomes were assessed in the same manner within groups and between groups.

An example of an outcome measure that is objective, accurate, and reliable is death–the outcome measured with more accuracy than any other. But even with a measure as objective as death, there can be differences in the accuracy and reliability of how death was assessed by the investigators. Did they base it on an autopsy report, death certificate, death registry, or report from a family member? Another example is a study of whether dietary fat intake is related to blood cholesterol level (cholesterol level being the outcome), and the cholesterol level is measured from fasting blood samples that are all sent to the same laboratory. These examples would get a "yes." An example of a "no" would be self-report by subjects that they had a heart attack, or self-report of how much they weigh (if body weight is the outcome of interest).

Similar to the example in Question 9, results may be biased if one group (e.g., people with high BP) is seen more frequently than another group (people with normal BP) because more frequent encounters with the health care system increases the chances of outcomes being detected and documented.

Question 12. Blinding of outcome assessors

Blinding means that outcome assessors did not know whether the participant was exposed or unexposed. It is also sometimes called "masking." The objective is to look for evidence in the article that the person(s) assessing the outcome(s) for the study (for example, examining medical records to determine the outcomes that occurred in the exposed and comparison groups) is masked to the exposure status of the participant. Sometimes the person measuring the exposure is the same person conducting the outcome assessment. In this case, the outcome assessor would most likely not be blinded to exposure status because they also took measurements of exposures. If so, make a note of that in the comments section.

As you assess this criterion, think about whether it is likely that the person(s) doing the outcome assessment would know (or be able to figure out) the exposure status of the study participants. If the answer is no, then blinding is adequate. An example of adequate blinding of the outcome assessors is to create a separate committee, whose members were not involved in the care of the patient and had no information about the study participants' exposure status. The committee would then be provided with copies of participants' medical records, which had been stripped of any potential exposure information or personally identifiable information. The committee would then review the records for prespecified outcomes according to the study protocol. If blinding was not possible, which is sometimes the case, mark "NA" and explain the potential for bias.

Question 13. Followup rate

Higher overall followup rates are always better than lower followup rates, even though higher rates are expected in shorter studies, whereas lower overall followup rates are often seen in studies of longer duration. Usually, an acceptable overall followup rate is considered 80 percent or more of participants whose exposures were measured at baseline. However, this is just a general guideline. For example, a 6-month cohort study examining the relationship between dietary sodium intake and BP level may have over 90 percent followup, but a 20-year cohort study examining effects of sodium intake on stroke may have only a 65 percent followup rate.

Question 14. Statistical analyses

Were key potential confounding variables measured and adjusted for, such as by statistical adjustment for baseline differences? Logistic regression or other regression methods are often used to account for the influence of variables not of interest.

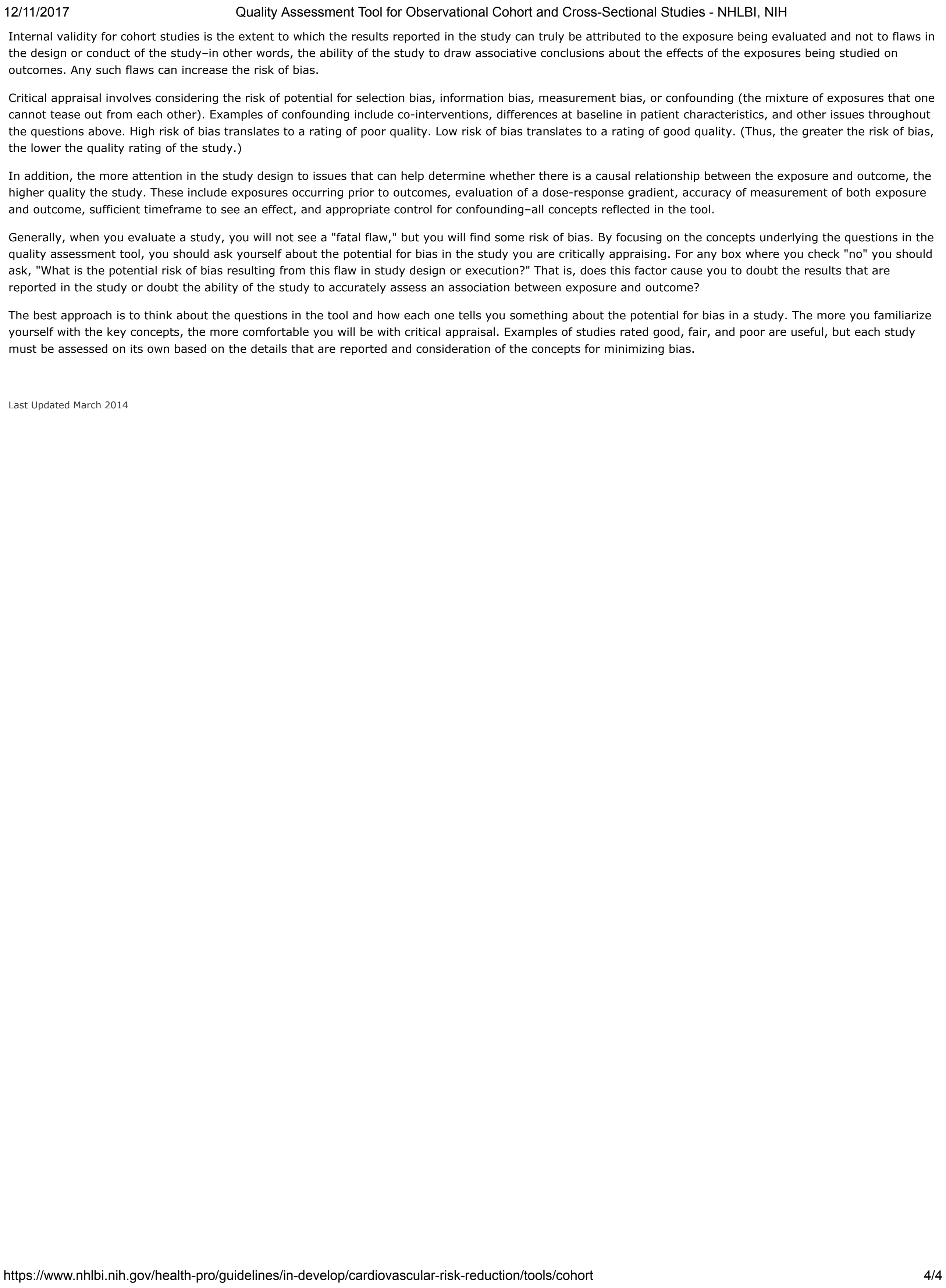
This is a key issue in cohort studies, because statistical analyses need to control for potential confounders, in contrast to an RCT, where the randomization process controls for potential confounders. All key factors that may be associated both with the exposure of interest and the outcome–that are not of interest to the research question–should be controlled for in the analyses.

For example, in a study of the relationship between cardiorespiratory fitness and CVD events (heart attacks and strokes), the study should control for age, BP, blood cholesterol, and body weight, because all of these factors are associated both with low fitness and with CVD events. Well-done cohort studies control for multiple potential confounders.

Some general guidance for determining the overall quality rating of observational cohort and cross-sectional studies

The questions on the form are designed to help you focus on the key concepts for evaluating the internal validity of a study. They are not intended to create a list that you simply tally up to arrive at a summary judgment of quality.

https://www.nhlbi.nih.gov/health-pro/guidelines/in-develop/cardiovascular-risk-reduction/tools/cohort 3/4



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Internal validity for cohort studies is the extent to which the results reported in the study can truly be attributed to the exposure being evaluated and not to flaws in the design or conduct of the study–in other words, the ability of the study to draw associative conclusions about the effects of the exposures being studied on outcomes. Any such flaws can increase the risk of bias.

Critical appraisal involves considering the risk of potential for selection bias, information bias, measurement bias, or confounding (the mixture of exposures that one cannot tease out from each other). Examples of confounding include co-interventions, differences at baseline in patient characteristics, and other issues throughout the questions above. High risk of bias translates to a rating of poor quality. Low risk of bias translates to a rating of good quality. (Thus, the greater the risk of bias, the lower the quality rating of the study.)

In addition, the more attention in the study design to issues that can help determine whether there is a causal relationship between the exposure and outcome, the higher quality the study. These include exposures occurring prior to outcomes, evaluation of a dose-response gradient, accuracy of measurement of both exposure and outcome, sufficient timeframe to see an effect, and appropriate control for confounding–all concepts reflected in the tool.

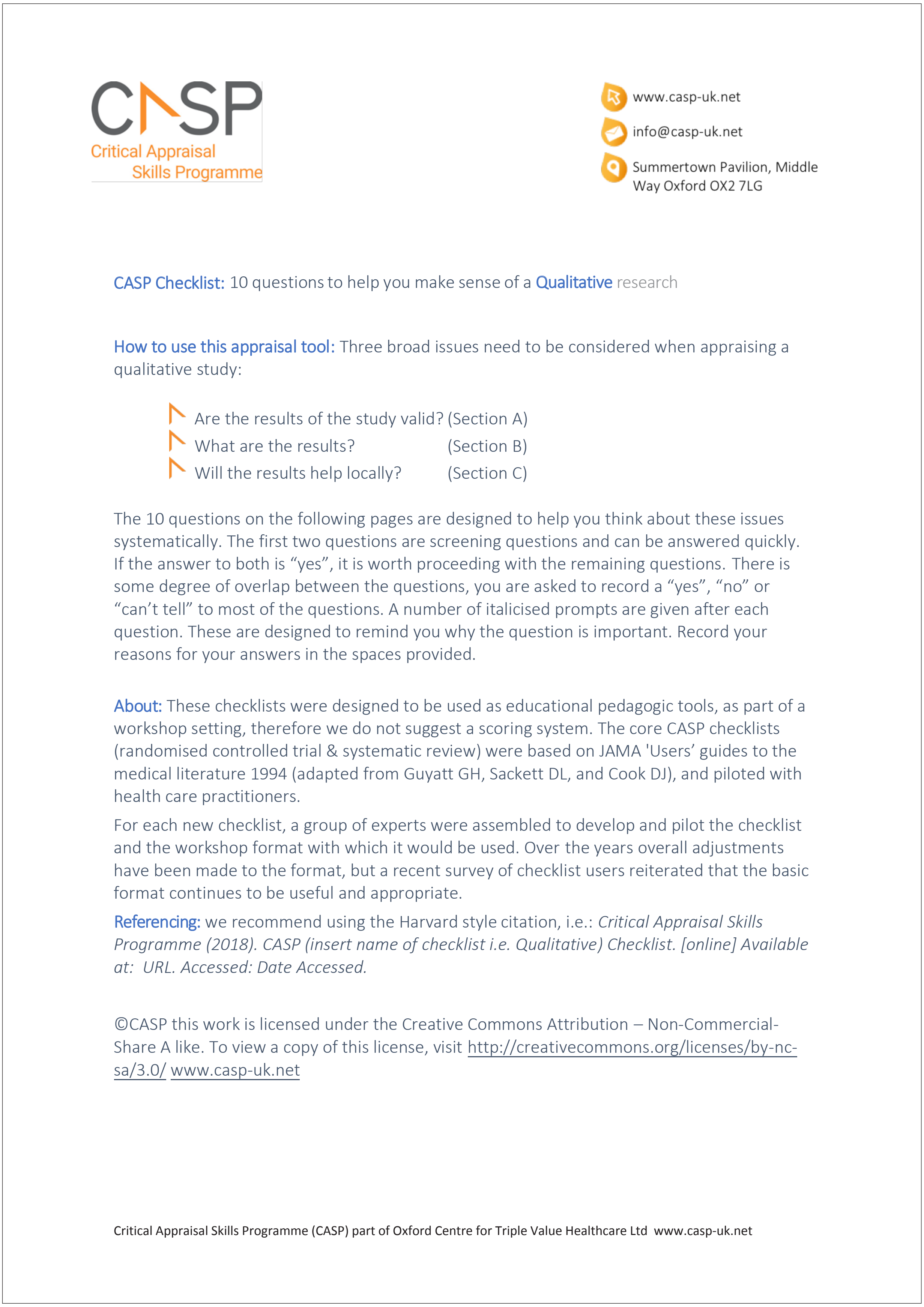
Generally, when you evaluate a study, you will not see a "fatal flaw," but you will find some risk of bias. By focusing on the concepts underlying the questions in the quality assessment tool, you should ask yourself about the potential for bias in the study you are critically appraising. For any box where you check "no" you should ask, "What is the potential risk of bias resulting from this flaw in study design or execution?" That is, does this factor cause you to doubt the results that are reported in the study or doubt the ability of the study to accurately assess an association between exposure and outcome?

The best approach is to think about the questions in the tool and how each one tells you something about the potential for bias in a study. The more you familiarize yourself with the key concepts, the more comfortable you will be with critical appraisal. Examples of studies rated good, fair, and poor are useful, but each study must be assessed on its own based on the details that are reported and consideration of the concepts for minimizing bias.

Last Updated March 2014

https://www.nhlbi.nih.gov/health-pro/guidelines/in-develop/cardiovascular-risk-reduction/tools/cohort 4/4

Appendix 5: CASP Qualitative Checklist



CASP
Critical Appraisal
Skills Programme

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CASP Checklist: 10 questions to help you make sense of a **Qualitative** research

How to use this appraisal tool: Three broad issues need to be considered when appraising a qualitative study:

- Are the results of the study valid? (Section A)
- What are the results? (Section B)
- Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a "yes", "no" or "can't tell" to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users' guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Referencing: we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.*

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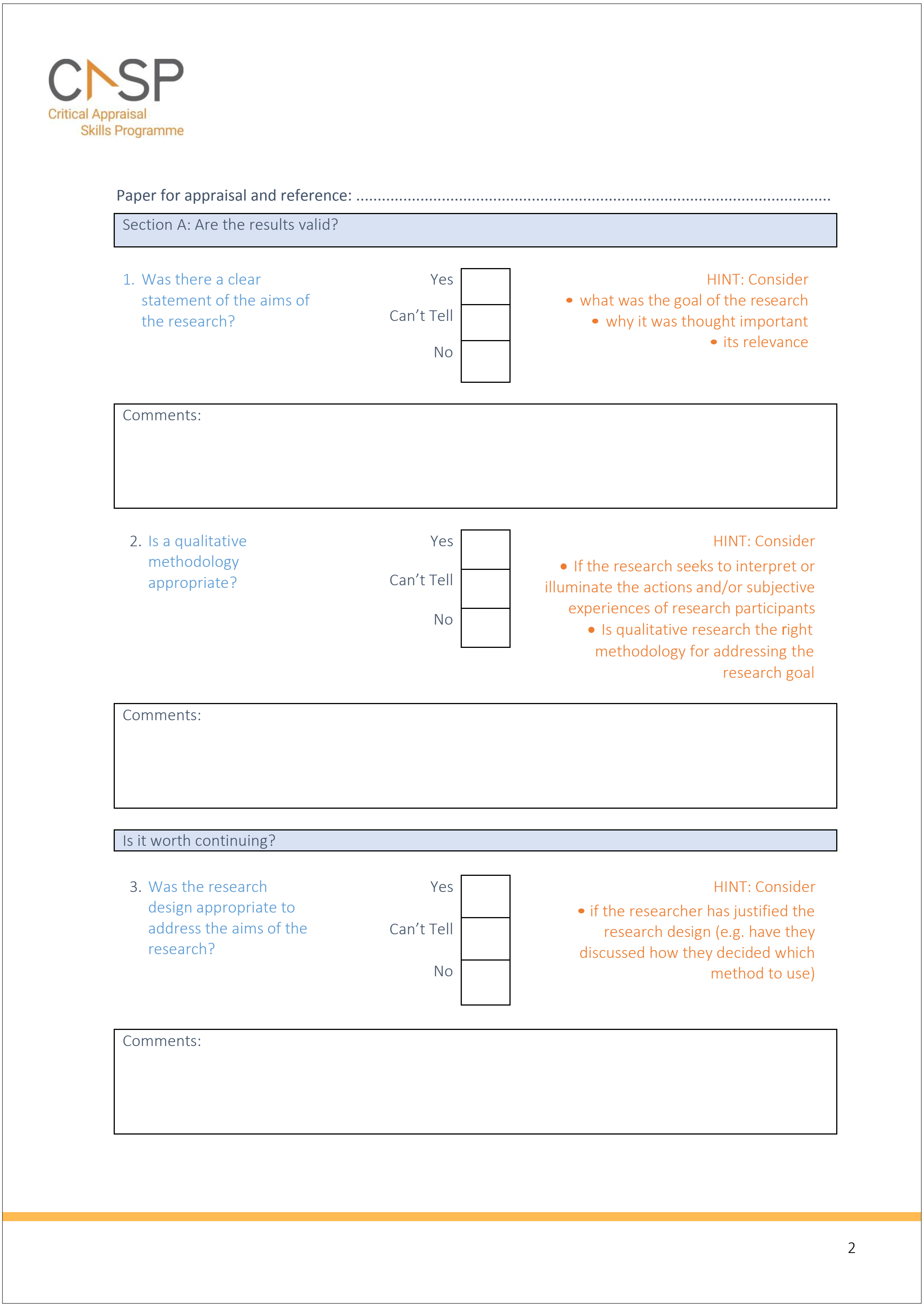

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Paper for appraisal and reference: ....

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- what was the goal of the research
- why it was thought important
- its relevance

Comments:

2. Is a qualitative methodology appropriate?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal

Comments:

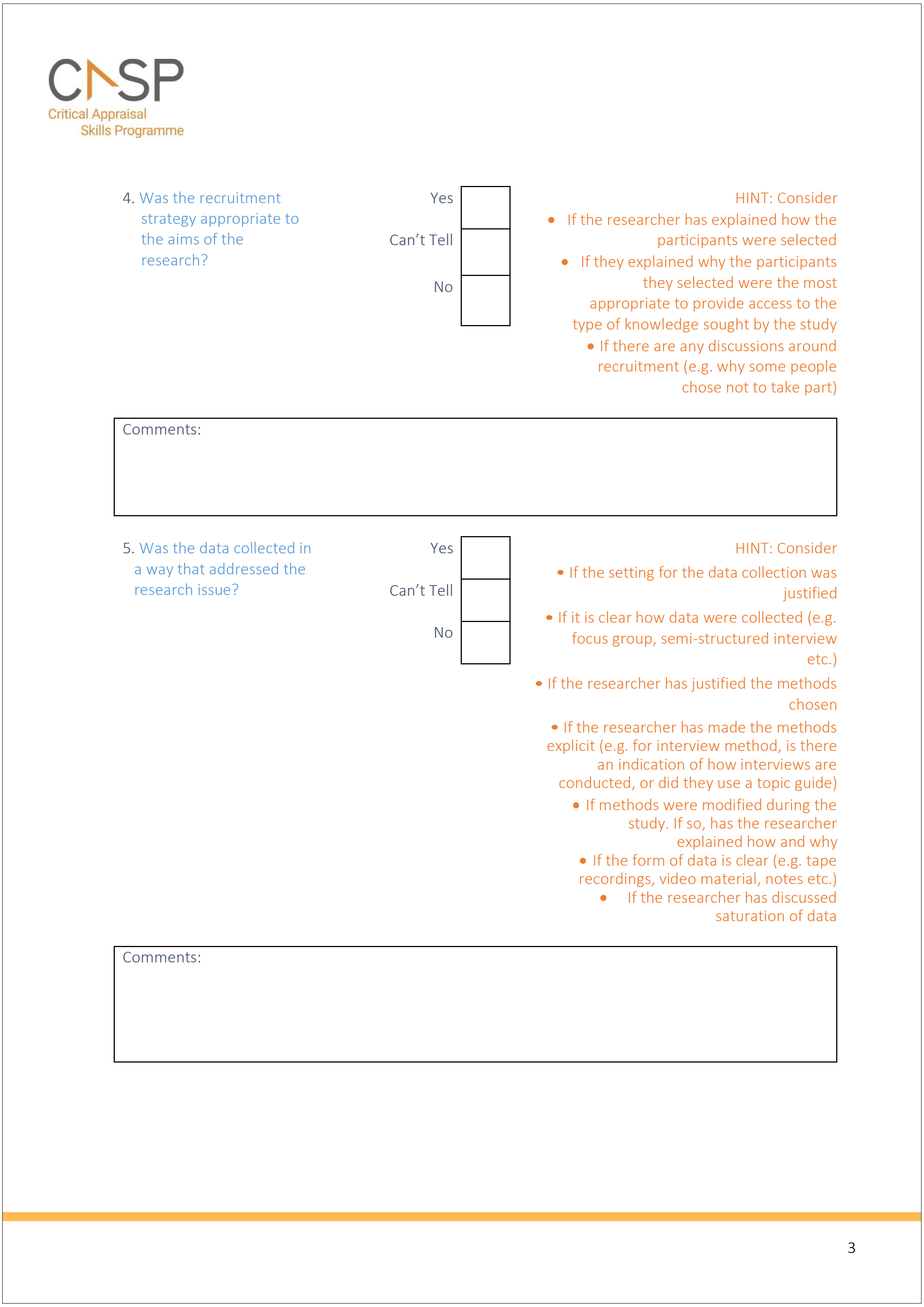
Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:



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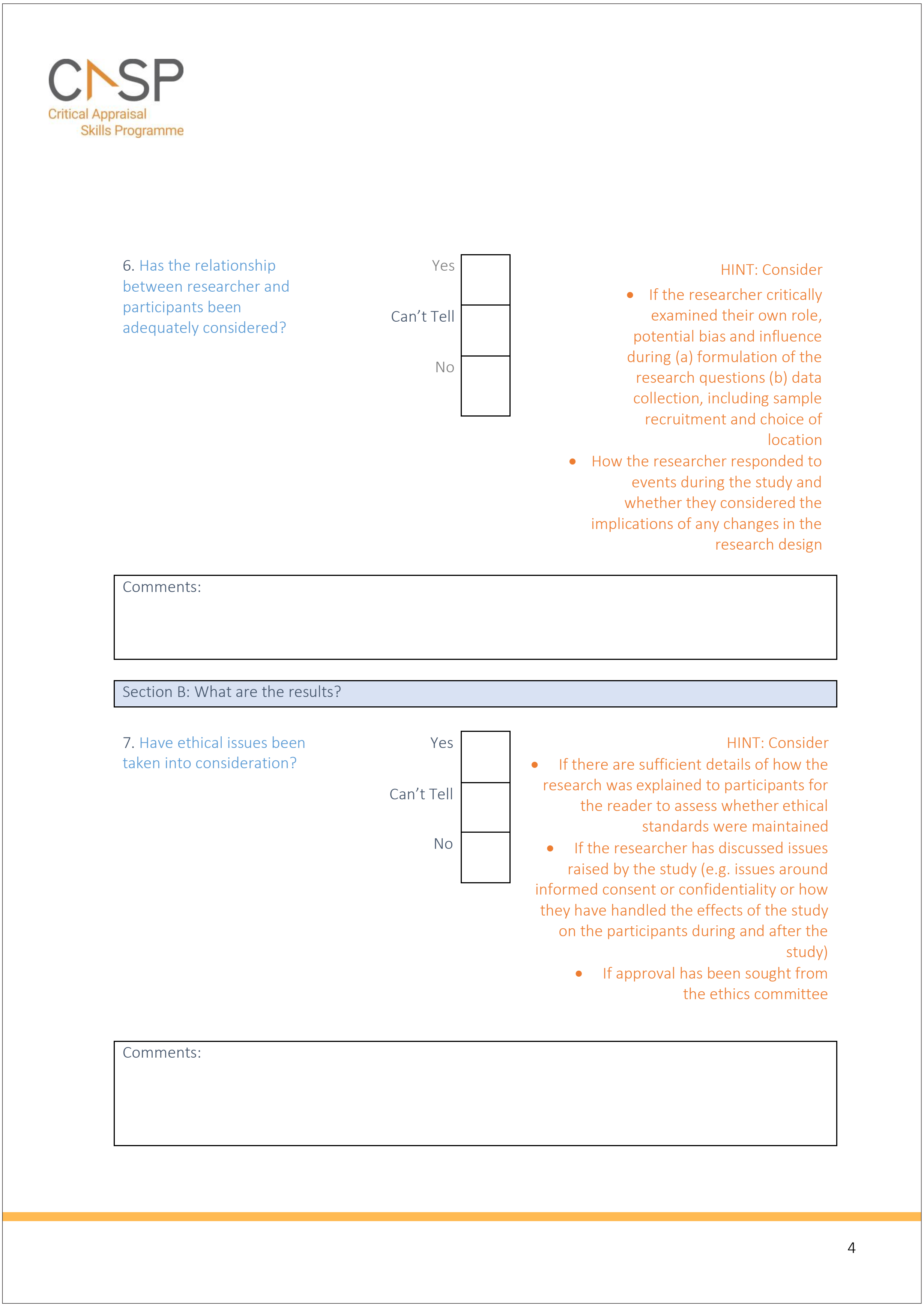
4. Was the recruitment strategy appropriate to the aims of the research?	Yes ☐ Can't Tell ☐ No ☐	HINT: Consider • If the researcher has explained how the participants were selected • If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study • If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments:

5. Was the data collected in a way that addressed the research issue?	Yes ☐ Can't Tell ☐ No ☐	HINT: Consider • If the setting for the data collection was justified • If it is clear how data were collected (e.g. focus group, semi-structured interview etc.) • If the researcher has justified the methods chosen • If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide) • If methods were modified during the study. If so, has the researcher explained how and why • If the form of data is clear (e.g. tape recordings, video material, notes etc.) • If the researcher has discussed saturation of data

Comments:

3



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6. Has the relationship between researcher and participants been adequately considered?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:

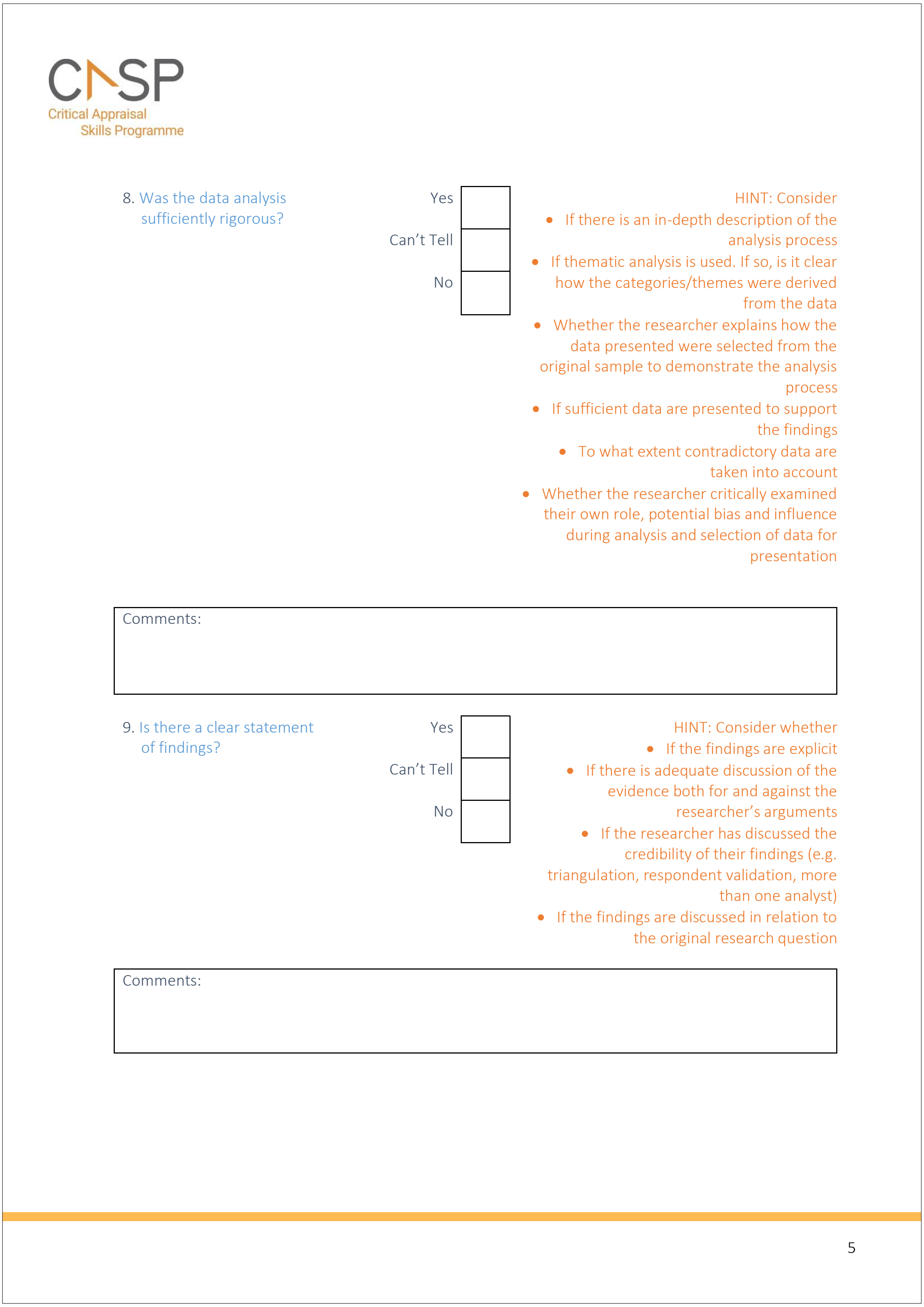
Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments:



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8. Was the data analysis sufficiently rigorous?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments:

9. Is there a clear statement of findings?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider whether
- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments:

5

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Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments:

Appendix 6: Characteristics of eligible studies (*n* = 34)#

Study (author & year, data collection period)	Study population	Unmet need investigated	Method of data collection/Instrument	Main findings
1. Cleary et al., 2013^, NR [28]	Women with gynaecological cancer diagnoses *N* = 8 (6 treatment complete) (ovarian = 4, vulval = 2, cervical = 2)	Intimacy/ interpersonal	Semi-structured interviews	› Issues related to sexuality increased in importance for survivors › Distressing alterations in all aspects of sexuality after diagnosis & treatment › Deficient verbal & written information & support from HCPs on sexual matters › Better if information provided during treatment, not diagnosis › Barriers to addressing sexuality in HCP interactions
2. Cleary et al., 2011^, NR [27]	Women with gynaecologic cancers diagnoses *N* = 106 (cervical, ovarian, endometrial & vulvar)	Intimacy/ interpersonal	Postal survey Body Image Scale, Sexual Esteem Scale, Sexual Self-Schema Scale, the Intimate Relationships Scale & the Arizona Sexual Experiences Scale	› 51% (*n* = 54) reported impact on femininity › 51% (*n* = 54) reported self-consciousness about appearance › 53% (*n* = 37) reported negative change in sexual relationship › 64% (*n* = 48) reported negative change in sexual functioning › 73% (*n* = 55) had decreased intercourse › 27% (*n* = 20) reported increased need for intimacy › 60% (*n* = 44) reported difficulties with sexual arousal
3. Cockle-Hearne et al., 2013^, Oct 2011-Jan 2012 [29]	Men with a diagnosis of PC living in Denmark, France, Ireland, Netherlands, Spain, Turkey, & UK *N* = 53 Irish survivors	Psychosocial/ emotional Intimacy/ interpersonal	Online & postal survey Supportive Care Needs Survey (SCNS) EuroQol EQ-5D-3L Scale developed by authors to measure experience of supportive nursing care	› Men in Ireland more likely to have psychological needs compared to men in Denmark (*OR* = 2.02; 95% CI [0.61 - 6.72]); › Men in Ireland more likely to have sexuality-related needs compared to men in Denmark (*OR* = 1.1; 95% CI [0.53 - 2.29])

Study (author & year, data collection period)	Study population	Unmet need investigated	Method of data collection/Instrument	Main findings
4. Davidson, F 2016, NR [30]	Members of the Ileostomy Association (IA) Ireland Ostomates~ *N* = 55 with cancer diagnosis	Physical Psychosocial/ emotional Intimacy Social Quality of Life (QoL)/Needs related to daily living	Postal survey Modified City of Hope QoL ostomy questionnaire	› 69% (n = 177) reported good-excellent QoL; 25% (n = 63) moderately good & 6% (n = 15) poor QoL › 66% (n = 167) had no/minor skin issues; 26% (n = 67) moderate & 8% (n = 20) had serious/severe issues › 66% (n = 165) had no/minor leakage; 26% (n = 63) moderate & 9% (n = 23) had serious/severe leakage › 49% (n = 124) had no/minor gas/wind; 35% (n = 89) moderate & 15% (n = 38) had serious/severe gas/wind › 96% (n = 241) reported no depression 6 months post-stoma or at time of survey (70%; n = 179) › 25% (n = 64) somewhat depressed; 19% (n = 48) seldom depressed ; 15% (n = 38) very depressed & 41% (n = 106) not depressed 6 months post-stoma › 59% (n = 138) resumed sexual activity › 53% (n = 101) reported erectile problems › 52% reported impact of stoma on intimacy as minimal; 18% moderate & 30% severe impact › 54% (n = 137) had community SCN (at home) with 95% (n = 127) finding it quite/very helpful › 45% (n = 114) reported 6 months until comfortable with stoma & 6% (n = 16) never comfortable › 58% belonged to support group & 65% had opportunity to talk to other stoma patient

Study (author & year, data collection period)	Study population	Unmet need investigated	Method of data collection/Instrument	Main findings
5. Droog et al., 2014, Jan-Dec 2010 [31]	Patients to review clinics for treatment since 2006/2007 *N* = 302 (3 BC teams)	Physical Psychosocial/ emotional Practical Health system/ information	Paper-based survey (face-to-face) Picker Ambulatory Oncology Survey Instrument New South Wales Picker Questionnaire (reworded to suit the Irish health system context)	> 95% reported high satisfaction with care > 81% reported high levels of satisfaction in following dimensions: – access to care (81%) – coordination & continuity of care (84%) – surgery-specific issues; waiting times & understanding surgery (92%) – physical comfort (90%) – information, communication & education (80%) – emotional support (75%) – respect for patient preferences (87%) > 59% reported "getting enough information about their nutritional needs" > Lack of information on emotional changes; nutritional information; lack of patient-nurse relationship

Study (author & year, data collection period)	Study population	Unmet need investigated	Method of data collection/Instrument	Main findings
6. Drummond et al., 2015a* NR [21]	PC survivors diagnosed January 1995 - March 2010; *N* = 3348 (whole Ireland) of which, *n* = 2338 ROI	Physical Psychosocial/ emotional Intimacy/ interpersonal Practical QoL/Needs related to daily living	Postal survey QLQ-C30 QLQ-PR25 EQ-5D-5L DASS-21 Control Preference Scale Decisional Regret Scale	**ROI findings:** › ROI respondents (*n* = 2338); 56% (*n* = 1872) with comorbidity at diagnosis – Proportion (mean): Decisional Regret scale = 0.30 (1.50); EORTC QLQ-C30 = 0.10 (1.94); EuroQoL EQ-5D-5L = 0.09 (0.27); EORTC QLQ-PR25 = 0.31 (2.96) & DASS-21 = 0.2 (2.24) › 3% (*n* = 72) received treatment with adverse effects reported by 3% (*n* = 63) › 42% were short term survivors, with 43% long term survivors & 16% very long term › Overall health state/utility score = 0.82, with mean levels of problems reported: pain/ discomfort = 1.60; mobility = 1.60; usual activities = 1.70; anxiety/depression = 1.40; & self-care = 1.20 › Common cancer-related physical symptoms: fatigue = 23.92; insomnia = 23.29; dyspnoea = 16.82; pain = 15.20, & constipation = 13.37 › General GHS score = 71.15, with highest functional domain = emotional (83.66); cognitive (82.24); physical (81.54); social (82.48); & role functioning (80.57) › Prostate-specific health related quality of life (HRQoL) reported mean functional scores in descending order: sexual activity (68.61); sexual functioning (48.08); & urinary symptoms (19.47) › Psychological wellbeing assessed with similar levels of depression (16.3%) & anxiety (16.1%) reported by all respondents; lower levels of distress were reported by all respondents (10.4%) › 72% (*n* = 1688) would participate in future research

Study (author & year, data collection period)	Study population	Unmet need investigated	Method of data collection/Instrument	Main findings
7. Drummond et al., 2015b* April-Sept 2012 [32]	PC survivors diagnosed January 1995 - March 2010; *N* = 3348 (whole Ireland) of which, *n* = 2338 ROI	Physical Psychosocial/ emotional Practical Intimacy/ interpersonal QoL/Needs related to daily living	Postal survey QLQ-C30 QLQ-PR25 EQ-5D-5L DASS-21 Control Preference Scale Decisional Regret Scale	**Whole Ireland findings:** › PC survivors up to 18 years post-diagnosis have variety of symptom burden & HRQoL depending on treatment › HRQoL did not differ across - radical prostatectomy (RP), external beam radiation therapy (EBRT) with concurrent androgen deprivation therapy (ADT) & observation groups however symptom pattern varied significantly › 49% aged 60 - 69 with those < 70 at diagnosis more likely = ROI › 34% had EBRT without concurrent ADT; 28% had RP & 18% had EBRT with concurrent ADT › HRQoL significantly varied across treatment groups ($p < 0.001$): – highest for brachytherapy (BT) treated men ($R^2 = 3.10$; 95% CI [-1.19, 7.39]) & lowest for ADT group ($R^2 = -7.62$; 95% CI [-10.88, -4.36]) – lower global HRQoL in EBRT without concurrent ADT ($R^2 = -3.64$; 95% CI [-5.75, -1.53]) or ADT ($R^2 = -7.62$; 95% CI [-10.88, -4.36]) compared to RP group › Very long term survivors had lowest HRQoL irrespective of treatment group › Physical, role & social functioning significantly different across treatment groups ($p \leq 0.001$) – BT group significantly better physical ($R^2 = 3.98$; 95% CI [0.03, 7.93]), role ($R^2 = 8.83$; 95% CI [3.63, 14.03]), & social functioning ($R^2 = 7.83$; 95% CI [3.10, 12.57]) than RP & all other groups – EBRT without concurrent ADT significantly lower physical & role functioning compared to RP ($p = 0.002$) – ADT alone group significantly lower physical ($p < 0.001$), role ($p < 0.001$), & social functioning ($p = 0.050$) compared to RP › Highest QLQ-C30 symptom scores/ burden across treatment groups = fatigue & insomnia – BT group had lowest symptom burden, compared to RP – EBRT without concurrent ADT group had significantly higher fatigue ($R^2 = 3.70$; 95% CI [1.43, 5.97]) & dyspnoea ($R^2 = 3.21$; 95% CI [0.64, 5.77]) than RP –RP had a significantly higher financial difficulty score 14.1 than BT (6.00) › QLQ-PR25 subscales varied significantly across treatment groups ($p < 0.001$) – EBRT with ADT ($R^2 = 3.23$; 95% CI [1.76, 4.71])/ without concurrent ADT ($R^2 = 3.75$; 95% CI [2.53, 4.98]) had significantly worse bowel symptoms than RP group ($p < 0.001$) – sexual activity significantly worse for ADT alone group ($R^2 = 13.52$; [9.00, 18.03]), or EBRT with concurrent ADT ($R^2 = 7.38$; [3.94, 10.82])/ without concurrent ADT ($R^2 = 6.00$; 95% CI [3.09, 8.91]) compared to RP

Study (author & year, data collection period)	Study population	Unmet need investigated	Method of data collection/Instrument	Main findings
8. Drury et al., 2017 Sept 2014 -Jan 2016 [33]	Colorectal cancer (CRC) survivors $N = 252$	Physical - pain burden QoL/Needs related to daily living	Online & postal survey EuroQOL EQ-5D-3L Functional Assessment of Cancer Therapy-Colorectal Cancer (FACT-C) questionnaire	› 36% ($n = 90$; 95% CI [30 - 42%]) had pain at time of survey with 31% ($n = 77$; 95% CI [25 - 36%]) in week before › 95% had lack of energy; 74% bowel dysfunction; 76% sleep disturbance; & 75% reported interference with ability to enjoy life › Pain associated with poorer SRH & QoL scores on all subscales ($p = 0.05$) › Pain associated with younger age ($p = 0.003$; $OR = 2.3$); chemotherapy treatment ($p < 0.001$; $OR = 3.6$); radiotherapy treatment ($p = 0.006$; $OR = 2.20$) › Increasing pain over 2 time points associated with poorer SRH & QoL ($p = 0.05$)
9. Dunne et al., 2017, NR [34]	HNC survivors with functional & psychosocial impairments $N = 27$	Physical Cognitive Social QoL/Needs related to daily living	Semi-structured interviews	› Overall 20 self-management strategy types with 77 specific self-management strategies identified › 3 - 19 strategy types per survivor ($Mdn = 15$); 3 - 42 self-management strategies per survivor ($Mdn = 24$) › Common self-management strategy types=self-sustaining ($n = 26$) of which customising dietary practices ($n = 24$) ; self-motivating ($n = 25$) of which maintaining positive outlook ($n = 22$); proactive problem solving ($n = 25$) of which adaptive approaches to ongoing physical consequences ($n = 24$); using support ($n = 24$) of which receiving support from family/friends ($n = 20$); seeking normality ($n = 23$) of which focus on doing normal activities ($n = 16$); meaning-making ($n = 23$) of which appreciating support ($n = 15$) › Common self-management strategies=setting up facilitating conditions ($n = 15$); learning self-management skills ($n = 11$); pursuing existing hobby/activity ($n = 13$); taking a break ($n = 17$) & minimising stress ($n = 9$); reinterpreting negative consequences ($n = 17$); monitoring symptoms & SE ($n = 12$); accepting illness & consequences ($n = 20$); exercising behaviours ($n = 13$); avoiding harmful activities ($n = 10$); avoiding thoughts about cancer & consequences ($n = 16$); protecting others from harm ($n = 10$); laughing about cancer & consequences ($n = 6$)

Study (author & year, data collection period)	Study population	Unmet need investigated	Method of data collection/Instrument	Main findings
10. Gannon et al., 2017^^, Dublin NR [35]	Male survivors of oesophageal cancer *N* = 25 (adenocarcinoma = 20; squamous cell carcinoma = 4; & high grade dysplasia = 1)	Physical QoL/Needs related to daily living	Paper-based survey (face-to-face) EORTC QLQ-C30	› Mean Overall GHS ($\bar{X}$ = 75.67; *SD* = 18.15) lower than controls ($\bar{X}$ = 82.00, *SD* = 11.20) › Highest functioning = social ($\bar{X}$ = 96.00, *SD* = 9.95); physical ($\bar{X}$ = 90.67, *SD* = 9.81); role ($\bar{X}$ = 90.67, *SD* = 14.50); cognitive ($\bar{X}$ = 90.0, *SD* = 15.96); & emotional ($\bar{X}$ = 85.00, *SD* = 16.49) › Common symptoms reported fatigue ($\bar{X}$ = 20.44, *SD* = 17.18); diarrhoea ($\bar{X}$ = 12.00, *SD* = 16.33); appetite loss ($\bar{X}$ = 10.67, *SD* = 23.01); & insomnia ($\bar{X}$ = 10.67, *SD* = 18.56)
11. Gavin et al., 2015* April-Sept 2012 [36]	PC survivors diagnosed January 1995-March 2010; *N* = 3348 (whole Ireland) of which *n* = 2338 ROI	Physical	Postal survey QLQ-C30 QLQ-PR25 EQ-5D-5L DASS-21 Control Preference Scale Decisional Regret Scale	**Whole Ireland findings:** › 75% reported one symptom; 29% ≥ 3 symptoms; & 4% ≥ 5 symptoms › Approximately 65% reported having current ED, UI, and/or bowel problems › 57% with at least one of the following: loss of libido, breast changes, fatigue/hot flushes

Study (author & year, data collection period)	Study population	Unmet need investigated	Method of data collection/Instrument	Main findings
12. Gavin et al., 2016* April-Sept 2012 [22]	PC survivors diagnosed January 1995 - March 2010; *N* = 2567	Physical Intimacy/ interpersonal Psychosocial/ emotional QoL/Needs related to daily living	N/A	**ROI findings:** › 56% (*n* = 1431) early disease & 16% (*n* = 407) late disease › Early disease symptoms: 56.1% erectile dysfunction; 41.3% libido loss; 17% fatigue; 14.3% urinary incontinence; 11.5% bowel problems; & 9% hot flashes › Late disease symptoms: 66.9% erectile dysfunction; 51.6% libido loss; 24.6% fatigue; 22.2% urinary incontinence; 18.8% hot flashes; & 14.2% bowel problems › Mean health state/utility score early disease = 0.90 › Mean scores of reported problems: insomnia = 21.00; fatigue = 19.90; dyspnoea = 12.20; constipation = 11.50; pain = 11.10; financial difficulties = 10.20 › Mean health state/utility score late disease = 0.80 › Mean scores of reported problems: insomnia = 26.20; fatigue = 27.10; dyspnoea = 26.20; constipation = 14.40; pain = 17.50; financial difficulties = 17.90 › Mean general GHS score early disease = 72.50; social = 86.10; physical = 85.90; role = 85.70; emotional = 84.80 & cognitive functioning = 83.00 › Mean early disease reported distress levels = 4.90; depression = 4.00; & anxiety = 3.20 › Mean general GHS score late disease = 67.80; emotional = 81.00; cognitive = 86.10; physical = 78.60; social = 76.40; & role functioning = 75.70 › Mean late disease reported stress levels = 5.70; depression = 40.00; & anxiety = 3.20

Study (author & year, data collection period)	Study population	Unmet need investigated	Method of data collection/Instrument	Main findings
13. Hackett et al., 2018, NR [37]	Lymphoma attending cancer centre 2011-2015 post-treatment *N* = 14	Physical Psychosocial/ emotional Social Practical Health system/ information	Semi-structured interviews	› Abrupt & traumatic transition after treatment, with loss of support & security › Most common persistent effects fatigue; recurrent infections & weight gain › FOR reported by many participants & linked to physical symptoms & follow-up care › Strong supportive relationships with partners/family reported as valuable › Support systems facilitated by open layout of day unit during treatment – but not available post-treatment with 2 using cancer support groups › Returning to work important part of returning to normality for many survivors › Most participants wanted written treatment summary & follow-up – with information on managing persistent symptoms; late effects & duration of expected recovery › Some reported information gap on ongoing effects of treatment & no opportunity to discuss these issues
14. Hanly et al., 2013 March 2010 – Jan 2011 [38]	Colorectal cancer survivors 6 - 30 months post-diagnosis in paid work at diagnosis *N* = 159	QoL/Needs related to daily living: work-related	Postal survey NCRI database National employment survey (2008)	› Of 159 survivors, 62% = males; median age = 55.30 years (male) & 53.70 (female) **Time Lost From Work** › 90% took temporary time off work after diagnosis (females = 93.3%; males = 88.7%) › Almost one-fifth returned to work on reduced hours with reduction higher in males than females (22.1 vs 12.4 hours) › More than one third left the workforce permanently after diagnosis (little gender difference (39.6% vs 39.1%) **Productivity Costs & Key Drivers** › Total colorectal cancer productivity costs = €205,847 – combined PM (43.6%) & PD linked to four fifths of total costs & 37.6%) – PM = €89,824 pp & PD (workforce departure) = €77,414 pp – permanent disability (reduced hours) accounted for 11.8% of total costs – TD for 6.9% **Productivity Costs: Gender Differences** › Lower productivity costs in females than males (20%): – greater difference for TD costs (-40%) & PD (reduced hours) costs (-34%) **Productivity: Retirement Age** › Increasing retirement age by 5 years (from 65 to 70 years) increased productivity costs by almost a half (€303,992 vs €205,827)

Study (author & year, data collection period)	Study population	Unmet need investigated	Method of data collection/Instrument	Main findings
15. Hanly et al., 2018 April - Sept 2010 [39]	Colorectal cancer survivors diagnosed October 2007 - September 2009 *N* = 496	Practical	Postal survey Scale developed by authors to assess cancer-related financial objective stress & subjective strain	› 40.9% reported objective stress or subjective strain (39.4%) › Depletion of savings (49.1%) the most prevalent coping strategy › Factors associated with increased objective stress: having a stoma (*OR* = 2.10; 95% CI [1.10 - 3.90]); using savings (*OR* = 9.40; 95% CI, [4.90 - 18.00]); formally borrowing money (*OR* = 3.1; 95% CI [1.00 - 9.60]); & loans from family members/friends (*OR* = 3.80; 95% CI [1.90 - 7.80]) › Decreased objective stress associated with not working (*OR* = 0.44; 95% CI [0.20-0.96]) › Predictors of subjective strain: having dependents; a stoma; using savings (*OR* = 5.30; 95% CI [2.90 - 9.50]); & loans from family members/friends (*OR* = 2.00; 95% CI [1.10 - 3.90])
16. Kelly M & Dowling M., 2011, NR [40]	Myeloma patients attending regional specialist haematology oncology centre, with diagnosis of more than 6 months *N* = 11	Physical Pyschosocial/ emotional Social Practical QoL/Needs related to daily living Health system/ information	In-depth interviews (phenomenological)	› All participants reported changes in bodily functions & physical appearance › Participants reported fatigue as most debilitating symptom › A feeling of loss was common among participants & 2 talked about stigma of having myeloma › Participants reported FOR throughout their disease trajectory › Psychological triggers for uncertainty – attendance at myeloma review clinic & hearing of other patients' disease progression › All participants attended specialised regional centre with access to specialist oncology nurses but reported lack of time with HCPs › All participants got strength & comfort from family & extended social networks but felt need to protect loved ones › Many participants expressed a negative outlook & reported they felt lucky › Participants focused on pain experienced pre-diagnosis

Study (author & year, data collection period)	Study population	Unmet need investigated	Method of data collection/Instrument	Main findings
17. Landers et al., 2014, (April – December 2010) [41]	Patients diagnosed with rectal cancer, 6 weeks - 40 months post-sphincter saving surgery *N* = 143	Physical Social	Postal survey Revised illness Perception Questionnaire (IPQ-R) 4 subscales Difficulties of Life Scale Illness Perception Questionnaire (IPQ) IPQ adapted by authors to assess frequency of post-operative bowel symptoms Scale developed by authors to measure self-care strategies	› Participants reported average of 4 bowel symptoms ($\bar{X}$ = 4.06, *SD* = 1.78) › 93% (*n* = 133) reported frequent bowel movement; 91% (*n* = 130) pain in ano-rectal area; 89% (*n* = 127) faecal incontinence; 87% (*n* = 125) bowel urgency & 86% (*n* = 123) with irregular bowel movement, diarrhoea, & constipation › 38% (*n* = 54) reported more bowel symptoms ≥ 18 months post-operation & 18% (*n* = 27) had symptoms persisting beyond 2 years post-operation › 50% (*n* = 69) reported bowel symptoms as not serious with 55% (*n* = 76) having no major life consequences › 58% (*n* = 79) expected symptoms to improve over time with 51% (*n* = 71) agreeing that symptoms went through cycles › 45% (*n* = 63) were embarrassed; 45% (*n* = 63) worried; or 41% (*n* = 59) felt anxious about symptoms › 54% (*n* = 76) did not feel physically comfortable if there was no toilet nearby › The four most effective self-care strategies were: proximity/knowing toilet location at all times; bowel medication; protective clothing; & incontinence pads › Most used strategies in functional & social activity categories: exercise (*n* = 101; 72%); proximity/knowing location of toilet (*n* = 99; 72%) & planned social events (*n* = 47; 35%)

Study (author & year, data collection period)	Study population	Unmet need investigated	Method of data collection/Instrument	Main findings
18. Maguire et al., 2017* NR [23]	PC survivors between 2- & 5-years post-diagnosis *N* = 817	Psychosocial/ emotional Treatment appraisals (level of regret over treatment decisions) Physical Health system/ information		**ROI findings:** › Mean HRQoL = 71.61 (*SD* = 21.15) › Participants reported on average 2 ongoing side-effects from their treatment › Mean Decisional Regret score = 18.02 (28.3% no regret whatsoever ##) › Most satisfied with information regarding treatment ($\bar{X}$ = 6.04; *SD* = 1.34) › FOR = low ($\bar{X}$ = 29.42; *SD* = 20.97) but 18.6% had scores > 50### › No significant difference in FOR between survivors suspected of having a recurrence & those who were not ($p > 0.05$) › Treatment regret ($p < 0.001$) & satisfaction with information regarding treatment (p = 0.003) significantly associated with FOR (adjusted for socio-demographic, disease, treatment & health-related factors › Lower satisfaction with information & higher regret over treatment decisions associated with higher FOR
19. Maguire et al., 2018a* NR [42]	PC survivors – same sample as Maguire et al. 2017 *N* = 817	Psychosocial/ emotional Treatment appraisals (level of regret over treatment decisions) Physical		**ROI findings:** › 30% reported ongoing treatment-related SE the same as expected; 24% were not as bad as expected; 25% were worse than expected; & 19% had no SE › FOR = generally low ($\bar{X}$ = 29.42; *SD* = 20.97) but 18.6% had scores > 50 › QOL = generally high; 86% with QOL scores in the top quartile ($\bar{X}$ = 86.56; *SD*=14.35) › FOR ($p < 0.001$) & expectations of SE ($p = 0.002$) were predictors of QOL (after adjusting for other factors) › Higher FOR & worse their experience of SE compared with previous expectations, associated with lower QOL › Significant predictors of higher QOL = fewer ongoing side-effects ($p < 0.001$); having fewer comorbid conditions ($p < 0.001$); having less invasive treatment ($p = 0.001$); & having earlier stage cancer ($p = 0.02$) › Mean number of comorbidities = 0.87, with 44% reported none

Study (author & year, data collection period)	Study population	Unmet need investigated	Method of data collection/Instrument	Main findings
20. Maguire et al., 2018b NR [24]	CRC survivors *N* = 141	Physical Practical QoL/needs related to daily living	Postal survey EORTC QLQ-C30 (to assess Global Health Status)	› Mean GHS score = 67.20 (range: min = 0; max = 100)
21. Meade et al., 2017 NR [43]	Post-menopausal BC survivors *N* = 51	Physical Practical Psychosocial/ emotional Health system/ information	6 focus groups	› Ten key issues in survivorship care highlighted: – meet the same HCP at each review visit – contact number of a named person if there are concerns between reviews – at each review visit, have a physical examination, blood tests & explanation from HCP outlining if follow up scans needed – information on signs & symptoms of recurrence; advice on diet, exercise, healthy lifestyle & advice on coping & pacing yourself – information & management SE of therapy-long & short term
22. Naidoo et al., 2013 NR [44]	BC patients discharged from medical oncology specialist clinic over 6 years; 2006-2012 *N* = 39	Physical Psychosocial/ emotional Social Spiritual Health system/ information needs	Postal survey Developed by authors from survivorship questionnaires used in European & American survivorship studies & U.S. cancer websites	› 51% reported fatigue; 44% had sleep disturbance; & 38% experienced pain › 69% (*n* = 27) reported FOR › 75% (*n* = 29) had no concerns regarding returning to work; 52% (*n* = 20) had no financial concerns; & 56% (*n* = 22) had no concerns related to health insurance › 84% did not need religious support (84%) or had concerns about loss of faith (89%) › 64% (*n* = 25) were satisfied with GP follow-up care but 59% (*n* = 23) reported treatment summary would have been beneficial › 59% required additional physical information; 55% wanted psychological information; 57% social information & spiritual information (34%) › 55% (*n* = 21) reported no adequate support group services; 69% (*n* = 28) had concerns about secondary cancers; & 48% (*n* = 19) reported lack of adequate services to address these concerns

Study (author & year, data collection period)	Study population	Unmet need investigated	Method of data collection/Instrument	Main findings
23. O' Brien et al., 2017, April 2012 [44]	HNC survivors, receiving follow-up care *N* = 583	Physical Psychosocial/ emotional Intimacy/ interpersonal Practical Health system/ information	Post-treatment survey; Supportive Care Needs Survey (SCNS-SF34 Oslo-3 Social support scale Scale developed by authors to assess financial burden	> Approximately 50% reported at least one unmet need: – highest in the psychological & physical domains (32 - 33%) – lower in the health system domain (21%) – lowest in the sexuality and care & support domains (14%) > Almost half experienced cancer-related financial hardship > Higher levels of unmet physical needs (48%) & health-information needs (34%) among those who experienced financial hardship
24. O' Shaughnessy et al., 2013 NR [46]	Men diagnosed with PC total *N* = 115 of which *n* = 11 (Irish respondents)	Intimacy/ interpersonal	Focus groups Interviews	> **Only extractable Irish data = free text responses** – Impact of treatment
25. O' Shaughnessy et al., 2015 ^^^ NR [47]	Men diagnosed with PC total *N* = 159 of which *n* = 15 (Irish respondents)	Physical Psychosocial/ emotional Intimacy/ interpersonal Social	Internet-based survey	> **Only extractable Irish data = free text responses** – ED & Urinary incontinence reported as significant physical adverse effects: – Diagnosis & treatment led to subtle relationship change – Need for further support – Men with partner less likely to be distressed & able to maintain their masculinity better than those without

Study (author & year, data collection period)	Study population	Unmet need investigated	Method of data collection/Instrument	Main findings
26. Pearce et al., 2015, NR [48]	HNC survivors at least 8 months post-diagnosis previously & employed at diagnosis *N* = 264	QoL/Needs related to daily living: - workforce participation patterns after HNC	Postal survey Scale developed by authors to describe workforce patterns & identify predictors of workforce participation	› Workforce participation patterns = complex & influenced by cancer, treatment & employment factors › Mean age at diagnosis = 52 years (*Mdn* = 53, range 23 - 81); mean time since diagnosis = 6 years (*Mdn* = 5, range: 8 months to 18 years) › 77% (*n* = 203) reported taking time off work with 59% (*n* = 119) returned to work › Extended period of return to work identified: 59 % returned to work within 6 months of diagnosis; 26% took 6-12 months; & 15% > 12 months › Mean amount of time taken off = 9 months (*Mdn* = 6, range 0 - 65 months) › 52% reported reduced working hours (mean=15 hours per week) › Reasons for reduced working hours reported by 58 survivors: 33% due to cancer & 14% linked to treatment side-effects › Factors that can increase workforce participation following HNC: not being eligible for free medical care (*OR* = 2.61, 95% CI [1.15 - 5.94]); having lip, mouth or salivary gland cancer (*OR* 2.79; 95% CI [1.20 - 6.46]); being self-employed (*OR* = 2.01; 95% CI [1.07 - 3.80]); having private health insurance (*OR* = 2.06; 95% CI [1.11 - 3.85]); not receiving chemotherapy (*OR* = 2.82; 95% CI [1.31 - 6.06]) › Only long term/persistent effect on workforce participation (after 5 years) = medical card status (*OR* = 4.03; 95% CI [1.69 - 9.62])
27. Pertl et al., 2014, Jan- July 2010 [49]	Cancer patients & survivors with cancer-related fatigue (CRF) *N* = 73	Physical Cognitive Health system/ information Patient-clinician communication	Thematic analysis of free text comments from postal survey	› Majority female (80%); mean age = 51 years (*SD* = 11.50); average time since treatment = 40 months (*SD* = 22). › variety of cancers: BC (*n* = 21; 28.8%); ovarian cancer (*n* = 16; 21.9%); lymphoma (*n* = 14; 19.1%); leukaemia (*n* = 10;13.7%); PC (*n* = 6; 8.2%); colon cancer (*n* = 2; 2.7%) & four with lung, sarcoma, gastric & cervical cancer › Overall theme = inadequate communication & understanding of CRF – family & friends did not appreciate extent of fatigue & lack of interest/support/ knowledge from HCPs – persistent/unexplained fatigue linked to distress & catastrophizing re recurrence › Barriers to CRF discourse identified: CRF not a medical condition & symptoms not clearly defined; cancer higher in 'hierarchy of illness' › Long-term impact of cancer dismissed: fatigue = part of cancer experience but not recognised at social/medical level

Study (author & year, data collection period)	Study population	Unmet need investigated	Method of data collection/Instrument	Main findings
28. Power & Hegarty, 2010** Jan/February 2009 [50]	Women with BC taking part in peer support program *N* = 8	Social Physical needs (impact of hair loss) Psychosocial/ emotional Health system/ information	Focus groups	› Need for support in relation to treatment-induced hair loss - little attention & sensitivity paid by HCPs to practical & emotional aspects of hair loss › Peer support programme participation led to: – emotional & appraisal support (mutual sharing of experiences, identification & understanding) – informational support (helped to consolidate information) – empowerment & aided decision making e.g. returning to work
29. Sharp et al., 2013, June- Oct 2008 [51]	Individuals > 6 months post-diagnosis with breast, PC, & lung cancer *N* = 654 (of which 449 BC; 182 PC; 17 lung cancer; & 6 unreported)	Practical QoL/Needs related to daily living	Postal survey Data derived from the National Cancer Registry (NCR) Depression Anxiety Stress Scales-21	Financial stress & strain associated with increased risk of adverse psychological outcomes › 49% reported increased financial stress & 32% increased financial strain › 36% reported depression; 29% anxiety & 29% distress - over 10% of these respondents reported severe or worse levels of depression (14%); severe or worse levels of anxiety (13%) and/or severe or worse levels of distress (13%) › Increased risk of depression linked to financial stress (OR= 2.79, 95% CI;1.87 - 4.17) & financial strain (OR = 3.56, 95% CI; 2.23 - 5.67) › Reporting 'severe or worse' depression linked to increased risk of financial stress (OR= 4.36, 95% CI 2.35 - 8.10) & financial strain (OR= 8.21, 95% CI 3.79 - 17.77) › Both financial stress & strain = significant predictors of anxiety (*LRT,* $p < 0.001$) › Both financial stress & strain = significantly related to distress (*LRT,* $p < 0.001$)
30. Sheehy et al., 2018^ NR [52]	BC survivors *N* = 105 Patients grouped by the years after the diagnosis (1, 3, & 5 years).	Health system/ information	Paper-based survey completed in clinics Toronto Information Needs Questionnaire for Breast Cancer (TINQ-BC)	› TINQ-BC; *Mdn* = 4.15 › High levels of information needs throughout follow-up period after diagnosis, median TINQ-BC scores in all questionnaire sections > 3 (scale of 1-5, with 3 ranked as 'moderately important') › Information on disease process rated as most important (*Mdn* = 4.50) & information regarding psychosocial aspect of disease ranked lowest (*Mdn* = 3.75) › Type of information sought changed over time - information regarding cancer disease process decreased from most important in year 1 to third most important in year 5 › 66% chose HCPs as preferred source of information on BC over information leaflets/ booklets (18%) & the Internet (6%)

Study (author & year, data collection period)	Study population	Unmet need investigated	Method of data collection/Instrument	Main findings
31. Steentjes et al., 2016*, April-Sept 2012 [53]	PC survivors N = 3,348 n = 2567 (76.7%) men from ROI & n = 781 (23.3%) from NI	Physical Intimacy	N/A	**Whole Ireland findings:** Respondents grouped into localised disease (stage I/II) & locally advanced/advanced disease (stage III/IV) for analysis: › Higher prevalence of both 'current' & 'severe side-effects ever 'experienced' in late disease group › 6.2% (n = 208) had multiple (> 3) comorbidities; 50.2% (n = 1682) had 1-2; & 43.5% (n = 1458) had none › 'current' side-effects: loss of libido (42.4% early disease vs. 57.0% late disease); hot flushes (8.8% early vs. 27.9% late); & fatigue (18.8% early vs. 30.5% late) › Multiple (> 3) comorbidities associated with higher risk of urinary incontinence (OR = 2.34; 95% CI [1.34 - 4.09]); loss of libido (OR = 1.68; 95% CI [1.03 - 2.75]); bowel problems (OR = 3.29; 95% CI [1.88 - 5.76]); & fatigue (OR = 2.07; 95% CI [1.21 - 3.53]) for 'current'/early disease › Multiple comorbidities associated with higher risk of bowel problems (OR = 2.80; 95% CI [1.22 - 6.43]) in severe/early group › Treatment = strongest factor associated with both 'current' & 'severe' physical side-effects (both early & late disease) › Men ≥ 70 years less likely to report physical side-effects ('current' & 'severe') compared to younger men (< 59) › Multiple (> 3) comorbidities associated with higher risk of urinary incontinence (OR = 2.34; 95% CI [1.34 - 4.09]); loss of libido (OR = 1.68; 95% CI [1.03 - 2.75]); bowel problems (OR = 3.29; 95% CI [1.88 - 5.76]) & fatigue (OR = 2.07; 95% CI [1.21 - 3.53]) › Factors associated with 'current' side-effects in early disease: – living with others associated with higher risk of 'current' loss of libido

Study (author & year, data collection period)	Study population	Unmet need investigated	Method of data collection/Instrument	Main findings
31. (cont.)				(OR = 1.56; 95% CI: [1.13 - 2.11]) & impotence (OR = 1.39; 95% CI [1.01 - 1.91]) – radical prostatectomy (RP) associated with higher risk of urinary incontinence (OR = 3.03; 95% CI [2.28 - 4.03]); loss of libido (OR = 1.72; 95% CI [1.33 - 2.22]) & erectile dysfunction (ED) (3.30; 95% CI [2.56 - 4.23]) – EBRT associated with higher risk of bowel problems (OR = 3.35; 95% CI [2.38 - 4.71]) & hot flushes (OR = 1.93; 95% CI [1.15 - 3.22]) – any hormonal therapy (HT) (previously & currently) associated with higher risk of loss of libido; breast changes & hot flushes while currently receiving HT was associated with higher risk of fatigue (OR = 2.16; 95% CI [1.44 - 3.26]) › Factors associated with ‘current’ side-effects in late disease: – RP associated with higher risk of urinary incontinence (OR = 4.45; 95% CI [2.97 - 6.66]) & erectile dysfunction (OR = 1.89; 95% CI [1.18 - 3.04]) – EBRT associated with higher risk of bowel problems (OR = 2.66; 95% CI [1.50 - 4.73]) & breast changes (OR = 2.06; 95% CI [1.13 - 3.78]) – pre-treatment ED was associated with higher risk of loss of libido (OR = 2.02; 95% CI [1.36 - 3.01]) & erectile dysfunction (OR = 1.87; 95% CI [1.19 - 2.96])
32. Thomas et al., 2014 NR [54]	HNC survivors N = 583	Physical Social Psychosocial/ emotional QoL/needs related to daily living	Postal survey Functional Assessment of Cancer Therapy (FACT-G) (for QoL – physical, social, emotional, functional domains) Functional assessment of cancer therapy head & neck scale (FACT-HN) (for QoL; HNC-specific domain only)	› Physical issues: 38% (n = 200) had problems with dry mouth; 28.3% (n = 150) had trouble swallowing naturally/easily with approximately 30% with lack of energy › Individual FACT domain scores (a higher domain score indicates higher QOL): – physical domain median score = 25.00; social domain median score = 21.00; emotional domain = 20.00; functional domain = 21.00; HNC-specific domain = 30.00 › Rural survivors reported higher physical, emotional & HNC-specific QOL than their urban counterparts › No significant difference in social & functional QOL between urban & rural

Study (author & year, data collection period)	Study population	Unmet need investigated	Method of data collection/Instrument	Main findings
33. Thomas et al., 2015 NR [55]	CRC survivors *N* = 496	Physical Practical	Postal survey EORTC QLQ-C30	› 36% reported financial difficulties › Physical symptoms-81% reported fatigue; 29% nausea/vomiting; 48% pain; 56% insomnia; & 41% diarrhoea › Median EORTC QLQ-C30, GHS score = 66.70 › Living remote from treating hospital associated with lower physical functioning & role functioning (ability to work) › Remoteness had significant negative relationship to GHS for men
34. Walsh & Hegarty, 2010, NR [56]	PC survivors 15 years or less post-radical prostatectomy (RP) *N* = 8	Physical Psychosocial/ emotional Family-related Social Health system/ information Patient-clinician communication Intimacy/ interpersonal	Semi-structured interviews	› Six themes in personal experience: process of diagnosis; support; normalisation; importance of information; defining moments; & primary concerns › Variety of feelings at diagnosis from shock to sadness to acceptance › All reported need for support with peer support perceived most important; some reported family as best support but others wanted to shield them; avoid being labelled by friends as 'dying'; variation in HCP support also reported › Normalisation linked to maintaining family relationships; maintaining public image & desire to return to work quickly post-surgery › Need for increased information from HCPs reported. Information sources included peers; GPs; urologists; & medical personnel with expertise in other possible treatment options ; leaflets provided by the GP; Urologist & Cancer Society; Internet; books; newspapers; & alternative therapist › ED most common concern & experienced by all › Main concerns = desire to overcome cancer & FOR

#34 papers from 27 studies; *PICTure whole Ireland study (70% of respondents from ROI, 30% from NI); seven papers report on data from this study. Of the seven papers, four of these present data separately for ROI and NI [21-23, 42]. For these papers only Republic of Ireland data are reported in this review. For the remaining three PICTure papers, all Ireland (Republic of Ireland and Northern Ireland) data are reported. ~ Ostomates (individuals who have undergone a surgical operation to create an opening in the body for the discharge of body wastes) made up of 55 with a colorectal cancer diagnosis, 129 with inflammatory bowel disease (IBS), and unknown disease conditions of remaining participants. Separate results not available for those with a cancer diagnosis: data presented in this table and remainder of the review document refers to all ostomates in the study (n = 256). ** Study involved a pre- and post-program evaluation of a 7-week facilitated breast cancer peer support Program. ##(scoring for DRS scale 0 to 100 (higher scores reflects higher regret). ###Scoring for FOR - a score of 0 to 100 (higher scores correspond to greater FOR). ^ Data reported for whole population as data could not be extracted separately for patients undergoing treatment and post-treatment patients. ^^ Matched control study with non-cancer control group. ^^^ Metastatic cancer not specifically considered for this review

Please see Page 42 for an explanation of the abbreviations used in this table.

Appendix 7: Frequency of supportive care needs (*n* = 34 papers)

Paper	Physical (*n* = 25)	Psychosocial/ emotional (*n* = 17)	Cognitive needs (*n* = 2)	Family-related (*n* = 1)	Social (*n* = 10)	Intimacy/ interpersonal (*n* = 12)	Practical (*n* = 11)	QoL/ needs related to daily living (*n* = 14)	Spiritual/ existential (*n* = 1)	Health system/ information (*n* = 11)	Patient-clinician communication (*n* = 2)
Cleary et al., 2011^ [27]						√					
Cleary et al., 2013^ [28]						√					
Cockle-Hearne et al., 2013^ [29]		√				√					
Davidson, 2016* [30]	√	√			√	√		√			
Droog et al., 2014 [31]	√	√					√			√	
Drummond et al., 2015a (PROMS)# [21]	√	√				√	√	√			
Drummond et al., 2015b# [32]	√	√				√	√	√			
Drury et al., 2017 [33]	√							√			
Dunne et al., 2017 [34]	√		√		√			√			
Gannon et al., 2017^^ [35]	√							√			
Gavin et al., 2015# [36]	√										
Gavin et al., 2016# [22]	√	√				√		√			

Paper	Physical (*n* = 25)	Psychosocial/ emotional (*n* = 17)	Cognitive (*n* = 2)	Family-related (*n* = 1)	Social (*n* = 10)	Intimacy/ interpersonal (*n* = 12)	Practical (*n* = 11)	QoL/ needs related to daily living (*n* = 14)	Spiritual/ existential (*n* = 1)	Health system/ information (*n* = 11)	Patient-clinician communication (*n* = 2)
Hackett et al., 2018 [37]	√	√			√		√	√		√	
Hanly et al., 2013 [38]								√			
Hanly et al., 2018 [39]							√				
Kelly & Dowling, 2011 [40]	√	√			√		√	√		√	
Landers et al., 2014 [41]	√				√						
Maguire et al., 2017# [23]	√	√								√	
Maguire et al., 2018a# [42]	√	√									
Maguire et al., 2018b [24]	√						√	√			
Meade et al., 2017 [43]	√	√								√	
Naidoo et al., 2013 [44]	√	√			√				√	√	

Paper	**Physical (*n* = 25)**	**Psychosocial/ emotional (*n* = 17)**	**Cognitive (*n* = 2)**	**Family-related (*n* = 1)**	**Social (*n* = 10)**	**Intimacy/ interpersonal (*n* = 12)**	**Practical (*n* = 11)**	**QoL/ needs related to daily living (*n* = 14)**	**Spiritual/ existential (*n* = 1)**	**Health system/ information (*n* = 11)**	**Patient-clinician communication (*n* = 2)**
O' Brien et al., 2017 [44]		√				√	√			√	
O' Shaughnessy et al., 2013~ [46]						√					
O' Shaughnessy et al., 2015~^^^ [47]	√	√			√	√					
Pearce et al., 2015 [48]								√			
Pertl et al., 2014 [49]	√		√							√	√
Power & Hegarty, 2010 [50]	√	√			√		√			√	
Sharp et al., 2013 [51]							√	√			
Sheehy et al., 2018^ [52]										√	
Steentjes et al., 2016# [53]	√					√					

Paper	**Physical (*n* = 25)**	**Psychosocial/ emotional (*n* = 17)**	**Cognitive (*n* = 2)**	**Family-related (*n* = 1)**	**Social (*n* = 10)**	**Intimacy/ interpersonal (*n* = 12)**	**Practical (*n* = 11)**	**QoL/ needs related to daily living (*n* = 14)**	**Spiritual/ existential (*n* = 1)**	**Health system/ information (*n* = 11)**	**Patient-clinician communication (*n* = 2)**
Thomas et al., 2014 [54]	√	√			√			√			
Thomas et al., 2015 [55]	√						√				
Walsh & Hegarty, 2010 [56]	√	√		√	√	√				√	√

^ data reported for whole population as data could not be extracted separately for patients undergoing treatment and post-treatment patients. * Ostomates (individuals who have undergone a surgical operation to create an opening in the body for the discharge of body wastes) made up of 55 with a colorectal cancer diagnosis, 129 with inflammatory bowel disease (IBS) and unknown disease conditions of remaining participants. Separate results not available for those with a cancer diagnosis – data presented in this table and remainder of the review document refers to all ostomates in the study (n = 256). # PiCTure study whole Ireland study (70% of respondents from ROI, 30% from NI). Seven papers report on data from this study. Of the seven papers, four of these present data separately for ROI and NI [21-23, 42]. For these papers only Republic of Ireland data are reported in this review. For the remaining three PICTure papers, all Ireland (Republic of Ireland and Northern Ireland) data are reported. ~ Australian PC study. ^^ matched control study with non-cancer control group. ^^^ metastatic cancer patients not specifically considered for this review. Please see Page 42 for an explanation of the abbreviations used in this table.

Appendix 8: Table of included conference abstracts

Abstracts (*n* = 6)	Main findings
1.Cooney et al., 2012 (BC survivors; *n* = 34; post-treatment; focus groups)	Physical effects (scars & lymphedema) linked to distress QoL difficulties with returning to work Hidden economic costs of BC
2.Cooney et al., 2012 (BC survivors; *n* = 296; post-treatment; survey)	Physical needs not being met (pain)
3.Hegarty, 2015* (Cancer survivors; *n* = 238; survey)	Unmet needs identified as follows: physical symptoms (pain, fatigue, memory loss); psychological effects of cancer and financial issues
4.Hegarty, 2015 (Cancer survivors; *n* = 206; mixed treatment group**; survey)	Survivor care identified as poor – less than 10% had care plans/discharge plans Poor functional and emotional well-being reported
5.Sharp et al., 2013* (Cancer survivors; *n* = 625; interviews)	QoL needs - patterns of workforce participation varied across cancer type
6.Timmons et al., 2012 (Cancer survivors; *n* = 17; post-treatment; interviews)	Gaps in survivor care post-treatment: information, psychosocial/emotional, practical, social and financial needs unmet

*Treatment status (i.e. undergoing or post-treatment) not reported. ** Mixed treatment group includes some patients undergoing treatment and those that have completed treatment – data in abstract presented for whole study population and not by treatment status. Please see Page 42 for an explanation of the abbreviations used in this table.

References for abstracts included in review synthesis (*n* = 6)

1. Cooney, M.A., Galvin, R., Stokes, E.K., & Connolly, E. (2012). Impairment, activity and participation after breast cancer: the lived experience. Support Care Cancer, 20 (Suppl 1): S1–S283. DOI 10.1007/s00520-012-1479-7

2. Cooney, M., Galvin, R., Connolly, E., & Stokes, E. (2012). Location and prevelance of pain in a cohort of women up to 4 years after treatment for breast cancer. Support Care Cancer, 21 (Suppl 1):S1–S301 DOI 10.1007/s00520-013-1798-3

3. Hegarty, J. (2015). The Experience of Individuals Who Live With, Through and Beyond Cancer in Ireland. Cancer Nursing, 38, No. 4S, 2015.

4. Hegarty, J. (2015). Cancer survivorship: the experience of patients and how the services ought to respond. Support Care Cancer, 23 (Suppl 1):S1–S388 DOI10.1007/s00520-015-2712-y

5. Sharp, L., O' Driscoll, D., Higney. K., & Bradley, C. (2013). Patterns and predictors of workforce participation in cancer survivors 6 and 12-months post-diagnosis: a longitudinal study. Support Care Cancer, 21 (Suppl 1):S1–S301 DOI 10.1007/s00520-013-1798-3

6. Timmons, A., Gooberman-Hill, R., O' Sullivan, E., & Butow, P. (2012). The supportive care needs of survivors of head and neck cancer in Ireland: are needs being met? Support Care Cancer 20 (Suppl 1):S1–S283 DOI 10.1007/s00520-012-1479-7

Appendix 9: References for studies/papers included in review synthesis (*n* = 34)

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