Chronic pain after cancer treatment: Insights from cancer survivors and healthcare professionals in England, UK to consider how cancer survivors' experiences can be improved

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Abstract

Chronic pain is a common side effect of cancer treatment. Pain is frequently cited as a top concern and unmet need for cancer survivors. This thesis explored experiences of cancer survivors living with chronic pain after cancer and investigated how their experiences can be improved.

A qualitative evidence synthesis highlighted a paucity of studies (n=4), all of which focused solely on women with breast cancer. Findings demonstrated pain sensations evoked memories of cancer diagnoses, treatment and subsequent threats to mortality and indicated this made pain harder to manage. These unique and bespoke dimensions to experiences of chronic pain are unreported in the non-malignant pain literature.

Qualitative interviews with cancer survivors (n=19) identified difficult and frustrating interactions with healthcare services: survivors did not feel informed or prepared about ongoing pain, nor heard or believed. Support was hard to identify and access, and the responsibility of this was left to the survivor. They experienced being bounced between services, often slipping between the gaps in provision, and reported healthcare professionals had little knowledge about pain after cancer. However, validation of their pain by healthcare professionals was key to improving experiences.

A survey was developed to gain insight into healthcare professionals’ knowledge, understanding and confidence about chronic pain after cancer. Respondents (n=135) acknowledged the significant clinical burden but demonstrated mixed levels of understanding of its impact. Approximately a quarter reported they never, or rarely, talked, listened or signposted about chronic pain after cancer.

Findings informed draft clinical recommendations. These were discussed and refined within expert review panels. Resultant clinical recommendations are summarised as: **PAINS: P**repare and inform, **A**cknowledge and listen, **I**ncrease healthcare professional knowledge, **N**ame and diagnose and **S**upported self-management interventions. Limitations include excluding those with treatable but not curable cancer and survivors of childhood cancer plus the challenges and complexity of the language of pain, chronicity, and cancer survivorship. Further research is needed to co-design, co-produce and evaluate patient information, healthcare professional educational resources and self-management interventions to support people with chronic pain after cancer treatment.

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Chapter 1: Introduction

This chapter explains the current context of cancer survivorship. Based on published literature, it identifies the problems, concerns and unmet needs experienced by cancer survivors and describes the impact on cancer survivors. Chronic pain after cancer treatment is introduced and the prevalence, risks and predictors are identified. Current clinical management and support services are identified. Next, a summary of the PhD is given including aims and objectives and operational terms. The chapter concludes with an introduction of the role of public contributors to this thesis.

1.1: The current context of chronic pain after cancer

Cancer survivorship

Survival rates for cancer are improving and more people are living for longer following their cancer treatment (NHS Digital, 2022; Siegel and Miller, 2019; Maddams, Utley and Møller, 2012). Approximately half of all people diagnosed with cancer will survive for ten years or more (Allemani *et al.*, 2018). In 2018, there were 43.8 million people living with cancer worldwide who were diagnosed in the last five years (Society, 2019). Within the UK, it is predicted there will be four million cancer survivors by 2030 (Maddams, Utley and Møller, 2012). Whilst cancer survival rates are increasing, it is known that not everyone is living well after cancer treatment and people can experience many physical and psychological symptoms after cancer (Emery *et al.*, 2022; Jefford *et al.*, 2022; Fitch, Lockwood and Nicoll, 2021; Maher *et al.*, 2018). These concerns can be long-term treatment effects (i.e., side-effects that begin during and extend beyond treatment completion) and also late effects, which occur months or years after treatment is finished (Emery *et al.*, 2022).

Problems, concerns and unmet needs in cancer survivorship

Cancer survivors can experience a range of problems including loss of physical performance, pain, fatigue, sleep problems, anxiety, depression, neuropathy, fear of recurrence, memory and concentration problems, sex and intimacy concerns, fertility issues, incontinence, body image concerns and worries about work and finances (Emery *et al.*, 2022; Schmidt *et al.*, 2022; Fitch, Lockwood and Nicoll, 2021; Batehup *et al.*, 2021; Fitch, Nicoll and Lockwood, 2020; So *et al.*, 2019; Sodergren *et al.*, 2019; Cupit-Link, Syrjala and Hashmi, 2018; Drury, Payne and Brady, 2017a; Capelan *et al.*, 2017; Wells *et al.*, 2015; Glare *et al.*, 2014; Bennion and Molassiotis, 2013; Armes *et al.*, 2009). Some cancer types have additional and specific concerns. Survivors of head and neck cancer can experience dry mouth, concerns about speech/voice, swallowing and taste changes (So *et al.*, 2019; Wells *et al.*, 2015). Colorectal cancer survivors have concerns relating to weight changes, upper gastrointestinal disturbances and bowel dysfunction (Drury, Payne and Brady, 2017a), and breast cancer survivors can experience hot flushes, mood swings and menopausal symptoms (Peate *et al.*, 2021; Schmidt, Wiskemann and Steindorf, 2018; Capelan *et al.*, 2017). Haematological cancer survivors, whose treatment included a haemopoietic stem cell transplantation can experience problems with chronic graft versus host disease following their cancer treatment (Barata *et al.*, 2016).

It is known that cancer survivors can have multiple unmet supportive care needs. A study conducted in the UK, of 1,425 patients who had received treatment for either breast, prostate, colorectal, gynaecologic or non-Hodgkins lymphoma, found a third of participants reported five or more unmet needs at the end of cancer treatment, and for 60% of these patients, the situation did not improve over time. Furthermore, a small proportion (11%) with no or few unmet needs at the end of treatment reported unmet needs six months later (Armes *et al.*, 2009). This seminal study was one of the first to show that cancer survivors may not have a steady trajectory of recovery to pre cancer levels of quality of life.

Armes and colleagues investigated unmet needs six months after cancer treatment finished (Armes *et al.*, 2009). Studies looking at longer survivorship periods have shown cancer survivors continue to have concerns and unmet needs. In the UK, a study investigating the supportive care needs of colorectal cancer survivors at 15 and 24 months after cancer treatment (n=526 and n=510 respectively) found nearly a quarter (24.9%) experienced at least one moderate to severe unmet need at 15 months following cancer treatment (Sodergren *et al.*, 2019). Sodergren and colleagues found 28.1% had at least one moderate to severe unmet need at 24 months following colorectal cancer treatment; 327 patients reported no needs at 15 months, but 15% (n=49) of these patients reported at least one unmet need at 24 months. 54 patients reported having five or more moderate or severe unmet needs at 15 months and 35 of these (63.6%) continued to report five or more unmet needs at 24 months (Sodergren *et al.*, 2019). In studies with larger sample sizes, greater numbers of unmet needs have been identified. A large study of 12,929 Canadian cancer survivors, aged 30 years and over and between one and three years following cancer treatment, found 87% reported experiencing at least one physical concern, with 58% experiencing three or more (Fitch *et al.*, 2019). Further, 78% experienced at least one emotional issue with 42% experiencing three or more and almost half (44%) experienced at least one practical challenge.

Similar levels of problems and concerns were reported in a German study. Schmidt *et al.,* (2022) investigated potential long term, late effects and burdens of cancer of 1,348 cancer survivors with mean time since diagnosis of 4.4 years (Schmidt *et al.*, 2022). Schmidt and colleagues found only 16.3% of cancer survivors did not report any burden with at least moderate level, 28% felt burdened with one to three issues, 30.9% by four to nine issues and 24.8% with more than 10 issues. Neither Fitch *et al.* (2019) or Schmidt *et al.* (2022) used a validated tool to collect their data. Schmidt and colleagues constructed a list of potential problems, symptoms and unmet needs from those described in the literature as well as problems discussed by patients on online platforms. Fitch and colleagues used a survey developed by their team. The survey was informed from a literature review and consultations with 15 cancer survivors (11 adult, 4 adolescents and young adults), 12 clinicians and 8 system leaders. Cognitive interviews were conducted with 15 cancer survivors to evaluate the survey's meaningfulness, clarity, understandability and ease of completion and the final survey was performance tested with 96 cancer survivors. Thus, measures were taken to test the survey, however, a formally validated tool could have been used.

Tools to investigate unmet needs in cancer survivors include the Cancer Survivors' Unmet Needs measure (CaSUN) (Hodgkinson *et al.*, 2007), the Survivor Unmet Needs Survey (SUNS) (Campbell *et al.*, 2011) and Short-Form Survivor Unmet Needs Survey (SF-SUNS) (Campbell *et al.*, 2014). However, whilst these tools have been purported to be validated by the authors, in a review of psychometric properties of needs assessment tools for post treatment cancer survivors, Jiao and colleagues concluded that none of the available tools assess for all domains of cancer survivorship care and none demonstrate adequate evidence of all recommended criteria for validity and reliability (Jiao *et al.*, 2018). Jiao and colleagues assessed against seven domains of cancer survivorship care namely physical, emotional, lifestyle or information needs, practical, family/relationships, sexual and cognition. The lack of validated tools in the cancer survivorship population may be justification for some studies investigating unmet needs in adult cancer survivors using the Supportive Care Needs Survey (SCNS), even though the SCNS was developed to investigate supportive care needs of adults with cancer rather than cancer survivors (Macleduff *et al.*, 2004; Bonevski *et al.*, 2000).

Despite these criticisms of the tools to measure unmet needs in cancer survivors, they continue to be used in research and provide useful descriptions of unmet needs in this population. In a systematic review of 26 quantitative studies investigating unmet needs in adult cancer survivors, 15 used the CaSUN, 10 utilised the SCNS and SUNS was used by one study (Miroševič *et al.*, 2019). Mazariego and colleagues (2020) used the CaSUN survey to assess long term unmet needs of 351 prostate cancer survivors and found over a third reported at least one unmet supportive care need 15 years after cancer diagnosis and treatment (Mazariego *et al.*, 2020). Whilst the sample size in the study by Mazariego and colleagues study was relatively small compared to the studies by Fitch *et al.* (2019) and Schmidt *et al.* (2022), the findings provide a valuable insight into the unmet needs of cancer survivors years after the completion of cancer treatment.

Miroševič and colleagues found the most frequently cited unmet needs across 26 studies investigating unmet need in adult cancer survivors to be in the psychological domain, particularly ‘managing concerns about the cancer coming back’, and in the information domain about ‘being informed about the things you can do to help yourself to get well’

(Miroševič *et al.*, 2019). However, Miroševič and colleagues included studies that had utilised the CaSUN, SCNS and SUNS assessment tools.

The CaSUN and SUNS assessment tools do not specifically have an item within the survey about pain, whereas the SCNS does include an item relating to pain. Studies that adopted the SCNS as a means of assessment, and therefore asked about pain, found that pain was frequently cited as problem. Pain was found to be a top 10 concern in a study of 200 Australian multiple myeloma patients and 257 Diffuse Large B Cell Lymphoma patients at 15 months post diagnosis (Oberoi *et al.*, 2017). Equally, O'Brien and colleagues found pain to be a top 10 most frequently cited unmet need in 583 head and neck cancer survivors in Ireland, 50% of whom were less than five years from cancer diagnosis and 50% of whom were more than five years from cancer diagnosis (O'Brien *et al.*, 2017). Pain was also identified by the SCNS as one of the top 10 most prevalent moderate or severe unmet needs at 15 and 24 months following colorectal cancer surgery by Sodergren and colleagues (Sodergren *et al.*, 2019).

In addition to studies investigating unmet needs of cancer survivors, studies reporting distress, concern and health burdens in cancer survivors have also identified pain as a frequently cited problem. In a study of 280 head and neck cancer survivors in Scotland, who had completed cancer treatment five years previously, Wells and colleagues found pain was cited as a top 10 most frequently selected cause of distress and 13th of the top 20 most commonly reported concerns (Wells *et al.*, 2015). Pain has been identified as an issue of greater concern in other studies investigating pain in head and neck cancer survivors. Cramer and colleagues asked 175 head and neck cancer survivors, with a median of 6.6 years after diagnosis 'Which issues have been the most important to you during the last seven days?' and pain was ranked as the third most important issue (Cramer, Johnson and Nilsen, 2018). Wells *et al.* (2015) and Cramer *et al.* (2018) had relatively small sample sizes, however, studies with larger sample sizes have mirrored the findings and have identified pain as a concern for cancer survivors. Pain was the 15th most frequently reported moderate or severe burden from 1,348 cancer survivors in Germany with mean time since diagnosis of 4.4 years (Schmidt *et al.*, 2022). In Canada, 13,534 cancer survivors, one to three years from completion of cancer treatment, were asked to identify the major challenges they faced following cancer treatment. Most reported challenges in the physical domain (n=10,259, 66.8%) and of these, pain was cited as the third most commonly experienced challenge (Fitch, Nicoll and Lockwood, 2020). Thus, collectively, this evidence highlights that pain is a frequently reported problem, concern and unmet need in cancer survivors. The prevalence of pain in cancer survivors will now be discussed.

Prevalence of pain in cancer survivors

The prevalence of pain after cancer treatment can vary according to tumour type and treatment. In a study of 410 breast cancer survivors in Israel, Hamood and colleagues found 74% (n=305) reported experiencing chronic pain (Hamood *et al.*, 2018). Dugué and colleagues identified a pain prevalence rate of 62.3% within 296 head and neck cancer survivors five years from diagnosis in France (Dugué *et al.*, 2022). However, these are single studies. When prevalence rates are pooled from multiple studies, the rates range from 35%-42%. Wang and colleagues pooled 187 observational studies, including 297,612 breast cancer survivors, to identify a pooled prevalence rate of 35% for persistent post-surgical pain following surgery (Wang *et al.*, 2020). Within the head and neck cancer survivor population, Macfarlane and colleagues identified a pooled pain prevalence rate of 42% in head and neck cancer survivors from a meta-analysis of 19 studies (Macfarlane *et al.*, 2012). However, Macfarlane and colleagues acknowledged the included studies were of mixed methodological quality and four did not specify timing of pain measurement in relation to cancer treatment. Similar rates of pain prevalence have been reported in systematic reviews that have included multiple cancer types. In a systematic review and meta-analysis of 29 studies which included 18,832 patients who had finished curative cancer treatment, Van den Beuken-van Everdingen *et al.,* (2016) calculated a pooled pain prevalence rate of 39.3% (95% CI 33.3-45.3). Van den Beuken-van Everdingen and colleagues included studies from across the world in their meta-analysis including 14 studies from Europe, 11 from North America, two from Asia, one from South America and one from Australia/New Zealand. The majority of studies reported pain prevalence rates in breast cancer survivors (n=15), or cancer survivors from all cancers combined (n=7). The remaining studies were from lung cancer survivors (n=2), gynaecological cancer survivors (n=2), urogenital cancer survivors (n=1), a combination of lung, colorectal or lymphoma cancer survivors (n=1) or malignant melanoma survivors (n=1). Van den Beuken-van Everdingen and colleagues acknowledge the high proportion of breast cancer survivors in their meta-analysis (15 studies, n=11,872 cancer survivors) may have distorted the pain prevalence rates. However, the pain prevalence rate they calculated has been mirrored in recent studies that found 34.6% (n=1,648) of American cancer survivors (Jiang *et al.*, 2019) and 34% (n=4,058) of Canadian cancer survivors experience pain (Fitch, Lockwood and Nicoll, 2021). With regards to severity of pain, over a quarter (27.6%, CI 18.9-36.3) of cancer survivors in the Van Den Beuken-Van Everdingen *et al*., (2016) meta-analysis rated their pain as moderate to severe (Van Den

Beuken-Van Everdingen *et al.*, 2016). Haenen and colleagues have recently updated the prevalence of pain in cancer survivors who finished cancer treatment at least three months ago (Haenen *et al.*, 2022). They included 38 articles published from 2014 and excluded any articles that had been included in Van den Beuken-van Everdingen and colleagues' systematic review. They considered that 26 of the 38 articles had a low risk of bias and 12 had a moderate risk. The pooled pain prevalence was 47% (95%CI 39–55) in cancer survivors at least three months from the end of cancer treatment. Thus, it appears the prevalence of pain in cancer survivors is increasing. However, it is not known whether the cancer survivors included in Haenen and colleagues review were already experiencing non-cancer-related pain or whether studies made a distinction between the assessment of cancer-related pain and non-cancer-related pain. Therefore, by not making this distinction, pain prevalence rates could be overstated.

Defining pain

Pain is defined as an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage (Raja *et al.*, 2020). Pain related to cancer treatment can be acute or chronic. Acute pain is characterised by a sudden onset within 90 days of cancer treatment, lasts a few weeks or months and then resolves. Some acute pain can persist and become chronic (Brant, 2022; Sundaramurthi, Gallagher and Sterling, 2017). Chronic pain can sometimes occur weeks, months and years after the delivery of cancer treatment, particularly radiation therapy (Brant, 2022; Vaz-Luis *et al.*, 2022; Karri *et al.*, 2021).

The terms 'chronic pain after cancer treatment', and 'persistent pain after cancer treatment', have been used interchangeably to describe long term pain in cancer survivorship. The International Association for the Study of Pain (IASP) and the International Classification of Diseases (IDC-11) define chronic post cancer treatment pain as "pain that persists or recurs for longer than three months and is caused by treatments for cancer such as surgery, chemotherapy and radiotherapy" (Bennett *et al.*, 2019c). This classification recognises that the one of the main sources for cancer-related chronic pain are the treatments used to cure it. Chronic pain may manifest from post-surgical pain (for example post mastectomy or post thoracotomy), cancer treatments (for example chemotherapy induced peripheral neuropathy), and radiation therapy (Brant, 2022; Glare *et al.*, 2014, 2022; Silbermann *et al.*, 2022; Bennett *et al.*, 2019c; Glare, Aubrey and Myles, 2019; Brown and Farquhar-Smith, 2017; Brown, Ramirez and Farquhar-Smith, 2014). Herein this thesis will refer to 'chronic pain after cancer treatment' defined as pain that persists or recurs for longer than three months and is caused by treatments for cancer such as surgery, chemotherapy and radiotherapy.

This review of the published literature has highlighted that cancer survivors can experience a multitude of problems, concerns and unmet needs following cancer treatment. A frequently reported problem, concern and unmet need is pain and prevalence rates of pain in cancer survivorship are approximately 40% (Fitch, Lockwood and Nicoll, 2021; Wang *et al.*, 2020; Jiang *et al.*, 2019; Van Den Beuken-Van Everdingen *et al.*, 2016; Macfarlane *et al.*, 2012). The following section explores the impact of living with chronic pain after cancer treatment on cancer survivors.

Impact of chronic pain after cancer treatment on cancer survivors

Studies adopting a quantitative methodology have demonstrated that living with chronic pain after cancer treatment is associated with a higher risk of feeling depressed, worried, nervous or anxious, and a poor quality of life (Poço Gonçalves, Veiga and Araújo, 2020; Bamonti, Moye and Naik, 2018; Cramer, Johnson and Nilsen, 2018).

Studies have highlighted a relationship between depression and pain in cancer survivors. Bamonti and colleagues from the USA collected data from 122 cancer survivors with either head neck cancer (n=42), colorectal (n=71) or eso-gastric (n=9) cancer at six, 12 and 18 months after cancer diagnosis. Bivariate correlations identified pain interference was significantly associated with reported depression at all time points. Whilst this study is limited to cancer survivors in early survivorship, it is interesting to note that pain impact scores remained constant at six, 12 and 18 months, therefore, for those that experienced pain, the impact of their pain did not diminish over time. The sample consisted of veterans, and veterans have greater risk of depression compared to non-deployed military personal (Blore *et al.*, 2015). However, recruiting from veterans resulted in the sample consisting of over 98.4% men. Thus, this study gives interesting and unique insights into the impact of pain and depression in male cancer survivors, as the majority of research into pain in cancer survivorship is in women (Van Den Beuken-Van Everdingen *et al.*, 2016). Cramer and colleagues investigated the impact of pain on quality of life in head and neck cancer survivors who were 6.6 years from diagnosis (Cramer, Johnson and Nilsen, 2018). Cramer and colleagues utilised the University of Washington Quality of Life measure. Pain was assessed by asking patients to self-report levels of pain (by agreeing with one of five statements ranging from ‘I have no pain’ to ‘I have severe pain, not controlled by medication') and also, if patients reported pain when asked 'What issues have been the most important to you during the last seven days?'. Cramer and colleagues found those with pain were significantly more likely to report issues with anxiety, appearance, recreation, mood, shoulder dysfunction, activity, chewing and swallowing. Patients with pain were also significantly more likely to screen positive for major depression. Explanations for the high rates of depression found in Cramer and Bamonti and colleagues' studies could be that they used self-report tools to determine depression. Levels of depression can be higher in self-report tools compared to diagnostic interviews in cancer patients during and after cancer treatment (Krebber *et al.*, 2014).

How participants are recruited can influence research findings (Bowling, 2014). Cramer and colleagues recruited from people who had been referred to a cancer survivorship clinic and thus participants had an increased symptom burden compared to the general head and neck cancer survivor population. However, this limitation was excluded by Dugué and colleagues who randomly selected head and neck cancer survivors to participate in a study in France of survivors who were under the age of 70 years (Dugué *et al.*, 2022). Dugué and colleagues also found depression was associated with patient reported pain. Further, chronic pain was also associated with the presence of anxiety, fatigue or co-morbidities and decreased physical activity and decreased physical and mental quality of life (Dugué *et al.*, 2022). Similarly, Drury and colleagues recruited 252 colorectal cancer survivors from routine follow up appointments in Ireland for a cross sectional study (Drury, Payne and Brady, 2017b). On the day of the survey, 40% indicated they had pain. Compared to participants who did not experience pain, those with pain were statistically significantly more likely to report lack of energy, body image disturbances or an inability to work. A high proportion indicated challenges with enjoyment of hobbies (79%), ability to work (79%) and enjoyment of life (75%). In total, 76% were discontented with their quality of life, compared to 41% with no pain. This is reflective of findings in other studies investigating the restoration of quality of life in colorectal cancer survivors. In a study of 1,017 non metastatic colorectal cancer survivors recruited from 29 recruiting centres in the UK, Wheelwright and colleagues found a third did not return to pre surgery levels of quality of life five years after treatment (Wheelwright *et al.*, 2020).

A limitation to the published papers reviewed is that it is not possible to establish if the pain experienced by cancer survivors was caused by cancer and its treatments, or by pain from a different source. For example, in Bamonti and colleagues' study, it was unclear if the pain was related to cancer and its treatment, different co-morbidities or a combination of both as participants had, on average, three additional health conditions (Bamonti, Moye and Naik, 2018). In contrast, in a study of 1,702 American, working age cancer survivors, Cox-Martin and colleagues specifically asked participants 'do you currently have physical pain caused by your cancer or cancer treatment' and thus the aetiology of the participants' pain was clarified. Cox-Martin and colleagues found those living with cancer-related chronic pain have more physically unhealthy days (63% more compared to those living without cancer-related pain), more mentally unhealthy days (52% more compared to those with no pain), and experience more than double the number of days with activity interference compared to survivors without pain (Cox-Martin *et al.*, 2020).

Having a cancer diagnosis can cause distress and hardship arising from the financial burden of cancer treatment (Longo *et al.*, 2020; Mols *et al.*, 2020; Gordon *et al.*, 2017;

Zafar and Abernethy, 2013). This can be referred to as financial toxicity (Zafar and Abernethy, 2013). A systematic literature review to establish the extent of financial toxicity among cancer survivors found a substantial proportion experience financial hardship (Gordon *et al.*, 2017). However, of the 25 studies included in the systematic review by Gordon and colleagues, most were from the USA (n=14) and none were from the UK. Similarly, Mols and colleagues conducted a systematic review of financial toxicity and employment status in cancer survivors and found being treated for cancer had serious negative consequences on employment and expenditure (Mols *et al.*, 2020). Mols and colleagues included 31 studies from across the world but again the majority of studies were from the USA (n=16) and only one was from the UK. This makes comparison to the UK population challenging, as the funding of the healthcare systems differ from individual to state funding. However, in the UK, a study of 298 cancer survivors with either breast, colorectal or prostate cancer at 12 months from diagnosis showed that cancer survivors can have out of pocket expenses (Marti *et al.*, 2016). Studies looking at the financial toxicity of specific symptoms have demonstrated that cancer survivors who are living in pain experience significant financial hardship (Tan *et al.*, 2022).

Tan and colleagues conducted a systematic literature review of 68 studies to investigate how cancer-related symptoms can influence employment outcomes in cancers (Tan *et al.*, 2022). They included 26 studies looking at the symptom of pain but noted over a quarter of studies did not use a validated patient reported outcome measure (PROM) to identify the presence or severity of pain. Tan and colleagues concluded that studies with more than 1000 participants (n=4) consistently showed that patients with more severe pain were less likely to return to work or be employed. However, none of these studies were from the UK, as one described cancer survivors from Denmark, Finland, Iceland and

Norway (Lindbohm *et al.*, 2014), one was from Germany (Mehnert *et al.*, 2017) and two were from USA (Cox-Martin *et al.*, 2020; Kenzik *et al.*, 2015). In the UK, a study of 290 cancer survivors with either breast, gynaecological, head and neck or urological cancer found those who experienced worst physical functioning returned to work later (Cooper *et al.*, 2013). Whilst Cooper and colleagues looked at cancer survivors in the UK, they only followed them for a median of 119 days from the start of cancer treatment, therefore, the survivorship period was short. Halpern and colleagues (2022) examined the impact of pain on employment and financial outcomes on American cancer survivors up to and over 10 years since cancer diagnosis and identified that cancer survivors living with chronic pain after cancer treatment experience significantly increased likelihood of adverse employment outcomes including early retirement and feeling less productive. Further, cancer survivors with pain experience significantly increased likelihood of adverse financial outcomes including borrowing money or going into debt (Halpern, de Moor and Yabroff, 2022).

A problem for all studies exploring quality of life in cancer survivors is the lack of a comprehensive assessment tool (van Leeuwen *et al.*, 2018). Assessment tools for long term cancer survivors are available, including the Quality of Life in Adult Cancer Survivors (QLACS) survey (Avis *et al.*, 2005) and Impact of Cancer (IOC) survey (Zebrack *et al.*, 2006). However, these primarily focus on psychosocial aspects of survivorship and pay little attention to assessment of chronic physical consequences of cancer and its treatment (Muzzatti and Annunziata, 2013). Further, they lack verified psychometric properties and have been based on a limited number of cancer survivors living in the USA (van Leeuwen *et al.*, 2018; Muzzatti and Annunziata, 2013).

The European Organisation for Research and Treatment of Survivorship Task Force (EORTC) has recognised the need to develop a patient reported outcome measure (PROM) that fully captures the ranges of issues that are relevant to disease free cancer survivors (van Leeuwen *et al.*, 2018). In response, the QLQ-SURV111 has been developed to identify the full range of physical, mental and social health related quality of life issues relevant to disease free cancer survivors. A phase three study has been reported with 492 cancer survivors, from 17 countries, with one of eleven cancer diagnoses, who tested the survey and the survey is now being further validated in a phase four international study (van Leeuwen *et al.*, 2022). The QLQ-SURV111 includes four items relating to pain: '1) Have you had aches and pains in your joints? 2) Have you had aches or pains in your muscles? 3) Have you had pain? 4) Did pain interfere with your daily activities?'. It is beneficial that the measure asks about both pain and aches as cancer survivors do not always label their pain as pain but may use alternative descriptions (Björkman, Arnér and Hydén, 2008). Thus, by asking about aches in addition to pain, there is greater likelihood that the full extent of the impact of pain and pain syndromes will be captured.

This review has demonstrated that chronic pain after cancer treatment has significant impact on cancer survivors' lives. Risks for developing post cancer pain, and the assessment and management of chronic pain after cancer treatment are outlined below.

Risks of developing chronic pain after cancer treatment

The type of surgical procedure, and treatment with chemotherapy and/or radiotherapy can impact the development of chronic pain after cancer treatment in cancer survivors (Brown and Farquhar-Smith, 2017; Brown, Ramirez and Farquhar-Smith, 2014; Glare *et al.*, 2014). Predictors of chronic pain after cancer treatment include younger age, adjuvant chemotherapy and/or radiotherapy, and the presence of postoperative pain (Cramer, Johnson and Nilsen, 2018; Wang *et al.*, 2016; Bruce *et al.*, 2014). In breast cancer survivors the following have been reported as associated with chronic pain after cancer treatment: more extensive surgery (for example total versus partial mastectomy), axillary node dissection and reconstruction, adjuvant chemotherapy or radiotherapy, higher body mass index, anxiety, depression, diabetes, smoking, preoperative pain and moderate to severe post operative pain (Lim *et al.*, 2022; Hamood *et al.*, 2018; Leysen *et al.*, 2017; Bruce *et al.*, 2014; Schreiber *et al.*, 2014). Individual variation in psychosocial functioning, including catastrophizing (exaggerated negative orientation), anxiety, depression, somatization (the physical manifestation of psychological concerns) and sleep quality, influence women's risk of developing chronic pain after breast cancer surgery (Schreiber *et al.*, 2014).

Identifying risks of chronic pain after cancer treatment is important to firstly mitigate against potential preventive risk factors, and secondly, provide guidance to healthcare professionals and cancer survivors to assess for chronic pain after cancer treatment in the future.

Chronic pain assessment

A clinical holistic needs assessment forms a key part of cancer survivorship care in the UK (Maher *et al.*, 2018) . Current UK health policy states that "every person diagnosed with cancer will have access to personalized care, including needs assessment, a care plan, and health and well being information and support" (Department of Health, 2019b, p.61). Clinical holistic needs assessment (HNA) is concerned with the whole person. It identifies patients' needs across domains such as physical, emotional, practical, social, environmental and spiritual through use of a structured assessment tool. The patient will then discuss the needs identified with the assessor and this discussion results in a care plan, which can include referrals or signposting to relevant services (Young *et al.*, 2015). Whilst some have questioned the evidence base for the holistic needs assessment (Johnston, Young and Campbell, 2019), it recognised that assessment is key to identifying clinical problems experienced by cancer survivors (Emery *et al.*, 2022; Jefford *et al.*, 2022). Further, a clinical holistic needs assessment can provide an opportunity to highlight red flags relating to the development of chronic pain after cancer treatment and can prompt a more detailed pain assessment (Pelvic Radiation Disease Association, 2022a).

Comprehensive and detailed assessment of chronic pain after cancer treatment is essential for optimal pain management and support (Brant, 2022; Pelvic Radiation Disease Association, 2022a). European standards for the management of cancer-related pain state that “Patients with a history of cancer should be routinely screened for pain at every engagement with a healthcare professional” (Bennett *et al.*, 2019a, p.661). Further, if the pain is new or acute, then cancer recurrence or progression should be investigated (Emery *et al.*, 2022). An holistic assessment recognises the impact the pain can have on the body, mind, and spirit (Saunders, 1988). Holistic assessment can provide information about the total suffering experienced by the patient and the multiple factors that may be contributing to the pain (Brant, 2022; Galligan, 2022a). This should include:

- history of the pain including onset and duration
- location and intensity of the pain
- the quality (how it feels) and temporality (how it changes over time) of the pain
- details of past cancer treatment

- information about past strategies used to manage pain and evaluation of effectiveness of strategies
- functional assessment, psychological assessment, social and spiritual history (Galligan, 2022a; Fink and Gallagher, 2019; Fink and Brant, 2018).

European standards state the importance of assessing cancer survivors for pain (Bennett *et al.*, 2019a) and Emery *et al.* (2022) recommended in the Lancet, that cancer survivors should have their pain assessed at every consultation.

Management of chronic pain after cancer treatment

The European Society for Medical Oncology (ESMO) Expert Consensus Statements on Cancer Survivorship supports that the management of long term and late effects of cancer, and their impact, requires clinical assessment of signs and symptoms, ideally using standardised assessment instruments (Vaz-Luis *et al.*, 2022). Implementation of effective pharmacological or non-pharmacological strategies should be employed as needed for the management of long term and late effects, such as pain (Vaz-Luis *et al.*, 2022).

Pharmacological interventions to alleviate chronic pain after cancer treatment include non-opioids and opioid drugs. NICE also recommend considering an antidepressant in the guideline NG193: Chronic pain (primary and secondary) in over 16s: assessment of all chronic pain and management of chronic primary pain (NICE, 2021). The choice of medication should be informed by the probable cause of pain (i.e. visceral, neuropathic, bone or referred pain) (Brant, 2022; Emery *et al.*, 2022).

Most of the evidence for the use of opioids for cancer pain have focused on advanced disease and their effectiveness is less well established for the use in disease free cancer survivors (Emery *et al.*, 2022; Boland and Ahmedzai, 2017). It is recognised that opioid analgesia may not always be suitable for long term management of pain in cancer survivors (Bennett *et al.*, 2019a). The adverse effects of opioids, such as sedation, dizziness and constipation may not be acceptable to cancer survivors, particularly if that impedes the restoration of activities, such as driving (Boland and Ahmedzai, 2017). In addition, cancer survivors can be hesitant to take opioids. Marshall and colleagues conducted a qualitative study of in-depth interviews with 25 breast cancer survivors, with an average of 3.92 years of cancer survivorship, who were prescribed opioids for pain management. They found the barriers to taking the prescribed opioids included self-mediated behaviours whereby participants would rather endure the pain rather than risk addiction to prescribed analgesia. Consequently, participants altered the dosing and self-regulated how much medication to take, even if that left them with ongoing pain (Marshall *et al.*, 2022).

Non-pharmacological management for chronic pain after cancer treatment mirrors recommendations for all chronic pain management (NICE, 2021) and includes a multi disciplinarily approach encompassing education interventions, exercise and physical activity, acupuncture, use of heat and cold, and psychological interventions and support (Brant, 2022; Emery *et al.*, 2022; NICE, 2021; De Groef *et al.*, 2019). The European standards for the management of cancer-related pain include support and advice for self-management (Bennett *et al.*, 2019a), and rehabilitation is considered key for chronic pain after cancer treatment (De Groef *et al.*, 2019).

Rehabilitation for chronic pain after cancer treatment in cancer survivors includes patient education, specific exercise therapy, manual therapy, general exercise therapy and mind-body exercise therapy (De Groef *et al.*, 2019). A recent systematic review of 95 papers found cognitive behavioural therapy (CBT) improves functional health in cancer survivors (Blumenstein *et al.*, 2022). Blumenstein and colleagues included 11 papers examining the impact of CBT on pain in cancer survivors specifically, and found CBT statistically significantly improved functional health. Mathew and colleagues found acceptance and commitment therapy (ACT) reduces anxiety, depression, and fear of cancer recurrence and improves psychological flexibility and quality of life in cancer survivors, but its impact on pain in this population is understudied (Mathew *et al.*, 2021).

Clinical guidelines are available to support healthcare professionals to manage chronic pain after cancer treatment (Bennett *et al.*, 2019a; Swarm *et al.*, 2019; Fallon *et al.*, 2018; Paice *et al.*, 2016) and in the UK, a framework and operational guidance has been developed to improve pain services for adults across the UK with cancer or life limiting disease, including cancer survivors (Faculty of Clinical Oncology, The Royal Colleage of Radiologists, 2019). The framework includes four levels and the target healthcare group, assessment and recommended interventions for each level are outlined in table 1.

Table 1: Levels of pain service provision for adults with cancer or life limiting disease in the UK

Level	Healthcare group/setting	Assessment	Intervention
1	All healthcare professionals	Recognition of pain Screening for pain	Effective information giving and compassionate support Referral to oncology or palliative care professional Initiation of conventional analgesia
2	All oncology and palliative care physicians and advanced practitioners	Assessment of pain Diagnosis of pain disorder	Management and titration of conventional analgesia Support for self-management Referral to Specialist Pain Management as required
3	Linked Palliative care and Specialist Pain Management in secondary care settings	Diagnosis of complex pain syndromes	Management of complex analgesic combinations, including high dose opioids Interventional procedures of varying complexity depending on local skills and resources Support for self management

			Referral to Adult Highly Specialist Pain Management as required
4	Adult Highly Specialist Pain Management in tertiary care settings	Diagnosis of complex pain syndromes	Interventional procedures not available at local Level 3 and including some more complex procedures (e.g., implanted intrathecal drug delivery systems, cordotomy and other neurolytic procedures) Rehabilitative programmes Managing distress or other behaviours related to poorly controlled mediation use

At level 4, there is a national rehabilitation service for cancer survivors living with chronic pain after cancer treatment. The Pain Related Complex Cancer Late Effects Rehabilitation Service (CLLERS) at the Royal United Hospitals Bath NHS Foundation Trust runs two-week residential rehabilitation programmes for cancer survivors with severe and chronic pain due to the consequences of cancer treatment (Royal United Hospitals Bath NHS Foundation Trust, 2020). To access the CLLERS service cancer survivors need to have been seen by local pain, rehabilitation and/or late effects cancer services, without improvement in symptoms.

Despite increasing guidelines and frameworks, evidence demonstrates that it is not easy for cancer survivors living with chronic pain to access support. In Canada, in a survey of 12,929 adult cancer survivors, 11,819 answered the question about prevalence of chronic pain and of these, 34% experienced chronic or long-term pain. Of these, 62% considered the concern to be 'big' or 'moderate' and 61% sought help for their chronic pain. However, 35% of those found it difficult to obtain help (Fitch *et al.*, 2019). Of those who reported physical problems but did not seek help, 33% indicated it was because someone had told them it was normal to expect symptoms and they did not think anything could be done. Ten percent said they did not want to ask for help (Fitch *et al.*, 2019).

In the UK, health policy focuses on those ‘living with and beyond cancer’ (Department of Health, 2017) and considers the needs of people affected by cancer collectively. However, whilst there may be some similarities in how chronic pain is experienced in those ‘living with’ cancer and those ‘living beyond’ cancer, there will undoubtedly be differences in the clinical services they have access to for support. During active treatment, people with cancer will be embedded in oncology services and should have access to support for symptoms, such as pain, during this time. Yet, research has identified that cancer survivors can feel ‘dropped from the system’ when treatment finishes and struggle to understand what to expect from healthcare systems after cancer (Mead *et al.*, 2020; Matthews and Semper, 2017; Armes *et al.*, 2009). Challenges include difficulties regarding access, professional responsiveness, co-ordination, communication, involvement in care and workforce shortages (Fitch, Lockwood and Nicoll, 2021; Mead *et al.*, 2020; Jacobs and Shulman, 2017). Cancer survivors may also lack confidence or feel vulnerable asking for help; or may not expect chronic pain to occur after cancer treatment (Foster and Fenlon, 2011). Thus, cancer survivors can face difficulty in obtaining the help they need for chronic pain. Therefore, it is important to capture the views of those ‘living beyond’ cancer as their experiences of chronic pain, and of services to support them, may be unique to this population.

No research has been identified exploring UK cancer survivors’ experiences of accessing support for chronic pain after cancer treatment. However, it is known that seeking help for chronic pain after cancer treatment can be additionally complicated because pain can occur as a late effect of cancer treatment. Late effects of cancer bring their unique challenges. Often, survivors can lack understanding and awareness of the risks of late effects of cancer (Brown, Greenfield and Thompson, 2015). In a study of 36 breast cancer survivors with an average time since cancer diagnosis of 8.45 years, many were not aware of the risks of late effects of cancer treatment and reported anxiety upon developing late effects symptoms as they had assumed the onset signified a cancer recurrence (Rosenberg, Butow and Shaw, 2022). Participants expressed desire for knowledge about chronic late effects to set more realistic expectations for what life post-treatment would look like (Rosenberg, Butow and Shaw, 2022).

Challenges with reviewing literature on chronic pain after cancer treatment in cancer survivors

Reviewing the literature on chronic pain after cancer treatment in cancer survivors presents challenges. Two large meta-analyses have identified pooled prevalence rates of pain after cancer treatment as 39.9% (Van Den Beuken-Van Everdingen et al., 2016) and 47% (Haenen et al., 2022). However, it is difficult to establish the extent co-morbidities and other (non-cancer) pain conditions may have influenced these findings. Further, it is not clear if participants experienced chronic pain or isolated pain incidents at the time of data collection. Even within studies that have specifically investigated the prevalence of chronic pain in cancer survivors, many have used different definitions of the term "chronic". For example, Jiang and colleagues (2019) defined chronic pain as: pain on most days, or every day, in the past six months, whereas Sanford and colleagues (2029) used pain lasting for a three-month period to define chronicity.

Variations in pain assessment can also present challenges when interpreting pain prevalence rate data. Haemen and colleagues (2022) recognised that across the studies included in their meta-analysis, different pain assessment criteria were adopted, various scoring thresholds were used to define the presence of pain, and different assessment methods were used (i.e., numerical scales, psychophysiological tests, or questionnaires). Furthermore, many researchers have relied on participant recall of pain, which may have introduced additional bias (Schoth, Radhakrishnan and Liossi., 2020).

The language surrounding pain can be emotive and can influence reporting. People may be hesitant to disclose they are experiencing pain (Salgado et al., 2020). Reluctance to report pain may be due to stoicism, concern about being a bother to others or fear of stigmatisation (Cagle and Bunting, 2017). Further, cancer patients can use metaphors, such as 'like an electric shock' to describe their discomfort (Björkman, Arnér and Hydén, 2008, pp. 1022) but not necessarily label such sensations as 'pain' and therefore not identify as someone 'in pain'. These factors may lead to inaccurate reporting and over or underestimation of pain prevalence.

Comparisons between studies are further complicated by definitions of who is a cancer survivor, and at what time this term is used following cancer treatment. In the studies reviewed, it is not always clear if participants were cancer free, had metastatic disease or had stable, chronic cancer that was managed by maintenance therapy. Further, prevalence studies used differing timepoints for the period of cancer survivorship, including five years (Dugué et al., 2022), two years (Sanford et al., 2019) and one year from cancer treatment (Hamood et al., 2018), and as little as three months from cancer treatment (Jiang et al., 2019).

Finally, it should also be noted that studies included in the pooled prevalence rates of pain in cancer survivors are skewed towards those with breast cancer and women (Haemen et al., 2022; Van Den Beuken-Van Everdingen et al., 2016). In their meta-analysis of 38 studies, Haemen and colleagues (2022) noted that 30 studies (80.9%) were in breast cancer, and 84.2% of studies only included women. Yet studies looking at different cancers have provided higher prevalence rates of chronic pain. For example, Dugue and colleagues calculated a prevalence rate of 62.3% in head and neck cancer survivors five years from diagnosis. However, they did not articulate the cause of pain and thus pain may not have been related to cancer or its treatment but other pain conditions, and this may have inflated the prevalence.

Collectively, the challenges of reviewing the pain literature complicate the interpretation of pain prevalence data and consequently reported prevalence rates should be viewed with caution.

In summary, this introduction has highlighted that cancer survivors can experience a variety of symptoms and problems after cancer treatment has ended and pain is a common issue (Schmidt et al., 2022; Fitch, Nicoll and Lockwood, 2020; Sodergren et al., 2019; Cramer, Johnson and Nilsen, 2018; Oberoi et al., 2017; Wells et al., 2015). Quantitative survey data have demonstrated that living with chronic pain after cancer treatment is associated with a higher risk of psychological morbidity, unemployment, financial hardship and needing assistance with activities of daily living (Halpern, de Moor and Yabroff, 2022), and high levels of unmet need (Schmidt et al., 2022; Miroševič et al., 2019; Capelan et al., 2017). However, these studies have relied on large scale questionnaire data, and without opportunity to probe or clarify, it is plausible that some of the richness and nuances of the impact of living in chronic pain after cancer treatment may be lost. Available research does not explain the qualitative experiences of what it is like to live with chronic pain after cancer treatment, yet it is acknowledged that understanding lived experiences is essential in order to identify and address need (Maher et al., 2018; McConnell, White and Maher, 2017). This leads to the research question: What is the experience of chronic pain after cancer treatment in adult cancer survivors and how can their experiences be improved? This thesis aims to address this question.

1.2: Thesis summary

This thesis uses knowledge gathered from literature and new insights from cancer survivors and healthcare professionals, to establish the experiences of cancer survivors living with chronic pain after cancer treatment in England, UK and to consider how their experiences can be improved.

Overall PhD Question

What are the experiences of cancer survivors living with chronic pain after cancer treatment in England, UK and how can their experiences be improved?

Overall PhD Objectives

- To identify, review and synthesise the qualitative literature surrounding the experience of chronic pain after cancer in adult cancer survivors.
- To qualitatively explore the experiences, needs and service provision for cancer survivors living with chronic pain after cancer treatment.
- To establish healthcare professional knowledge, understanding, experience, and confidence regarding chronic pain after cancer treatment.
- To describe future research and clinical recommendations to improve patient experiences relating to chronic pain after cancer treatment in people living with and beyond cancer.

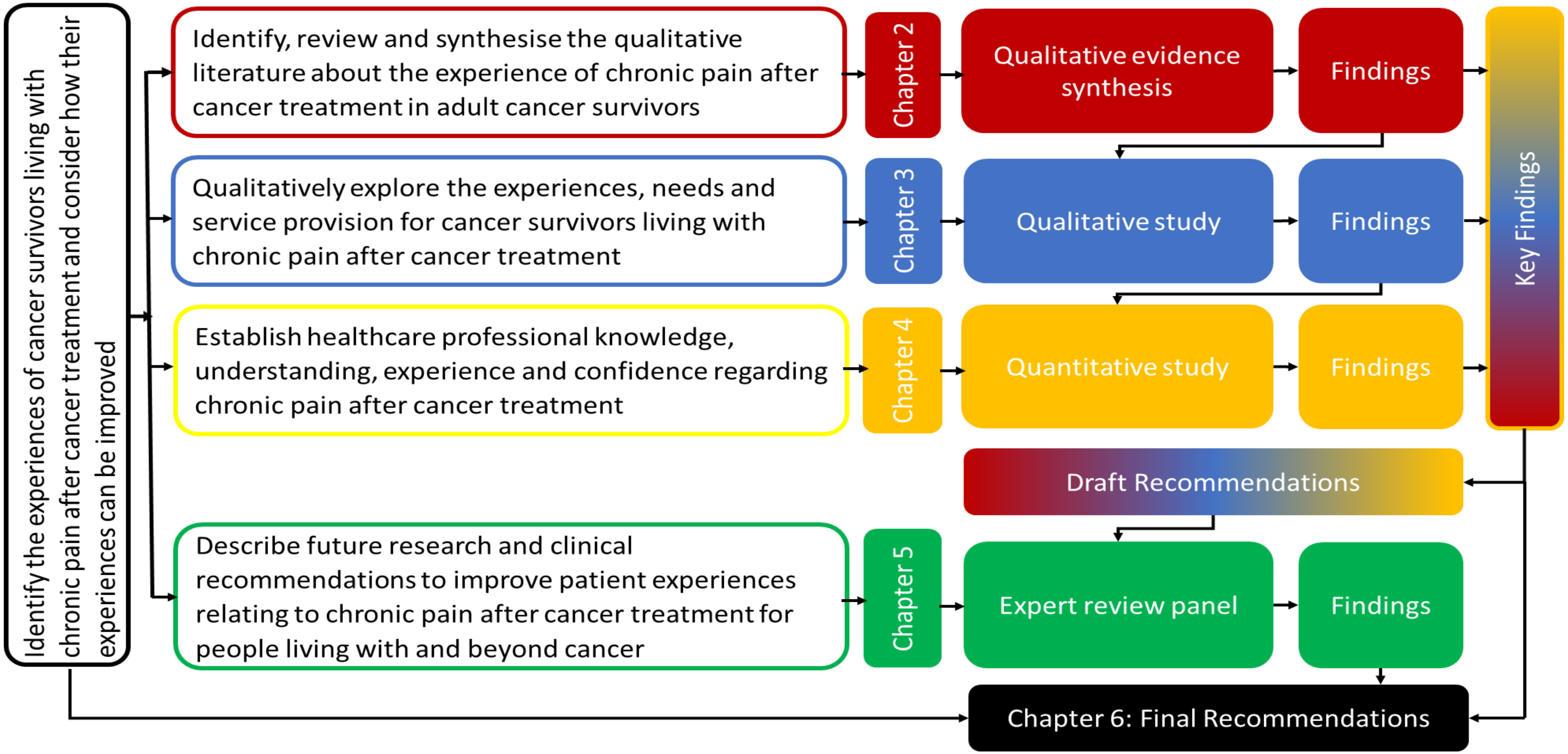
Thesis outline

Each chapter describes a study that addresses one of the PhD objectives:

- Chapter 2: A qualitative evidence synthesis of the experience of chronic pain after cancer treatment for cancer survivors.
- Chapter 3: A qualitative study exploring experiences and needs of cancer survivors with chronic pain after cancer treatment and their views of service provision.
- Chapter 4: A quantitative study of healthcare professionals' knowledge, understanding, experience and confidence regarding chronic pain after cancer treatment.
- Chapter 5: A series of stakeholder events and targeted engagement activities to develop clinical recommendations to improve patient experiences relating to chronic pain after cancer treatment in people living with and beyond cancer.

The findings from these individual studies are used collectively to identify key findings and clinical recommendations to address the overall aim of the PhD (figure 1). The thesis concludes with areas for future research and reflections on the strengths and weaknesses of the work.

Figure 1: An outline of the thesis



Identify the experiences of cancer survivors living with chronic pain after cancer treatment and consider how their experiences can be improved

Identify, review and synthesise the qualitative literature about the experience of chronic pain after cancer treatment in adult cancer survivors

Qualitatively explore the experiences, needs and service provision for cancer survivors living with chronic pain after cancer treatment

Establish healthcare professional knowledge, understanding, experience and confidence regarding chronic pain after cancer treatment

Describe future research and clinical recommendations to improve patient experiences relating to chronic pain after cancer treatment for people living with and beyond cancer

Researcher perspective

The researcher (JA) has been a cancer nurse for over twenty years. The first 12 years involved full time clinical work, briefly in a hospice and then predominantly in haematology. During this time JA worked as a staff nurse on the haematology unit, in the cancer clinical trials team, as a bone marrow transplant clinical nurse specialist and senior practice educator. In 2012, JA moved to the University of the West of England (UWE) as a Senior Lecturer. JA embedded cancer education across the UWE pre-registration nursing programme (Armoogum and Hepplewhite, 2015) and had her academic post adopted by Macmillan Cancer Support in 2016. JA completed an MSc in Advanced Cancer Nursing in 2009, a Post Graduate Certificate in Teaching and Learning in 2015, and a predoctoral fellowship in 2017. In 2021, JA co-founded the Aspirant Cancer Career and Education Development programme (ACCEND) with partners from Health Education England, Macmillan, the UK Oncology Nursing Society (UKONS) and the Royal College of Nursing (RCN).

Prior to starting the PhD JA had fundamental knowledge of chronic pain after cancer treatment but no specialist clinical expertise and has been grateful to learn more about the experiences of cancer survivors living with chronic pain and collaborate with experts in research, cancer survivorship, chronic pain, and education throughout the PhD. JA had wanted to complete a PhD for many years and was delighted to have the opportunity to commence a part time PhD in 2017 whilst continuing her role as a Macmillan Senior Lecturer.

1.3: Defining a cancer survivor and operational terms

There is no consensus in the literature or national clinical guidelines regarding the definition of a cancer survivor. Policy makers within the UK refer to cancer survivors as anyone living with or beyond cancer (Department of Health, 2017, 2019a). Similarly, the National Coalition for Cancer Survivorship in the United States of America adopt a broad definition and include anyone “from the time of diagnosis and for the balance of life” (National Coalition for Cancer Survivorship, n.d.). The definition from the European Organisation for Research and Treatment of Survivorship Task Force (EORTC) focuses on those after treatment and defines a cancer survivor as any person diagnosed with cancer, who has completed his or her primary treatment (with exception of maintenance therapy) and who has no active disease (Moser and Meunier, 2014). In addition to the variety of definitions of a cancer survivor, the term itself can be contentious. It has been recognised for years that not all people who have had cancer identify themselves as a ‘survivor’ (Wee *et al.*, 2022; Cheung and Delfabbro, 2016; Bell and Ristovski-Slijepcevic, 2013; Chambers *et al.*, 2012). Most recently, in a survey of 539 people diagnosed with colorectal cancer, the words aversion, discomfort, indifference, reluctance and acceptance were associated with the term ‘cancer survivor’ (Wee *et al.*, 2022). Whilst recognising these differing views, this thesis adopted the term ‘cancer survivor’. This was primarily because the focus of the PhD is people who had finished their cancer treatment yet have no active disease, and thus are ‘cancer survivors’ as defined by EORTC, secondly, the public contributors considered this to be the most appropriate term and finally, the absence of a more suitable or satisfactory alternative description.

Operational terms:

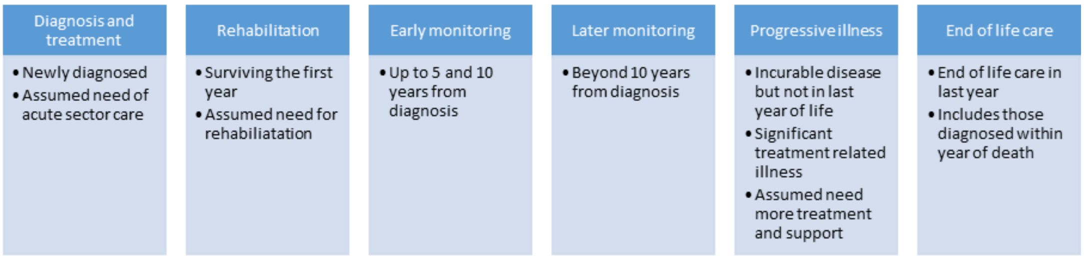
Cancer survivor: This thesis will adopt the EORTC (European Organisation for the Research and Treatment of Cancer) definition that defines cancer survivor as any person diagnosed with cancer, who has completed his or her primary treatment (with the exception of maintenance therapy) and who has no active disease (Moser and Meunier, 2014).

Chronic pain after cancer treatment: Chronic post cancer treatment pain that persists or recurs for longer than 3 months and is caused by treatments for cancer such as surgery, chemotherapy and radiotherapy (Bennett *et al.*, 2019c).

Cancer care pathway: According to Maher and McConnell (2011) the five main phases of the cancer care pathway are (figure 1):

1. Diagnosis and treatment (assumed to be a year from diagnosis)
2. Rehabilitation (assumed to be the year after treatment, estimated to be the second year since diagnosis)
3. Monitoring – split between early and late monitoring (includes those at risk of recurrence or treatment complications but with no active cancer or treatment related illness)
4. Progressive illness (includes incurable cancer but not those in the last year of life, and significant treatment illness)
5. End of life – (includes those in the last year of life, including those diagnosed within a year of death)

Figure 1: Main phases of the cancer care pathway (Maher and McConnell, 2011)



Diagnosis and treatment	Rehabilitation	Early monitoring	Later monitoring	Progressive illness	End of life care
• Newly diagnosed • Assumed need of acute sector care	• Surviving the first year • Assumed need for rehabiliatation	• Up to 5 and 10 years from diagnosis	• Beyond 10 years from diagnosis	• Incurable disease but not in last year of life • Significant treatment related illness • Assumed need more treatment and support	• End of life care in last year • Includes those diagnosed within year of death

Services: Interactions between cancer survivors and healthcare professionals within the NHS or a third sector organisation e.g., follow up clinics, telephone support, specialist services, primary care, Macmillan health and wellbeing events.

Public contributor: People who are actively involved with the research design and process (National Institute for Health Research, 2022). For this research the public contributors are cancer survivors who are living with chronic pain after cancer treatment.

Healthcare professional: Anyone working with people living with and beyond cancer in a health-related supportive role e.g., nurse, doctor, allied health professional, cancer support worker.

1.4: Public and patient involvement

Patient and Public Involvement (PPI) in research is the development of an active partnership between patients and/or members of the public and researchers (Price *et al.*, 2022; Ocloo *et al.*, 2021; National Institute for Health Research, 2014). The contributions of PPI can be extremely valuable to shape research and provide different views from those of the research team or NHS staff based on their understanding and lived experience of their condition. They may have alternative aspirations and ideas about health outcomes that healthcare professionals and researchers may not have considered.

(Price *et al.*, 2022; National Institute for Health Research, 2014). In 2019, the National Institute for Health Research (NIHR) published UK standards for public involvement (UK Public Involvement Standards Development Partnership, 2019). These include:

- Inclusive opportunities: offer public opportunities that are accessible and that reach people and groups according to research needs
- Working together: Work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships
- Support and learning: Offer and promote support and learning opportunities that build confidence and skills for public involvement in research
- Communication: Use plain language for well-timed and relevant communication, as part of involvement plans and activities
- Impact: Seek improvement by identifying and sharing the difference that public involvement makes to research
- Governance: Involve the public in research management, regulation, leadership and decision making

It was fundamental to this research that the public were involved. In September 2018, there were discussions within the supervisory team about why, who, how, what and when the public should be involved. At the time, the role of the public in research was often referred to as a ‘public research partner’, however, ‘public contributor’ has since been adopted as an umbrella term to describe members of the public who take part in patient and public involvement activities (National Institute for Health Research, 2022). Herein, the term ‘public contributor’ will be used. It was decided to aim to recruit up to three public contributors, who are adult cancer survivors living with chronic pain after cancer treatment. At the start of this doctoral programme, the NIHR UK standards for public involvement outlined above had not been finalised and published, therefore, guidance was sought from the INVOLVE NIHR Public involvement in research: values and principles framework (INVOLVE, 2016). Prior to recruiting public contributors, consideration was given to the role they would play in the research. Using the INVOLVE template, a job description was created which included a background to the project, outlined the public contributors' and research groups' responsibilities, gave details of the duration of the role, payment and expenses and person specification (Appendix 1). Ensuring public contributors are paid for their time is essential to respecting their contribution to the research and ensuring inclusive opportunities (UK Public Involvement Standards Development Partnership, 2019; INVOLVE, 2015). Funding was agreed at the standard university rate for public contributors, plus travel expenses.

Public contributors were recruited by:

1. Discussion with the supervisory team to see if they were aware of anyone who may be suitable

Discussion with the supervisory team resulted in the identification of two possible public contributors. Both were contacted by JA and the role was explained. One agreed to be involved (MP) and the appropriate employment documentation was completed to ensure they were registered on the university database for public contributors and with faculty payroll. The recruited public contributor lived more than 120 miles away from Bristol but was visiting a hospital near to JA's place of work, so JA went to meet them face to face to build a rapport, discuss the research in more detail and pick up documentation. The other potential public contributor was initially keen, however, ultimately declined.

They felt passionate about the research area and were keen to help. However, when we had a more detailed conversation about the project and the role of a public contributor, they explained they would rather not be involved as living in chronic pain made them extremely fatigued and they did not feel they had the energy. Patient levels of wellness can be a barrier to PPI involvement (Ocloo *et al.*, 2021).

2. Dissemination via local cancer networks

The opportunity was disseminated to the South West Cancer Alliance Cancer Operations Group and Somerset, Wiltshire, Avon and Gloucestershire (SWAG) Cancer Alliance Macmillan Patient and Public Engagement Lead. The SWAG Patient and Public Engagement lead was very enthusiastic about the research, but as they had just formed a new public involvement group and the boundaries of the group were being established, the Lead felt it was inappropriate to ask anyone to be involved at that time.

3. Advertisement of the opportunity on cancer and research websites. The use of twitter to promote the posts on the above websites

An advert was placed on the NIHR People in Research and the Jo's Trust website in October 2018. JA's twitter account was used to promote the adverts when they were published. More than 15 responses were received, however, many of those were from people who would like to participate in the research, rather than be involved with the development of the study. A holding email was sent to all respondents whilst JA sought guidance from the supervisory team about how to proceed. It is important that processes for involving the public in research are clear and transparent and reflect equality and diversity duties (UK Public Involvement Standards Development Partnership, 2019). It was decided that the first step was to clarify to respondents that this opportunity involved being part of the team to develop the study, rather than to participate in the research. An email was sent to all respondents thanking them for their interest and explaining that we were looking for two or three members of the public, who are cancer survivors living with chronic pain, to become public contributors and join an advisory group for the project. This would involve advising on the project plan, reviewing protocols and possibly working with us on the analysis of the findings. The email clarified that public contributors would not be interviewed as part of the study. It was explained that travel expenses and an hourly rate of pay would be available. From this correspondence, one person expressed an interest in being a public contributor, three declined and the remainder did not respond. In a follow up telephone call between JA and the potential public contributor (JH), the project and role were discussed in more detail, and they agreed to become a member of the team. The first meeting between JA, the public contributors and the PhD supervisory team took place in January 2019 via Skype. JH lived relatively close to the university campus and offered to come in person. JA arranged parking and they had lunch in advance of the meeting to discuss the research and build a rapport.

It is important to identify and share the difference that public involvement makes to research. Furthermore, the opportunity to evaluate and reflect on the impact of the public contributors can help us understand the changes, benefits and learning gained from the insights and experiences of patients, carers and the public (UK Public Involvement Standards Development Partnership, 2019). Details of a small scale evaluation of the impact of the public contributors on this PhD are described in chapter six.

Chapter summary

This chapter has highlighted the problems and concerns experienced by cancer survivors. The prevalence of chronic pain after cancer treatment has been outlined, alongside the impact on cancer survivors' lives. A summary of the PhD has been given and the recruitment of two public contributors has been explained. The following chapter addresses the first objective of the thesis, to identify, review and synthesise the qualitative literature surrounding the experience of chronic pain after cancer in adult cancer survivors

Chapter 2: Qualitative Evidence Synthesis

This chapter presents a qualitative evidence synthesis of the experience of chronic pain after cancer treatment. The chapter is guided by the ENTREQ (Enhancing Transparency in Reporting the Synthesis of Qualitative Research) framework (Tong *et al.*, 2012). The study has been published in the European Journal of Cancer Care (Armoogum *et al.*, 2020).

2.1: Introduction

Many cancer survivors can experience chronic pain after cancer treatment (Jiang *et al.*, 2019; Van Den Beuken-Van Everdingen *et al.*, 2016) and this can negatively impact on their health related quality of life (Poço Gonçalves, Veiga and Araújo, 2020) and leave them with high unmet need (Schmidt *et al.*, 2022; Miroševič *et al.*, 2019; Capelan *et al.*, 2017). Whilst this demonstrates that pain is a significant problem for cancer survivors, it does not describe cancer survivors' experiences of pain. There is limited knowledge in the qualitative literature about the experience of pain in those who have finished their cancer treatment, as to date, qualitative researchers have focused on the experiences of those with cancer pain who are undergoing cancer treatment. For example, Dunham, Allmark and Collins (2017) reviewed diaries and qualitatively interviewed nine older adults with cancer pain and found participants suffered a loss of identity and grieved for their former selves (Dunham, Allmark and Collins, 2017). Torresan *et al.* (2015) conducted a phenomenological study with cancer patients with severe cancer pain. All participants found the experience of pain adversely affected all aspects of their lives. The experience of being a patient in the care pathway was extremely important to participants and the quality of relationships and communication they had with healthcare professionals was of particular importance for the management of their cancer pain. However, it is unknown if this reflects the experiences of those who have finished their cancer treatment. Understanding the experiences and needs of cancer survivors is key to improving how well people live after cancer (Maher *et al.*, 2018).

Most of the qualitative research into the experience of living with chronic pain been conducted in the non-cancer population (Toye *et al.*, 2021). As no literature syntheses have been identified that explore chronic pain after cancer treatment among cancer survivors, it is necessary to explore the non-malignant chronic pain literature to learn about the experience of living with chronic pain. Whilst this thesis focuses on chronic pain in cancer survivors, it is still important to understand the experiences of living with chronic non-malignant pain, so that these experiences can be compared and contrasted to the experiences of chronic pain after cancer treatment in cancer survivorship. Toye *et al.* (2017) conducted the first *mega*-ethnography of qualitative evidence syntheses to bring together 11 qualitative evidence syntheses that explored patients' experience of living with chronic non-malignant pain to develop a conceptual understanding about what it is like to live with chronic non-malignant pain. The 11 qualitative evidence syntheses included a total of 187 qualitative studies reporting more than 5,000 international participants living with chronic non-malignant pain. Table 2 summarises the seven conceptual categories Toye *et al.* (2017) proposed about the experience of living with chronic non-malignant pain.

Table 2: Conceptual categories of experience of living with chronic non-malignant pain (Toye et al., 2017)

Conceptual category	Explanation
My life impoverished and confined	Featured in seven out of 11QES* and describes the all-pervading nature of pain. Pain invades all aspects of my day and night. Life is impoverished and confined. I am uncertain of what the future will bring and am confined to live in the moment
Struggling against my body to be me	Featured in seven out of 11 QES and describes the struggle to maintain my sense of self. My body has become alien and malevolent and I cannot fulfil my normal duties. I am now irreparably altered.
Quest for the diagnostic 'holy grail'	Featured in all 11 QES and describes patients' strong desire for a medical diagnosis. If the doctor can't find anything then people will not believe me. I must have something or why would it hurt? I just want to find out what is wrong with me and so it can be cured.
Lost personal credibility	Featured in 10 out of 11 QES and describes a loss of personal credibility. No one believes me because there is nothing to prove that my pain is real.
Trying to keep up appearances	Featured in 7 out of 11 QES and describes the need to put on a show and keep up appearances. I keep my pain to myself because I don't want to be judged as being weak, and I don't want to spoil things for everyone else. If I keep quiet about it no one will notice that I am no longer the person that I was.
Need to be treated with dignity	Featured in 8 out of 11 QES and describes a negative experience of the healthcare system. No one is hearing my story or involving me in decisions about my care. I need to be treated with some dignity. I feel like a shuttlecock in the care system where nothing is being done to help. I feel like I am being sent around in circles.
Deciding to end the quest for the grail is not easy	Featured in 7 out of 11 QES and describes the personal challenge of giving up the quest for a diagnosis and learning to live with pain. There is a sense that this hinges upon a realisation that there is no fix for chronic pain.

*QES=Qualitative Evidence Synthesis

A key theme within their *mega*-ethnography of qualitive studies for non-malignant chronic pain was the quest for the diagnostic 'holy grail' (Toye *et al.*, 2017), however, it is not known if this is important or significant to cancer survivors living with chronic pain after cancer treatment, as they may understand the aetiology behind their pain. Whilst no reviews or syntheses into the experiences of chronic pain in cancer survivors have been identified, a study has been conducted that explores the experience of chemotherapy induced peripheral neuropathy (CIPN) in the cancer population (Tanay, Armes and Ream, 2017). This qualitative evidence synthesis looks at all symptoms of CIPN (such as pain, numbness, tingling, muscle weakness and sensitivity to cold) and therefore did not distinguish between the symptoms of CIPN and chronic pain or include chronic pain that did not arise from CIPN. Furthermore, they included studies with participants on active cancer treatment. This group of patients is not the focus of this thesis, however, the study findings are still relevant because the study incorporated pain and considered cancer patients' experiences of a chronic condition arising from cancer treatment. Tanay, Armes and Ream (2017) found that CIPN was an unclear experience, a less important risk, impacts on patient quality of life and is a feature of cancer survivorship.

The literature demonstrates that for cancer patients with chronic pain, being in the cancer care system and the relationships with healthcare professionals within that system are important (Torresan *et al.*, 2015). However, it is also known that chronic pain after cancer treatment can occur as a late effect of cancer and therefore does not manifest until years after cancer treatment has finished (Emery *et al.*, 2022). Thus, cancer survivors experiencing chronic pain after cancer treatment may not still see healthcare professionals in the cancer care system. To address this gap in knowledge, it is important to understand the experiences of cancer survivors living with chronic pain after cancer treatment. The study outlined below aimed to identify, review and synthesise the qualitative literature describing the experience of chronic pain after cancer in adult cancer survivors and sought to answer the question: What is the experience of chronic pain after cancer treatment in adult cancer survivors?

2.2: Methodology

This question is most appropriately addressed by qualitative research as this seeks to understand personal experience, behaviours and social contexts to explain phenomena of interest (Braun and Clarke, 2013, 2022). A qualitative evidence synthesis is a systematic review of qualitative research that enables collation of multiple inter-related qualitative studies to expand understanding of the topic (Noyes *et al.*, 2015). The Cochrane Qualitative and Implementation Methods Group advocate the use of the umbrella term 'qualitative evidence synthesis' to encompass over 20 different methods and methodologies of qualitative synthesis (Booth *et al.*, 2016).

Qualitative evidence synthesis

There is increasing recognition of the value of qualitative evidence synthesis within healthcare. In recent years established methods for systematic reviews of qualitative research have been summarised and outlined by the Cochrane Collaboration (Noyes *et al.*, 2017) and guidance has been produced to support researchers to select the most appropriate synthesis method (Booth *et al.*, 2016). Methods for qualitative evidence synthesis can be on a continuum between description and interpretation. Descriptive syntheses seek to explore 'what the data says' whereas interpretive syntheses ask 'what does the data mean?' (Booth *et al.*, 2016). Table 3 compares the commonly used approaches to descriptive and interpretive syntheses.

Table 3: Comparison of the commonly used approaches to descriptive and interpretive qualitative evidence synthesis (Dixon-Woods, 2011; Hannes and Lockwood, 2011; Thomas and Harden, 2008; Dixon-Woods *et al.*, 2006)

Approach	Purpose	Search strategy	Critical appraisal	Methods of synthesis	Outcome
Framework synthesis (descriptive)	To aggregate findings to test theory	Comprehensive	Required. 10 standardised criteria used	Adopts a matrix or theoretical framework. Themes and concepts identified a priori from outset and combined with other themes and concepts that emerge de novo during analysis	Creation of model to directly inform practice
Thematic analysis (descriptive)	To aggregate findings of original research papers	Usually comprehensive, although open to argument of conceptual saturation	Use of framework or checklist for critical appraisal	Line by line coding, development of descriptive and analytical themes	Summary of findings of primary studies under thematic headings
Meta-aggregation (descriptive)	To aggregate findings of included studies	Comprehensive, detailed search strategy outlined at protocol stage	Required, using standardised critical appraisal tool	Aggregation of findings into categories and of categories into synthesized findings	Synthesized statements known as ‘lines of action’ informing practice or policy in the form of a standardised chart
Critical interpretive synthesis (interpretive)	To deconstruct research traditions and theoretical assumptions to contextualise findings	Identification of potentially relevant papers to provide a sampling framework	Quality judged as to the extent to which it informs theory	Identification of recurrent themes and development of a critique (on the included literature) that informs sampling, selection and theory generation	Based on a critique of epistemological and normative assumptions of the literature, phenomenon is reconceptualised
Meta-ethnography (interpretive)	To generate new knowledge and theory	Not comprehensive, seeks saturation – theoretical sampling	Not required. Only exclude studies if they do not provide insight into phenomena of interest	Refutational and/or reciprocal translation (exploring and explaining contradictions between studies), line of argument synthesis	Higher order interpretation of study findings
Grounded formal theory (interpretive)	Generation of theory	Not comprehensive, seeks saturation – theoretical sampling	Limited. Only discussed in terms of a ‘personal reaction note’ regarding context, quality and usefulness of study	Constant comparison	Generalizable explanations for phenomena under study

Justification for method

To help reviewers choose an appropriate method for conducting a qualitative evidence synthesis, Booth *et al.* (2018) have developed a framework of criteria, the RETREAT framework, which has seven domains: review question, epistemology, time/timeframe, resources expertise, audience and purpose and type of data (Booth *et al.*, 2018). The framework was used to guide the decision over the choice of method used for this review. Table 4 outlines each domain of RETREAT and the questions Booth and colleagues recommend reviewers ask themselves plus information to guide selection. It was anticipated the review would include rich and detailed data, therefore, for this aspect of RETREAT, either interpretive or descriptive approaches could be taken. However, using the framework, it can be seen this review addresses a stand-alone project with a fixed question and takes a realist approach. This approach aligns with a descriptive methodology. Further, with respect to expertise, this was the first qualitative evidence synthesis the author had conducted so it was considered sensible to adopt one of the descriptive methodologies, therefore primary qualitative expertise within the supervisory team could be drawn upon if required. The likely audience for the review is healthcare professionals working with cancer survivors with chronic pain after cancer treatment, thus an approach, such as thematic synthesis, that directly informs practitioners, is appropriate. Therefore, on balance, it was decided that a descriptive method was most suitable and thematic synthesis was selected. Thematic synthesis involves three stages: 1. free line-by-line coding of the findings from the primary studies, 2. the organisation of the ‘free codes’ into ‘descriptive themes’ and 3. the development of ‘analytical’ themes (Thomas and Harden, 2008).

Table 4: RETREAT Framework (Booth et al., 2018)

Domain	Questions for reviewers to consider	Information to guide selection
R – Review question	- To what extent is our review question already fixed (an anchor) or likely to be emergent (a compass)? - Is our review planned as a stand-alone project or is it intended to be compatible with, or even integrated within, an effective review?	Interpretive methodological approaches tend to address emergent approaches thus fixed questions align with descriptive approaches
E- Epistemology	- To what extent do we wish to acknowledge the different underpinning philosophies of included studies, and to operationalise these differences within our final review? - Where does our review team position itself with regard to an idealist-realist continuum? - What is the intended role of theory within our planned review – will we ignore, acknowledge, generate, explore or test theory within our review?	Idealist approaches are more iterative, have less a priori quality assessment procedures and more inclined to problematize the literature. In contrast, realist approaches are more linear, have well developed approaches to quality assessment and do not problematize the literature (Barnett-Page and Thomas, 2009)
T – time/ timeframe	- Will our review seek to generate knowledge de novo or to use existing knowledge resources (categories, classifications, frameworks or models) as a vehicle for accelerating the review process? - Is our intention to aim for comprehensive coverage of all studies that meet our eligibility criteria or to accelerate the review process through purposive sampling? - Overall, will our review strategy privilege breadth of scope or depth of interpretation?	Time (intensity) and timeframe (duration) should not singularly determine choice of method however it is important to recognize some methods may be vulnerable to lack of time or competing pressures.
Resources	- To what extent is our review predominantly a literature-based project and to what extent must we factor wider involvement and collaboration into our funding plans? - Do the methods to which our team is gravitating rely heavily upon proprietary software or enabling technologies or could we develop generic in-house solutions (	The availability of resources impacts upon the feasibility of preferred review approaches.
Expertise	- To what extent do we already possess necessary skills and expertise within our core team? - What patterns of expert input will our preferred qualitative evidence synthesis method require during the life span of the review project; anticipable or ad hoc, intensive, or periodic?	All qualitative evidence synthesis methods require generic synthesis expertise (including searching, data extraction, quality assessment, interpretation) and access to topic expertise. Interpretive methods of synthesis such as meta-ethnography typically require at least one member of the research team who is already familiar with the method. In contrast, methods derived from primary qualitative methods, for example, thematic synthesis (from thematic analysis) and framework synthesis (from framework analysis) may be sustained by primary qualitative expertise present within the team.
Audience and purpose	- What does our review team know about the preferences of our intended primary audience with regard to types of findings and data presentation? Descriptive or interpretive, textual or graphical, practical recommendations or conceptual enlightenment? - How do our intended audience plan to use our synthesis product? Can we access past examples of review methods used by knowledge synthesis outputs aimed at this particular audience and/or for a similar purpose?	Outputs from some methods of synthesis (thematic synthesis, textual narrative synthesis, framework synthesis, and ecological triangulation) can be more relevant to policy makers and designers of interventions than the outputs of methods with a more constructivist orientation (meta-study, meta-ethnography, grounded theory), which are generally more complex and conceptual (Barnett-Page and Thomas, 2009). Thomas and Harden (2008) conclude that thematic synthesis produce findings that directly inform practitioners.
Type of data	- How conceptually ‘‘rich’’ are included studies likely to be? - How contextually ‘‘thick’’ are included studies likely to be? - How many studies will we analyze, and what is their ‘‘typical’’ methodological quality?	When data from studies are rich and/or thick, a review team is limited in the number of studies that they can collectively comprehend and process. ‘‘Thin’’ data, from brief case reports or textual responses to surveys, will not sustain contextual interpretation.

The remainder of this chapter will describe a qualitative evidence synthesis that aims to answer the question: What is the experience of chronic pain after cancer treatment in adult cancer survivors?

2.3: Aim

To identify, review and synthesise the qualitative literature surrounding the experience of chronic pain after cancer treatment in adult cancer survivors.

2.4: Method

Protocol and registration

A protocol for this study was registered with the International prospective register of systematic reviews (PROSPERO) in December 2017 (PROSPERO 2017 CRD42017082562).

Literature search and selection

A comprehensive search strategy was developed to locate all available studies. Key search terms were used to search relevant databases including CINAHL Plus, Medline, PsycINFO, Embase and Cochrane (Table 5). The search terms were informed by cancer survivor and pain literature and discussion with the supervisory team. Identifying relevant qualitative literature from databases is not straightforward, as not all journals provide indexing services, not all titles reflect the methodology or topic and indexing for qualitative studies is not as advanced as for quantitative studies (Green and Thorogood, 2018; Hannes and Macaitis, 2012; Thomas and Harden, 2008). Therefore, reference lists were reviewed, and hand searches took place for relevant journals. The original search took place in December 2018. The search was repeated in January 2023 and no additional papers were found.

Table 5: Key search terms

Cancer **OR**		Pain		Chronic **OR**		Qualitative **OR**		Survivor*
Oncol*	**AND**		**AND**	Chronic	**AND**	Mixed method*	**AND**	Patient*
Hemat*				Long-term		Mixed-method*		End N4 treatment
Haemat*				Long-standing				End N4 chemo*
Malignan*				Long term				End N4 radio*
Carcino*				Long standing				Completed N4 treatment
								Completed N4 chemo*
								Completed N4 radio*

Due to time and resources of the research team, only papers published in English were included. Figure 2 outlines the search strategy.

Figure 2: Qualitative evidence synthesis search strategy

S1 cancer
S2 oncol*
S3 heamat*
S4 hemat*
S5 malignan*
S6 carcino*
S7 S1 OR S2 OR S3 OR S4 OR S5 OR S6
S8 pain
S9 chronic
S10 persistent
S11 long term
S12 long-standing
S13 S9 OR S10 OR S11 OR 12
S13 qualitative
S14 mixed method*
S15 mixed-methods*
S16 S13 OR S14 OR S15
S17 survivor*

S18 patient*
S19 end N4 treatment
S20 end N4 chemo*
S21 End N4 radio*
S22 completed N4 treatment
S23 completed N4 chemo*
S24 completed N4 radio*
S25 S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24
S26 S7 AND S8 AND S13 AND S16 AND S25
S27 survivor* NOT childhood NOT paediatric NOT pediatric
S28 patient* NOT childhood NOT paediatric NOT pediatric
S29 end N4 treatment NOT childhood NOT paediatric NOT pediatric
S30 end N4 chemo* NOT childhood NOT paediatric NOT pediatric
S31 end N4 radio* NOT childhood NOT paediatric NOT pediatric
S32 completed N4 treatment NOT childhood NOT paediatric NOT pediatric
S33 completed N4 chemo* NOT childhood NOT paediatric* NOT pediatric
S34 completed N4 radio* NOT childhood NOT paediatric NOT pediatric
S35 S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 AND S7 AND S8 AND S13 AND S16 AND S25 **Limiters** - Published Date: 20070101-20181231

Participants/populations

This study explored the experience of pain in adult cancer survivors using the EORTC definition of cancer survivor: any person diagnosed with cancer, who has completed primary treatment (with exception of maintenance therapy) who has no active disease (Moser and Meunier, 2014).

Inclusion and exclusion criteria

Inclusion:

- Primary research adopting a qualitative methodology (either stand alone or as a discrete element of mixed method research)
- Explores cancer survivors' experience of chronic pain after cancer treatment
- Includes populations of adults over 18 years old when diagnosed and treated for cancer

- Published in English
- Full peer review articles (not abstracts or conference proceedings only)

Exclusion:

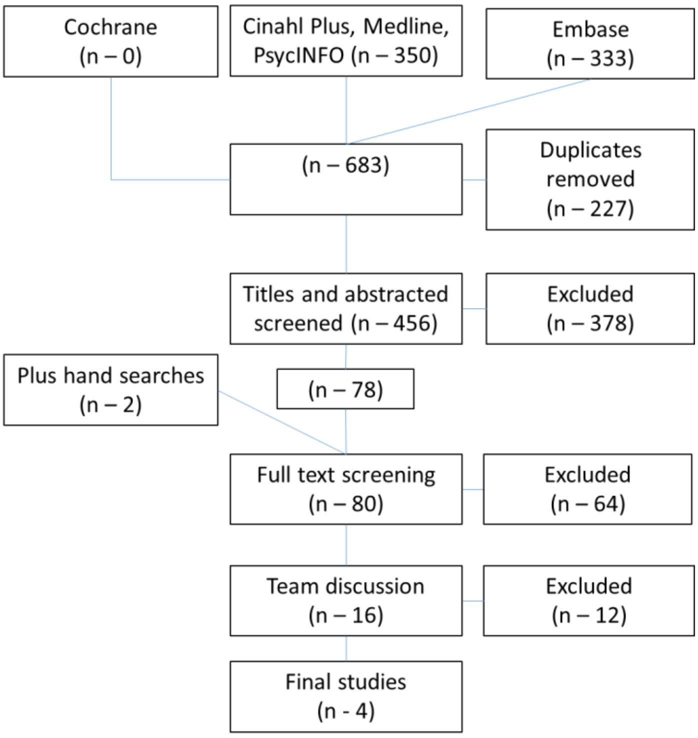
- Quantitative research
- Commentary articles and clinical updates
- Studies including sample populations of those exclusively on active treatment or end of life care
- Studies of survivors of childhood cancer

Survivors of childhood cancer or those at the end of life were excluded. This was because survivors of childhood cancer may have experiences that are unique to that population such as challenges with social integration (Lea *et al.*, 2019) and transitioning from paediatric to adult cancer services (Tonorezos *et al.*, 2022; Otth *et al.*, 2021; Nandakumar *et al.*, 2018; Casillas *et al.*, 2010) or disruption in schooling (Martinez-Santos *et al.*, 2021). Equally, those at the end of life have unique needs (Gerber *et al.*, 2022; Hackett, Godfrey and Bennett, 2016; Wilkie and Ezenwa, 2012). A limit of studies published since 2007 was applied to ensure the most up to date research was identified. A significant change in direction of cancer services was introduced in the 2007 Cancer Reform Strategy (Department of Health, 2007) and the National Cancer Survivorship Initiative (NCSI) was launched in 2008. The aim of the NCSI was to achieve a cultural shift in the approach the UK health system took to supporting people in the survivorship phase of cancer. Thus, it felt important to capture the experiences of those cared for in recent years. Furthermore, the application of the limiter of studies published from 2007 onwards enabled the number of potential studies identified to be manageable within this programme of work.

Study screening methods

The search resulted in 683 potential studies. Figure 3 outlines the study selection process.

Figure 3: Process of study selection



Titles and abstracts were reviewed against the inclusion and exclusion criteria and were excluded or referred for full text review. Decisions regarding which studies to include and exclude are among the most influential decisions in the review process and Cochrane recommend at least two reviewers independently assess studies against the eligibility criteria (Lefebvre *et al.,* 2022). JA and Alison Llewellyn (AL) independently reviewed full texts of remaining studies. AL is a supervisor for this PhD. Initially 64 papers were excluded because the study design or patient population did not meet the inclusion criteria for this synthesis, the studies were presented as abstracts only or not published in English. JA and AL met and discussed decisions and brought the remaining studies (n = 16) to the wider team for further discussion. This resulted in clarification of the inclusion and exclusion criteria:

- If the population has completed anti-cancer therapy but were on hormone treatment, they could be included
- If the population had metastatic disease, they would be excluded
- If populations included a mix of those who had completed treatment and those on treatment, but results could not be separated between groups, then the study would be excluded
- If studies initially appeared to meet inclusion criteria, but on closer reading did not fully explore experiences of chronic pain as there was only a passing comment about pain, then authors would be contacted to request more data (if available) about the experience of chronic pain

Twelve authors were contacted for more information about their study (Selove *et al.*, 2017; Vogel *et al.*, 2017; Jones *et al.*, 2016; Cal and Bahar, 2016; Padman *et al.*, 2015; Schaller *et al.*, 2015; Wang *et al.*, 2012; Levangie *et al.*, 2011; Davidge *et al.*, 2010; Rosedale and Fu, 2010; Beck *et al.*, 2009; Cappiello *et al.*, 2007). From these, five replied to say they had no further information about the experience of chronic pain or did not have the data readily accessible (Selove *et al.*, 2017; Jones *et al.*, 2016; Schaller *et al.*, 2015; Wang *et al.*, 2012; Levangie *et al.*, 2011). The remaining authors did not reply. Consequently, all 12 papers were excluded from the final review. This resulted in four studies proceeding to the quality assessment stage.

Quality assessment (selection and evaluation criteria)

Quality assessment of studies was undertaken using an adapted version of the Critical Appraisal Skill Programme (CASP) Checklist for Qualitative Research (Critical Skills Appraisal Programme, 2018) to ensure methodological rigour and ethical standards were met. JA and AL independently assessed and then reached agreement over the quality of the included studies (table 6)

Table 6: Quality assessment

Protocol statement	**CASP Questions**	**Paper, author (date)**			
		Björkman, Arnér and Hydén (2008)	**Hellerstedt-Börjesson *et al.* (2016)**	**Hovind, Bredal and Dihle 2013)**	**Peretti-Watel *et al.*, 2012)**
Adopted an appropriate method and design to meet the aims of the study	Was there a clear statement of the aims of the research?	Yes	Yes	Yes	Yes
	Is a qualitative methodology appropriate?	Yes	Yes	Yes	Yes*
	Was the research design appropriate to address the aims of the research?	Yes	Yes	Yes	Yes
Used a suitable data collection strategy	Was the recruitment strategy appropriate to the aims of the research?	Yes	Yes	Yes	Yes
	Was the data collected in a way that addressed the research issue?	Yes	Yes	Yes	Yes
	Has the relationship between researcher and participants been adequately considered?	Not known	Yes	Yes	Not known
Included pertinent methods of data analysis	Was the data analysis sufficiently rigorous?	Yes	Yes	Yes	Yes
Drew conclusions and interpretations that reflected the findings of the study	Is there a clear statement of findings?	Yes	Yes	Yes	Yes
	How valuable is the research?	Valuable	Valuable	Valuable	Valuable
Obtained ethical approval	Have ethical issues been taken into consideration?	Yes	Yes	Yes	Yes

*interview data

Data extraction

A standardised form, based on Noyes *et al. (*2015) and Tanay, Armes and Ream (2017) was used to extract data. To ensure accuracy, data were extracted from each study by two authors. JA extracted data from all studies and Candy McCabe (CMC) and Claire Foster (CF) extracted data from two studies each. CMC is the Director of Studies for this PhD and CF is a PhD supervisor. Thomas and Harden (2008) suggest that all text labelled as ‘results’ or ‘findings’ should be extracted. The team discussed findings that included direct participant quotes and authors’ interpretations of the interview data. The team decided that during the analysis and synthesis phase, when direct participant quotes were provided, then they should be analysed as much as possible. When a quote was not available, author interpretations were to be used. It was agreed that without using both participant quotes and author interpretations, then some of the richness of the papers would be lost.

Strategy for data synthesis

Data synthesis followed Thomas and Harden’s (2008) method of thematic synthesis of qualitative research. During stage one, JA and Diana Harcourt (DH) independently coded each line of text according to its meaning and context. DH is a supervisor for this PhD. During stage two, ’descriptive themes’ were created to summarise meanings of initial groups of codes. The final stage involved ‘going beyond’ the context of original studies to generate ‘analytical themes’. The team discussed the analytical themes and they were further refined until sufficient to reflect all initial descriptive themes.

Epistemology

When conducting qualitative evidence syntheses, the reviewer should consider the philosophical foundations and integrity of the primary research and ensure that the method selected is compatible with the epistemology of the included studies. This has greater prominence with some methods, such as meta-ethnography or grounded formal theory, as they frequently refer to epistemological considerations throughout the review process. However, some methodologies are considered to be more epistemology-neutral and less emphasis is placed on underlying epistemologies, such as framework synthesis, narrative synthesis and thematic synthesis (Booth *et al.*, 2016). As this review adopted a thematic synthesis approach, the underlying epistemological perspectives of studies were considered, however, these will not be the main focus when reporting findings.

2.5: Synthesis of findings

The four studies were identified. A synopsis of the included studies can be found in table 7.

Björkman, Arnér and Hydén (2008) conducted a two-year longitudinal prospective and explorative study to explore women's personal descriptions of if and how phantom breast phenomenon appears within painful sensations. They analysed their data using a combination of discourse and narrative analysis.

Hellerstedt-Börjesson *et al.* (2016) adopted a phenomenological lifeworld approach to explore memories of chemotherapy induced pain (CHIP) and any experiences of long-standing treatment related pain. Hellerstedt-Börjesson *et al.* (2016) created an intentional thread linking the woven structure of the memory of past, present and

Table 7: Synopsis of included studies

Study details	**Björkman, Arnér and Hydén (2008)**	**Hellerstedt-Börjesson *et al. (*2016)**
Country	Sweden	Sweden
Aims of study	To explore women's personal descriptions of if and how phantom breast phenomenon appears within painful sensations	To explore memories of CHIP and any experience long-standing treatment related pain
Study setting	Tertiary university hospital	3 different oncology day care units
Study context	Sub study in longitudinal study to investigate how patients understand and describe phantom breast phenomena.	Sub-study to larger study investigating CHIP during adjuvant treatment
Research design/theoretical framework	A 2 year longitudinal prospective and explorative	Phenomenological lifeworld approach
Data collection method	Semi structured interviews 4 x 1 hour Participant choice for location of interview (home, clinician/academic office) Interviews taped and transcribed	Interviews 30 – 90 minutes Conducted in hospital setting, woman's home or workplace Audio taped
Type of analysis/data analysis approach	Combination of discourse and narrative analysis.	Guided phenomenological reflection (van Manen) Multiple reviewers (1, then 2, then 2)
Sampling approach	Invited to participate 10 days after the mastectomy	Consecutive recruitment
Inclusion criteria	Mastectomy No specific selection criteria regarding disease stage or type of mastectomy	Inclusion criteria for the main study: treatment with chemotherapy in doses of 75 mg/m2 or more of epirubicin and docetaxel and scoring pain of ≥ 4 visual analogue scale (VAS) during treatment
Exclusion criteria	Assessed as medically or mentally unstable and patients who were participating in other studies	

Table 7: Synopsis of included studies (continued)

Study details	**Hovind, Bredal and Dihle (2013)**	**Peretti-Watel *et al.* (2012)**
Country	Norway	France
Aims of study	Perception of pain and improvement of pain management	1) Compare WHOQOL-BREF questionnaire and interview data 2) Explore attitude and meaning to pain
Study setting	Three different hospitals	
Study context	Sub study in larger quantitative study	Sub study investigating how breast cancer patients deal with post treatment life
Research design/theoretical framework	Descriptive qualitative approach	Inductive approach based on grounded theory
Data collection method	Semi structured interviews 1 hour Conducted at women's homes Interviews taped and transcribed	In-depth semi structured interviews 1 and 4 hours Conducted in participants' homes Interviews taped and transcribed
Type of analysis/data analysis approach	Qualitative content analysis. 3 step process by Kvale (1996)	Inductive approach based on grounded theory First and second round coding. Analysed concurrently and emergent themes informed data collection
Sampling approach	Purposive recruitment based on diagnosis, pain score, age, language	Purposive recruitment ('not randomly selected') to recruit women with contrasting ages and contrasting PHY and PSY scores (check meaning)
Inclusion criteria	Early-stage breast cancer without metastases, chronic pain after cancer treatment rated at 3–5 on a 11-point numerical rating scale (NRS), 18–65 years, able to understand spoken and written Norwegian	Younger (aged 18–40) and older (aged 65 and over) women already enrolled in a cohort study ELLIPSE
Exclusion criteria	Women who rated their level of pain above 5 on the NRS (0 is no pain and 10 is worst possible pain)	

consciousness future of the participants and consequently presented their findings as past, present and future perspectives.

Hovind, Bredal and Dihle (2013) used a descriptive qualitative approach to explore women's experience of acute and chronic pain after cancer treatment following breast cancer surgery. They aimed to gain knowledge about how women experienced pain and identify areas where pain management could be improved. They utilised Kvale's (1996) three step process of qualitative content analysis. This involved self-understanding, whereby the reviewer reads all the material several times to gain a general picture of the content as whole to create 'meaningful units'. In step two Hovind, Bredal and Dihle (2013) searched for patterns and variations in the women's experiences to build a picture of emerging themes. During the third step, alternative interpretations were compared with each other and previous research to achieve theoretical understanding.

Peretti-Watel and colleagues (2012) sought to document patients' experience of chronic pain after cancer treatment and how it affected their everyday lives. They did this by comparing in-depth interviews with results from the WHOQOL-BREF questionnaire regarding chronic pain after cancer treatment and its impact on everyday activities. To better understand the discrepancies revealed by this comparison, their paper focused on respondents' attitudes toward pain, especially in terms of how they gave meaning to it and how they dealt with it in their daily lives. To achieve this, they use an inductive approach based on grounded theory that included first and second round coding. This was analysed concurrently and emergent themes informed data collection.

Collectively, the four studies generated findings from 52 female breast cancer survivors. Three studies were from Scandinavia and one from France. Sample sizes ranged from 8 to 21 and women ranged from 26 to 83 years with a median age of 54.5 years. All women were treated with surgery and some with adjuvant radiotherapy, chemotherapy and/or hormone therapy. All were sub studies to larger studies, all used interviews for their data collection method and interviews lasted between 30 minutes and four hours (table 8).

Table 8: Sample population in included studies

Population	**Björkman, Arnér and Hydén (2008)**	**Hellerstedt-Börjesson *et al.* *(*2016)**	**Hovind, Bredal and Dihle (2013)**	**Peretti-Watel *et al.* (2012)**
Sample size	8	15	8	21
Age	47-72 years	Mode 50-59 years (range 30-79 years)	Mean 55 years (range 44-65)	26-83 years 2 cohorts, 26 – 43 years (n – 8) and 66 – 83 years (n – 13)
Gender	Women	Women	Women	Women
Cancer type	Breast	Breast	Early stage breast	Breast
Treatment	Surgery +/- radiotherapy +/- endocrine or hormonal therapy	Surgery +/- chemotherapy +/- radiotherapy +/- hormone therapy	Surgery +/- chemotherapy +/- radiotherapy	Surgery +/- chemotherapy +/- hormone treatment
Timepoint	1 month, 6 months, 1 year, and 2 years after mastectomy	One year after treatment	Between 12 and 30 months after surgery	24 months after diagnosis
Severity of pain	Not given	VAS ≥4 at time of treatment	Average rating of 4 on the numerical rating scale (NRS) (out of 11)	10 reported daily chronic pain after cancer treatment

By following the thematic synthesis process outlined by Thomas and Harden (2008), six analytical themes were developed from the studies:

- An interwoven relationship between experience of cancer and chronic pain after cancer treatment
- Lack of preparedness and support for chronic pain after cancer treatment

- The physical impact of chronic pain after cancer treatment
- Employing coping strategies
- The emotional experience of chronic pain after cancer treatment
- Conceptualisation of chronic pain after cancer treatment.

Table 9 outlines the presence of themes in each paper.

Table 9: Presence of themes in each paper

Theme	**Björkman, Arnér and Hydén (2008)**		**Hellerstedt-Börjesson *et al. (*2016)**		**Hovind, Bredal and Dihle (2013)**		**Peretti-Watel *et al.* (2012)**	
	*	*1	*	*1	*	*1	*	*1
Interwoven relationship between experience of cancer and chronic pain after cancer treatment	x			x		x		x
Lack of preparedness and support for chronic pain after cancer treatment				x		x	x	
The physical impact of chronic pain after cancer treatment				x		x		x
Employing coping strategies				x		x		x
Emotional experience of chronic pain after cancer treatment	x			x		x		x
Conceptualisation of chronic pain after cancer treatment		x		x		x		

* Author interpretation *^{1} Participant quote

Each theme is presented below. When direct participant quotes are used the quotes are written in italics and include the ID number or pseudonyms attributed by the authors. When author interpretations are quoted, they are presented in the standard font without italics.

An interwoven relationship between the experience of cancer and chronic pain after cancer treatment

The women in the studies had been given a cancer treatment to save their lives, yet the pain they experienced as a consequence prevented them from fully physically, and psychologically, recovering from their cancer treatment. The pain sensations the women experienced evoked memories of their cancer diagnosis, its treatment and the subsequent threat to their mortality. The pain meant they were locked in the state of heightened worry and concern that accompanies a cancer diagnosis. Each pain sensation resulted in anxiety about the status of their cancer and thus made them question if their cancer had returned. This inhibited the restoration of a sense of wellbeing as every time they experienced pain, they were reminded of the negative connotations of cancer. This unique and bespoke dimension to their experiences of chronic pain is not reported in the non-malignant pain literature. The presence of pain was viewed by many as an indicator of their current cancer status. Some women immediately started to question what the pain represented and wondered what it meant in terms of their cancer – was something wrong? Increased physical symptoms could 'automatically reawaken worries about the progress of the cancer' (Björkman, Arnér and Hydén, 2008, p.1023). Consequently, some exhibited signs of somatization as they feared for the worse and the pain made them feel vulnerable:

'You really listen to your body in quite a different way now. Every little thing you feel in your body could be signs of something abnormal' (10) (Hellerstedt-Börjesson *et al.*, 2016)

Yet for others, the presence of pain was reassuring and a positive indicator of their cancer status, as they interpreted the pain as a sign that the cancer treatment was working or had worked:

*'(the pain) was proof that everything was reactivated, it was being renewed' (*Sharon) (Peretti-Watel *et al.,* 2012)

The presence of pain complicated their feelings and perceptions about finishing their cancer treatment because, whilst they had completed treatment for their cancer, they still experienced pain and the pain sensations 'coexisted with a continuum of other altered sensations and sensation disorders' (Bjorkman, Arner and Hyden, 2008, p.1022). Thus, they were balanced between a state of health and of illness:

'Now I've finished my treatment but am stuck in a period where I sit and think 'am I healthy or am I not?' It's like something in between' (10) (Hellerstedt-Börjesson *et al.,* 2016).

'When you think about what you've been through, it's like the pain doesn't only exist in my arm, but in my whole body' (3) (Hellerstedt-Börjesson *et al.,* 2016).

The pain also served as a reminder of the threat that they had experienced to their mortality. This manifested in both an impatience with others and recognition that they had survived their treatment:

'It felt like everyone was driving too slowly and I didn't have the time to sit there and wait … I felt like 'you have all the time in the world, but my time's running out' (11) (Hellerstedt-Börjesson *et al.,* 2016).

'There is always someone worse off than yourself. There are those who do not have the chance to live' (Stella) (Peretti-Watel *et al.,* 2012).

Lack of preparedness and support for chronic pain after cancer treatment

It was evident that many of the women were unprepared for the experience of chronic pain after cancer treatment. They expressed an expectation that they would experience acute pain during treatment, and many of the women felt supported during this time, yet they did not recall being given information about chronic pain after cancer treatment. When chronic pain after cancer treatment manifested, they felt healthcare professionals avoided addressing it or dismissed their concerns and thus they felt abandoned and alone in the responsibility to manage their pain.

The absence of preparedness for chronic pain after cancer treatment was evident as 'some participants clearly lacked information about pain' (Peretti-Watel *et al.*, 2012, p.6) as *'No one told you what kind of pain you could develop' (No 7)* (Hovind, Bredal and Dihle, 2013). Yet it was acknowledged that, at the time of intensive treatment, chronic pain after cancer treatment may have been mentioned but women did not view it as important at the time because they were *'not concerned about pain. My focus wasn't there'* (No 8) (Hovind, Bredal and Dihle, 2013).

When pain persisted, women felt it was not recognised or acknowledged by some healthcare professionals as when women asked them about it *'they were…forthcoming, calming… but in terms of pain, I have to talk about it myself' (No.3)* (Hovind, Bredal and Dihle, 2013). However, in some instances, when women did tell physicians about their pain, they felt either dismissed as *'they (the doctors) told me it was normal (to feel pain)'* (Eva) (Peretti-Watel *et al.,* 2012) or were sent to a psychiatrist. Peretti-Wate*l et al.* (2012) consider that 'such 'psychiatrization' of pain made women feel impotent and guilty because it implied that their pain was not 'real'. This emphasised that women felt abandoned by healthcare professionals and alone in managing their pain as they were not given support to self-manage it or its impact:

'I wished that my pain at home was followed up much more (No 7) (Hovind, Bredal and Dihle, 2013)

The problems start after that (the end of treatment): whom do you turn to when you have pain in your hip like I do? (4) (Hellerstedt-Börjesson *et al.,* 2016)

The lack of preparedness may have also contributed to a perceived gap in expectation of recovery from women themselves and also their family members:

'They (the doctors) said in a year you'll be back to your regular everyday life, and I'm not. It's a disappointment (13) (Hellerstedt-Börjesson *et al.,* 2016)

'I also see that my family demands more of me now, which I'm not always able to live up to' (13) (Hellerstedt-Börjesson *et al.,* 2016)

The combination of these elements may have given rise to the feeling of being alone in an existential way – as one women expressed, she *'felt disappointed in life, like I was abandoned and totally alone. Not abandoned by my fellowman but abandoned by life…'* (Hellerstedt-Börjesson *et al.,* 2016).

The physical impact of chronic pain after cancer treatment

The physical impact of the pain on women came across in three studies and was described in terms of both physical limitations and the fact that the pain was ever present as a bodily sensation. Women felt it *'doesn't go away'* (Emmy) (Peretti-*Watel et al.,* 2012, p.4) and is now a '*permanent'* (Sharon) (Peretti-Watel *et al.,* 2012, p.4) element of their life. One woman said that her pain '*doesn't only exist in my arm, but in my whole body' (*3) (Hellerstedt-Börjesson *et al.,* 2016).

Living with chronic pain after cancer treatment was hard on the women as it hindered them at work, in physical activities and in their social and personal lives. The physical aspects of the pain caused difficulties in performing day-to-day activities:

[what kind of domestic activities did you stop doing because of the pain?] *'cleaning, ironing, washing the windows of course, and I cannot drive on long trips'(Nancy)* (Peretti-Watel *et al.,* 2012)

'I can't ride a scooter, I can't raise my arms… I can't lift a pack of milk, it's too painful' (Emmy) (Peretti-*Watel et al.,* 2012)

'When I want to peel something, I drop it' (8) (Hellerstedt-Börjesson *et al.,* 2016)

For one participant, a hairdresser, pain prevented her from drying as many clients' hair as before, therefore, it caused both a physical limitation and negatively affected her ability to work:

'Before my cancer I used to blow dry 20 clients' hair every day, but now after 4 or 5 I must stop because my arm hurts too much' (Cindy) (Peretti-*Watel et al.,* 2012).

Employing coping strategies

Women adopted a variety of methods of coping with their chronic pain after cancer treatment. These included adapting and altering daily activities to work around their pain and the use of social comparison as a coping method. Social comparison was used by the women themselves and also healthcare professionals. For some, there was an acceptance of pain as a normal phenomenon of a cancer journey and recovery, and consequently women 'expressed a desire to live as normal a life as possible' despite the pain (Hovind, Bredal and Dihle, 2013, p.1048).

Women adapted and altered their daily lives to help them cope with their pain in a physical and social sense. They planned and incorporated regular breaks into their activities and changed how they carried out domestic duties in response to it:

'I have to make plans, to be careful when moving' (No.6) (Hovind, Bredal and Dihle, 2013)

'If I sit down in the evening, my body starts to twitch, then I have to get up and around again. Just like in the morning, I have to sit for a while' (8) (Hellerstedt-Börjesson *et al.,* 2016)

'I learned to change some of my movements. I learned movements that relieve. Instead of wringing the kitchen glove like that, now I wring it like this, against the side of the sink' (Linda) (Peretti-Watel *et al.,* 2012)

They adapted their activities throughout the day, ensuring they were sufficiently rested, to enable them to have maximum energy for when they felt they needed it most, for example, to care for their children:

'*The space I had when they were in school and at leisure time, when I was able to be at home and rest, gave me energy to take off when they arrived back home again (13)* (Hellerstedt-Börjesson *et al.,* 2016)

In addition to changing how they carried out certain activities, women in the Peretti-Watel *et al.* (2012) study used downward social comparison as a coping mechanism. Some women were able to take comfort from comparing their pain to others' experiences and if they felt others had more challenging conditions to cope with:

'I prefer to be like this than in a wheelchair. There are some who are more unfortunate than me. Not thinking only about myself comforts me' (Mary) (Peretti-*Watel et al.,* 2012)

'My boyfriend's situation is worse than mine, he had mouth cancer. They ripped out all his teeth and now he has a special apparatus because he cannot eat, he cannot chew, he must suffer a lot (Eva) (Peretti-*Watel et al.,* 2012)

However, whilst social comparison could be used positively and empower women to feel that they could face the challenge of chronic pain after cancer treatment, for some, social comparison could be used as a means to dismiss concerns and worries. This appeared to be used by women but also by healthcare professionals:

'When I saw myself in this state I thought: there are some people who are worse off. So then I told myself: I have no right to complain… there is always someone worse off than yourself. (Stella) (Peretti-*Watel et al.,* 2012)

'Yes there are difficult moments. But you see, I had two small pupils who had leukemia…. Seeing all these little children, with such large perfusions… you know, when I start to complain about my pain, I think about her… and I feel I have no right to complain (Linda) (Peretti-*Watel et al*., 2012)

'There is a doctor who told me 'you know, if you feel pain madam, take a short tour of accident and emergency and you'll see, you will immediately get better' He said' go and see a few kids at A&E, you'll stop complaining all the time' I was so shocked that I never returned to that hospital' (Nancy) (Peretti-Watel *et al.,* 2012).

The emotional experience of chronic pain after cancer treatment

A wide range of emotions were expressed when describing the experience of living with chronic pain after cancer treatment and the emotional aspect of experiencing it during cancer survivorship was evident in all the papers. Women were stoical about how they discussed their pain, talked with seeming acceptance as they tried not to let it have too great an impact and attempted to carry on with what they wanted to do:

'We must learn to live with it' (Emmy) (Peretti-Watel *et al.,* 2012)

'I try to ignore the pain and continue with what I'm doing' (No.7) (Hovind, Bredal and Dihle, 2013)

Yet some women also felt frustration with their pain, experienced fatalism that it would carry on and expressed resignation that this was how life was going to be for them now:

'I can't use the body as I wish to' (8) (Hellerstedt-Börjesson *et al.,* 2016)

'I suppose that this is how I have to live' (No.1) (Hovind, Bredal and Dihle, 2013)

'If it was going to disappear, I think it would already be gone' (Bree) (Peretti-Watel *et al.,* 2012)

Living with chronic pain after cancer treatment also raised fears for the future and the "symptoms constantly reminded them of their own or close relatives'/friends" vulnerability' (Hellerstedt-Börjesson *et al.,* 2016, p.469) and uncertainty of what lay ahead:

'*Sometimes when I wake up I think 'will the pain be like this everyday, always, always… that's hard to manage sometimes'* (15) (Hellerstedt-Börjesson *et al.,* 2016)

Conceptualisation of chronic pain after cancer treatment

It was evident in the studies that women struggled to conceptualise and articulate the physical sensation and impact of their pain, and often used metaphors to help to describe it:

'I felt like I'd been run over by a steamroller' (14). (Hellerstedt-Börjesson et al., 2016)

'I felt like I was in a dryer, and I was thrown back and forth, like I was torn and ripped into pieces' (3). (Hellerstedt-Börjesson *et al.,* 2016)

'It kind of radiates somehow, it's like there are flashes that come into my breast – they come very suddenly, like a wind' (W5) (Björkman, Arnér and Hydén, 2008).

Over time, it appeared women were more likely to label the sensations they experienced as pain. This was observed most clearly in the longitudinal study by Bjorkman and colleagues (2008) which explained that 'sensory disturbances' were evaluated (by participants) in different ways at different points in time. During later interviews, women retrospectively expressed 'sensory disturbances … had been rather painful… in retrospect, the word pain could appear in their descriptions, when it had not … in earlier interview (s)' (Björkman, Arnér and Hydén, 2008, p.1023) and 'it was striking how they initially steered clear of or directly avoided calling their sensations pain, even though the sensations could cause them some discomfort' (Björkman, Arnér and Hydén, 2008, p.1021). In keeping with this, Hovind, Bredal and Dihle (2013) commented that words other than pain were used such as:

*'It is prickly, it hurts and is tender' (*No.3) (Hovind, Bredal and Dihle, 2013)

To summarise, women's experiences of pain and of cancer were interwoven and chronic pain after cancer treatment was unexpected. When it did occur, they did not feel supported to manage it. Chronic pain after cancer treatment had a physical and emotional impact on the women, and they utilised various ways of coping. Women had often used metaphors to help describe and conceptualise their pain.

2.6: Discussion

This qualitative evidence synthesis sought to identity and review literature surrounding experiences of chronic pain in adult cancer survivors. Thus, whilst it is established that almost 40% of cancer survivors experience pain after cancer treatment (Van Den Beuken-Van Everdingen *et al.*, 2016), very little is known about the experiences and needs of those living with chronic pain.

All participants were female and breast cancer survivors despite the inclusion criteria stipulating that all cancer survivors were included. No research was located that included men or those with non-breast cancer malignancies. It could be that breast cancer survivors have more pain than survivors of other cancers, and thus, research has focused on them. However, in the UK breast cancer receives the most funding for research (National Cancer Research Institute (NCRI), n.d.) therefore it could be that pain is reported more in the breast cancer population because there is less research into other cancer sites, rather than survivors from other sites not experiencing chronic pain.

The chronic pain that women experienced had a physical impact on their daily lives. This reflects the literature into the experiences of non-malignant chronic pain. Toye *et al.* (2017) in their synthesis of qualitative evidence syntheses of experiences of living with chronic non-malignant pain, cite the "all-pervading nature of pain which invades all aspects of my day and night" (Toye *et al.,* 2017, p.5). This suggests it is the symptom of chronic pain and the ever-present bodily sensation of pain, rather than the aetiology, which causes the physical impact on daily life. The most evident theme in this qualitative evidence synthesis, which featured in all the identified papers, was an interwoven relationship between the experience of cancer and chronic pain. Thus, the pain was not considered in isolation but was related to the cancer experience. The experience of pain and cancer were intrinsically linked together and pain was viewed as an indicator of cancer status. The pain caused the women to question if their cancer was returning. This is reflected in the wider literature in which researchers have suggested that new symptoms can be interpreted by cancer survivors as a sign of cancer recurrence (Raphael, Frey and Gott, 2019) and the presence of physical symptoms, like pain, can lead to increased risk of fear of recurrence (Simard *et al.*, 2013). Van Den Beuken-Van Everdingen and colleagues (2008) found pain to be a strong predictor of fear of recurrence and Cupit-Link, Syrjala and Hashmi (2018) discuss this in the context of Damocles' syndrome, whereby the fortune of survivorship is tempered by persisting fears of recurrence and long term health sequelae after treatment. Bovbjerg and colleagues (2019) found cancer survivors with chronic breast pain had significantly higher levels of emotional distress, pain catastrophizing and worry that breast pain indicates cancer compared to survivors without chronic breast pain (Bovbjerg *et al.*, 2019).

It was evident in the studies that patients felt they had not been given sufficient information regarding the risks of chronic pain. Women expressed they had felt prepared for the risk of acute pain but not chronic pain. Women did acknowledge however, that at diagnosis and treatment, chronic pain may have been mentioned but that it did not seem important at the time. This is similar to suggestions that other late effects, such as chemotherapy induced peripheral neuropathy, are considered to be of minimal importance in the context of a cancer diagnosis (Tanay, Armes and Ream, 2017) but become more significant once experienced. However, in this synthesis, it appears women's information needs were met at the beginning of treatment, but less so at the end. This is reflected in a scoping review that highlights a paucity in literature relating to information needs following completion of treatment (Fletcher *et al.*, 2017). This may have also contributed to feelings of abandonment that some women expressed. Feeling abandoned by the healthcare system is an experience that has been reported by many cancer survivors at the end of treatment (Bellas *et al.*, 2022; Bennion and Molassiotis, 2013; Parry *et al.*, 2011). Equally, a lack of empathy by healthcare professionals towards women with chronic pain was shown in the synthesis. Feeney et al., (2018) recognise that a lack of empathy towards patients can lead to mistrust and anger that can ultimately damage therapeutic relationships.

2.7: Limitations

The search strategy included multiple descriptors of meaning for 'cancer', 'chronic' and 'survivor' (figure 2), however, it is acknowledged that additional words could have been used including 'neoplasm' in the cancer group and 'longitudinal' or 'late onset' in the chronic group. Further, only one word was used to identify 'pain'. In hindsight, the choice of the search terms used demonstrates the assumptions made by the researcher as they considered that the word 'pain' would capture all relevant studies exploring pain experiences. This was the first study conducted for this PhD and the researchers' knowledge and understanding of the complexity of pain has increased over the duration of the doctoral study, especially with the light shed in later phases of the work with regards to the identification and naming of pain. The researcher now understands that patients, and healthcare professionals, use many different terms to describe pain, and thus, it could have been beneficial to include additional terminology such 'tingling', 'numbness', 'arthralgia' or 'allodynia' or cancer related conditions whose symptoms include pain (for example lymphedema or chemotherapy induced peripheral neuropathy). This may have resulted in identification of more studies.

Only four studies were identified. This means limited conclusions can be drawn as there is so little information available. This supported the decision to use a descriptive methodology for the synthesis, however, by their very nature, descriptive qualitative evidence syntheses allow for limited interpretation of meaning. An interpretive methodology would have allowed for deeper interpretation and the creation of new concepts.

2.8: Conclusions

This synthesis has highlighted that chronic pain after cancer treatment results in physical difficulties and emotional upheaval for cancer survivors (Armoogum *et al.*, 2020). This finding could be predicted and reflects the experiences of those living with non-malignant chronic pain (Toye *et al.*, 2013). However, a key finding from this study is that the experience of chronic pain after cancer treatment for cancer survivors appears to be intrinsically interwoven with their experiences of cancer and cancer care. Women in the studies questioned the meaning of the pain and what it could represent in relation to their cancer. They felt the pain was unexpected, they alluded that they were abandoned by healthcare professionals and they were left to manage their chronic pain after cancer treatment on their own. It is important to explore these themes in more detail to learn more about the experiences of cancer survivors with chronic pain after cancer treatment – what is it like for cancer survivors to live with chronic pain after cancer treatment? What do they need from healthcare services?

Foster and colleagues (2018) recommend that we need robust research that takes into consideration the complexities of cancer to help inform clinical practice and policy directions (Foster *et al.*, 2018). Yet this synthesis has highlighted that there is sparse information available about what it is like to be a cancer survivor living with chronic pain after cancer treatment. In particular, no literature was found from any cancer sites other than breast cancer and no studies explored male perspectives. The four published studies focused on early survivorship and no literature was identified that explored experiences of those living with chronic pain after cancer treatment beyond 30 months from the end of treatment. No studies were found from the UK. This highlights a need for more research into the experiences, needs and service provision for cancer survivors. The next chapter outlines a qualitative study that aims to address this knowledge gap.

Chapter 3: A qualitative exploration of the experiences, needs and service provision of cancer survivors with chronic pain after cancer treatment

3.1: Introduction

The introduction to this thesis highlighted that living in chronic pain after cancer treatment impacts negatively on cancer survivors' lives. Consequently, they have more physical and mental unhealthy days (Cox-Martin *et al.*, 2020), are less likely to be in employment (Halpern, de Moor and Yabroff, 2022; Cox-Martin *et al.*, 2020), have poor self-rated health and overall quality of life (Drury, Payne and Brady, 2017b) and greater depression, anxiety, poor recreation and low overall quality of life (Cramer, Johnson and Nilsen, 2018) compared to those without pain. However, this does not provide insight into their qualitative experiences of living with pain, or the services used to support them. The previous chapter demonstrated the paucity of qualitative research exploring the experience of living with chronic pain after cancer treatment. From the limited evidence available, cancer survivors living with chronic pain after cancer treatment appear to experience physical and emotional difficulties, lack information, and consider their experience of chronic pain and cancer to be intrinsically interwoven. However, these studies did not include the experiences of those in England or the UK, nor men, and focused only on those in the early stages of survivorship from breast cancer (Armoogum *et al.*, 2020). Yet pain can occur as a late effect of cancer treatment from many other tumour types (Karri *et al.*, 2021; Van Den Beuken-Van Everdingen *et al.*, 2016; Macmillan Cancer Support, 2013). It is known that cancer survivors can experience challenges accessing support including difficulties regarding access, professional responsiveness, co-ordination, communication, involvement in care and workforce shortages (Fitch, Lockwood and Nicoll, 2021; Mead *et al.*, 2020; Jacobs and Shulman, 2017), however, no qualitative research has been identified exploring this issue in cancer survivors living with chronic pain after cancer treatment. To understand this in more depth, it is important to qualitatively explore what it is like to live with chronic pain after cancer treatment and gain cancer survivors' views and experiences of services used to help them manage their pain.

3.2: Aim

To explore the experiences, needs and service provision for cancer survivors living with chronic pain after cancer treatment in England, UK.

3.3: Methodology

Theoretical framework

Research sits within two paradigms – quantitative and qualitative. Broadly, quantitative research uses objective, numerical data to identify relationships between variables to help explain or predict areas of interest with an aim to generalise the findings to the wider population. Conversely, qualitative research seeks to understand phenomena using words to interpret and discern meaning. It embraces subjectivity and places importance on the reflexivity of the researcher and recognises that data are gathered within a context. Qualitative research is exploratory, open-ended and organic and results in in-depth, rich and detailed data (Braun and Clarke 2013, Green and Thorogood 2018).

Within qualitative research, there are two broad orientations: experiential and critical. Experiential orientations explore views, perspectives and experiences as expressed in the data. It focuses on what participants think, feel and do and is underpinned by the theoretical assumption that language reflects reality (either a singular universal reality or the perspective reality of a particular participant). In comparison, critical orientations interrogate meanings and experiences within the data and use these to consider different phenomenon. It considers that language creates, rather than reflects, reality (Braun and Clarke, 2013, 2022; Terry *et al.*, 2017). This study focused on the experiences of cancer survivors with chronic pain after cancer treatment and adopted an experiential theoretical framework. Therefore, it concentrated on participant standpoints and how they saw the world.

Ontological and epistemological position

Within a theoretical framework, considerations of epistemology and ontology are important. Ontology refers to theories concerning the nature of reality or being and epistemology involves discussions on the nature of knowledge (Green and Thorogood, 2018; Braun and Clarke, 2013, 2022).

Ontological positions range from realism whereby reality is considered to exist separately from human practices and understandings to relativism, whereby it is thought to be impossible to separate human interpretation and knowledge from reality and thus it always reflects our perspective (Braun and Clarke, 2013, 2022). Critical realism uses aspects of both approaches and assumes an ultimate, pre social reality but recognises that how reality is experienced and interpreted is shaped by culture, language and political interests (Braun and Clarke 2013, 2022, Green and Thorogood, 2018). Critical realists accept that access to the ultimate, pre social reality is always mediated by sociocultural meanings and, within qualitative research, participants' and researchers' interpretative resources. Thus, direct access to reality is never possible. People's words provide access to their particular version of reality and qualitative research produces interpretations of this reality (Terry *et al.*, 2017).

Epistemological positions move from a positivist approach, in which researchers view the world as independent of how humans experience it and thus ‘truth’ can be found if variables are controlled, to constructionism. Constructionism argues that there are no stable, pre-existing phenomena but these are created through social processes. There is not one truth or knowledge but knowledges, thus knowledge is always rooted in the social world and as this changes, ‘truth’ changes (Green and Thorogood, 2018; Braun and Clarke, 2013, 2022). Within the middle of these two views is contextualism. Contextualism is ‘the human act in context’ (Pepper, 1942 cited in (Tebes, 2005). It recognises knowledge arises from social, historical and cultural contexts and reflects researchers’ positions and therefore is local, situated and provisional. However, it is still concerned with understanding truth, and acknowledges propositions will be true and valid in certain circumstances (Braun and Clarke, 2013; Tebes, 2005).

This research adopted a critical realist ontological perspective within the broad epistemological framework of contextualism. Thus, this approach assumed meaning related to the context in which it was produced. The critical realist position informed the analysis as participants’ words were used to access their reality and describe their experiences; however, it was recognised in the analysis that their words and experiences are influenced and shaped by the society we live in. Therefore, societal views of cancer survivors, expectations of survivorship, acceptance of chronic pain after cancer treatment, trajectory of chronic pain after cancer treatment experiences and alike may have played a part in the words participants used and the interpretations of their experiences. The research produced an interpretation of this reality but was also shaped by the researcher's (JA) resources. For example, JA has never had cancer, lives in a society that has certain views about cancer, has a professional background as an acute cancer nurse and is currently an academic with an interest in those living with and beyond cancer. JA does not live in chronic pain after cancer treatment, nor do any of her immediate friends and family and she has had limited specialist clinical experience of pain management. Thus, the research captured participants' experiences as lived realities that were produced, and existed, within broader contexts (Terry *et al.*, 2017).

3.4: Method

Research Ethics Approval

Ethical considerations are the fundamental to high quality research. The study obtained the necessary ethical approvals prior to commencing and there was active communication with the ethics committee throughout the study. Initial approvals included:

- NHS Research Ethics Approval, granted on 11.10.19 (Appendix 2)
- Health Regulatory Authority (HRA) approval, granted on 16.10.19 (Appendix 3)
- UWE Ethics approval as sponsor, granted on 18.10.19 (Appendix 4)
- Access to recruiting centres (Appendix 5 and 6)

A timeline from ethical application to approval is in appendix 7.

Assessment and management of risk

A full risk analysis for the study was conducted and a UWE risk assessment was completed and verified by the university. A UWE Research Governance Record and data management plan was maintained throughout the study.

Recruitment

Inclusion criteria

- Adults over 16 years old when diagnosed and treated for cancer in England
- People who self-report as having completed anti-cancer therapy (with the exclusion of hormone treatment) as per EORTC definition
- People with self-reported chronic pain after cancer treatment that persists or recurs for longer than three months
- People able to communicate in the English language

Exclusion criteria

- Survivors of childhood cancer
- People with known active primary disease or metastatic disease
- People who are receiving active anti-cancer treatment
- People who have known terminal disease
- People previously seen by a chronic pain clinical team for non-malignant chronic pain

Sampling framework

The study explored experiences of cancer survivors at different stages of survivorship and sought to recruit a mix of men and women from a range of cancers. To achieve this, purposive sampling, where the researcher selects data cases in order to include a range of pre-determined and information-rich cases, was adopted (Green and Thorogood, 2018). Braun and Clarke (2013) explain purposive sampling incorporates a variety of sampling strategies including stratification. Stratification enables researchers to ensure a range and diversity of different groups in a population are included in the sample and may be demographic, phenomenal or theoretically driven. In quantitative research, stratification can be used to produce a sample that matches the general population, whereas in qualitative research, the aim is to ensure diversity is included in the sample.

To this end, the sample for this study were purposively stratified by:

- Gender. Previous studies exploring the experiences of chronic pain after cancer treatment in cancer survivors have not included the experiences of men (Armoogum *et al.*, 2020) and it is known that men are underrepresented in qualitative research (Plowman and Smith, 2011).
- Cancer type. The majority of studies examining pain after cancer focus on those with breast cancer (Armoogum *et al.*, 2020; Van Den Beuken-Van Everdingen *et al.*, 2016).
- Stage of survivorship. No studies have been identified that explore the experiences of chronic pain after cancer treatment in those in the latter stages of cancer survivorship (Armoogum *et al.*, 2020).

Therefore, when recruitment sites were identifying participants, men and those with non-breast cancer, who met the inclusion criteria, were approached first. Maher and McConnell's (2011) cancer care pathway guided the timepoints for recruitment (Maher and McConnell, 2011):

- Rehabilitation (assumed to be the year after treatment, estimated to be the second year since diagnosis)
- Early monitoring 1 (up to 5 years from diagnosis)
- Early monitoring 2 (up to 10 years from diagnosis)
- Late monitoring (beyond 10 years from diagnosis)

To enable the stratified purposive sampling outlined above, four recruiting sites were identified:

1. Complex Cancer Late Effects Rehabilitation Service (CCLERS) at the Royal National Hospital for Rheumatic Diseases (RNHRD), Bath, (now known as the Pain-related Cancer Late Effects Functional Rehabilitation Service, Royal United Hospitals NHS Foundation Trust, Bath, UK) - an NHS cancer late effects service https://www.crpsandcancerlateeffects-bath.org.uk/
2. Penny Brohn UK, a national cancer charity running support services for anyone affected by cancer https://www.pennybrohn.org.uk/
3. Participants from a national cohort study, HORIZONS, exploring recovery of health and wellbeing following cancer treatment and run by the Support organisation for Psychosocial Research in Cancer (CentRIC$^+$) at the University of Southampton http://www.horizons-hub.org.uk/index.html
4. Radiotherapy Action Group Exposure (R.A.G.E), a support and campaigning group for those suffering injury from radiotherapy given as treatment for breast cancer https://www.rageuk.org/.

Size of sample

Qualitative studies often have small sample sizes compared to quantitative studies (Braun and Clarke, 2013). In the study protocol, the study aimed to recruit a maximum of 30 participants, with a representative spread of age, gender and time since treatment. Within this, the study sought to recruit 5-8 people at each stage of the cancer care pathway (excluding diagnosis and treatment and end of life) proposed by Maher and McConnell (2011) (table 10).

Table 10: Proposed sample sizes for each stage of the pathway and recruiting centres

Stage of cancer care pathway	Sample size	Recruiting site (definitions on page 83)
Rehabilitation (assumed to be the year after treatment, estimated to be the second year since diagnosis)	5-8	2, 3 and public
Early monitoring 1 (up to 5 years from diagnosis)	5-8	2, 3 and public
Early monitoring 2 (up to 10 years from diagnosis)	5-8	1, 2, 3 and public
Late monitoring (beyond 10 years from diagnosis)	5-8	1, 2 and public

The sample size of up to 30 individual interviews was decided upon at the time of protocol development based on discussions with the supervisory team and recommendations of sample sizes for studies which seek to identify patterns across data (Terry and Braun, 2011; Braun and Clarke, n.d.). Furthermore, Mason (2010) suggested up to 30 interviews would generate sufficient data for doctoral study using qualitative methodology. However, it was recognised that a pre-meditated approach to the sample size was not wholly congruent with the principles of qualitative research (Braun and Clarke, 2013; Mason, 2010) and the sample size may have changed as the study developed and if data saturation was reached (Green and Thorogood, 2018). Saturation is often used in qualitative research as a criterion for discontinuing data collection or analysis (Saunders *et al.*, 2018). At the time of protocol development, there was increasing recognition of need to clarify the difference between 'theoretical saturation' and 'data saturation' (Saunders *et al.*, 2018). Saunders and colleagues (2018) defined theoretical saturation as "the development of theoretical categories: related to the grounded theory methodology" and data saturation as ''the degree to which new data repeat what was expressed in the previous data". At that time, the protocol adopted Saunders *et al.,* (2018) definition of data saturation as "the degree to which new data repeat what was expressed in the previous data" (Saunders *et al.,* 2018, p.1897) and thus data collection would cease when this occurs. However, between protocol development and data analysis, Braun and Clarke published further discussions on saturation and questioned its usefulness as a concept in reflexive thematic analysis (Braun and Clarke, 2019b). They highlight that "what might constitute 'saturation' for reflexive thematic analysis is an interpretative judgement related to the purpose and goals of the analysis. It is nigh on impossible to define what might count as saturation in advance of analysis, because we do not know what our analysis will be, until we do it" (Braun and Clarke, 2019b, p. 10).

Participant identification

Identification of participants was specific to each recruiting site depending on their referral procedures and standard measurements for pain.

1: CCLERS team reviewed referral lists for CCLERS and identified potential participants.

2: Penny Brohn team reviewed registration forms of clients and identified clients who highlighted pain as a concern on myCAW assessment tool (Jolliffe *et al.*, 2015) and published the study via their virtual newsletter.

3: For round one of recruitment, the CentRIC$^+$ team identified participants who highlighted pain as a problem on the QLQ-C30 pain subscale (EORTC, n.d.) using a cutoff of >25 (the clinically significant cutoff) , and who had consented to hear about further research on their Case Report Form (CRF) and had not withdrawn from HORIZONS. All potential participants were status checked to ensure they had not died since the last contact with the centre. Due to poor recruitment, participant identification for round two of recruitment was altered to include participants who had cited pain as a problem on their CRF.

4: The R.A.G.E chair shared information about the study in their newsletter and interested participants contacted the Chair.

Potential research participants who were referred to sites 1 and 2 after the study had opened were identified by the organisations team on referral/self-referral.

Screening of participants – Sites 1, 2 and 3

JA provided sites with a screening log with predetermined study numbers. Participants were identified by the site teams as described above and teams entered participants on the screening log. The teams sent participants a study pack which included:

- A study introduction letter from the clinical/research team on site headed paper (Appendix 8)
- A Patient Information Sheet (Appendix 9)
- A reply slip addressed to Julie Armoogum
- A stamped return envelope

The site team emailed JA the study numbers when the study packs had been sent. JA contacted the site team three weeks later to request a follow up letter (Appendix 10) to be sent to any participants who had not responded.

Screening of participants – R.A.G.E

JA sent the R.A.G.E chair study packs including:

- A study introduction letter from the researcher on university headed paper (Appendix 8)
- A Patient Information Sheet (Appendix 9)
- A reply slip addressed to Julie Armoogum
- A stamped return envelope

Consent

After the participant had received the study pack and contacted JA to express their interest, JA contacted the participant via the contact details provided. During this telephone conversation, JA described the study in more detail, confirmed eligibility and answered any questions participants may have had. To confirm eligibility, JA completed an eligibility screen (Appendix 11). If participants were eligible and wanted to participate, the interview was arranged for a mutually agreeable time.

Consent was taken at the time of interview (Appendix 12) and was audio recorded. Participants were asked if they give permission for their General Practitioner (GP) to be informed of their involvement in the study. If so, a letter was sent to their GP (Appendix 13).

Data Collection

Data were collected by semi-structured telephone interview at a single time point. All participants were offered the choice of a face-to-face interview, a video call or a telephone interview. The interviews were conducted by JA. During the interviews, JA drew on her qualitative research and interview training, prior qualitative research experience, and her clinical experience of communicating with people with cancer. During the interviews care was taken to build a rapport with participants to enable them to speak freely about their issues. Participants were encouraged to share their story of their cancer diagnosis and treatment and were then asked about how things have been for them since. To gain rich information during the interview, participants were asked probing questions such as 'can you tell me more?', 'can you describe?', 'what do you think?', 'How do you feel?', 'can you reflect?' An interview schedule is in appendix 14.

After the interviews, participants were sent 'thank you' letters and a support leaflet (Appendix 15). The leaflet contained contact details of the research team and advice about where to access support, such as national cancer charities. Interviews were digitally audio-recorded and transcribed verbatim by university-approved professional transcription services. Each participant transcript was allocated an ID number constructed of the interview number, gender, cancer and time since diagnosis, for example 3FB4 (3=interview number 3, F=female, B=breast cancer, 4= late monitoring). At the end of the analysis, participant ID numbers (i.e., 1FB4) were replaced with pseudonyms.

Analysis

Braun and Clarke (2019a, 2022) suggest thematic analysis is an umbrella term incorporating three broad schools with different underlying philosophies and approaches to data analysis: a 'coding reliability' approach, a 'codebook approach' and a 'reflexive' approach. They argue coding reliability approaches are *partially* qualitative but the underlying logic is (post-) positivist. The process of coding aims to prioritise reliable data coding, by identifying accurate codes and themes within the data, often based on agreement between multiple coders. This consensus coding builds towards a shared, singular 'correct' analysis of the data. Conversely, reflexive thematic analysis is fully *qualitative,* with data collection and analysis techniques underpinned by qualitative philosophies and paradigms. It seeks to give a coherent and compelling interpretation of the data, grounded in the data. It views researcher subjectivity as not just valid, but as a resource. The researcher is a storyteller, who is actively engaged with interpreting the data 'through the lens of their own cultural membership and social positionings, their theoretical assumptions and ideological commitments, as well as their scholarly knowledge' (Braun *et al.*, 2018, p.848-849). Codebook thematic analysis sits between coding reliability and reflexive thematic analysis. It shares the structured approach to coding with coding reliability whilst reflecting the broadly qualitative underlying philosophy of reflexive thematic analysis. For this study, interview data were analysed using reflexive thematic analysis (Braun and Clarke, 2013, 2019a, 2022; Braun *et al.,* 2018). Reflexive thematic analysis involves interpretation. Braun and Clarke (2022) explain that although analyses can be situated on a continuum from primarily descriptive, whereby researchers stay close to the data, to more interpretive analysis, there is interpretation across the spectrum. Thus, this experiential, critical realist analysis 'stayed close' to the data and was closer to the descriptive end of the spectrum, but was informed by the reflexive lens of the knowledge, experience and perceptions of the researcher, insights from theory and an understanding of the wider context (Braun and Clarke, 2022).

Reflexive thematic analysis is a six phase approach that is not linear but reflexive and recursive (Braun and Clarke, 2006, 2013, 2019a, 2022; Braun *et al.,* 2018). Transcribed interviews were imported into NVIVO Pro version 12 (Lumivero, n.d.) and the first phase of analysis involved JA familiarizing herself with the data. Audio recordings were listened and re-listened to, transcriptions were read and re-read and initial ideas about the data were noted. During this process, JA read and listened actively, analytically and critically (Braun and Clarke, 2006, 2013, 2022). The second phase involved generating initial codes. 'Complete coding' was undertaken whereby everything relevant to the research questions were identified within the entire dataset. Semantic codes were applied to capture surface meaning of the data and latent codes were used to capture implicit meanings, assumptions and theoretical frameworks underpinning the data (Braun and Clarke, 2006, 2013, 2022). JA then reviewed and organised the codes to construct themes. Themes were built, moulded and given meaning at the intersection of data, JA's experience and subjectivity as a researcher and the research questions. Themes were then reviewed to ensure they captured the coded data extracts, had a central organising concept and reflected patterns across the dataset. Themes did not emerge from the data but were generated actively by JA reviewing, developing and rejecting candidate themes (Braun and Clarke, 2013, 2019a, 2022; Braun *et al.*, 2018). JA used visual mapping techniques to draw electronic thematic maps to help chart the development of the themes. These were shared with the supervisory team multiple times, an example from August 2020 is in appendix 16. Theme development was discussed within supervisory meetings and JA worked and reworked the themes to refine and define them. Further, JA shared the ‘work in progress’ themes with colleagues, peers and healthcare students during various dissemination activities including conference presentations, talks and teaching sessions (Appendix 17). Each time, this process helped JA move the analysis from topic summaries (everything that was said in the data about a subject) to themes (patterns of shared meaning underpinned by a central organising concept) (Braun and Clarke, 2021, 2022).

Impact of Covid-19 pandemic

During the study, there was a global pandemic related to Covid-19 and this impacted on the study. NHS, Health Research Authority (HRA) and university ethical approvals had been granted in October 2019. Participant screening and recruitment started in November 2019 and data collection commenced in January 2020.

In early March 2020, 14 participants had been recruited and a second round of recruitment letters had been sent to 13 participants. From mid-March measures were taken across the country to limit the effects of Covid-19 and these included a national ‘stay at home order’ referred to as ‘lockdown’ in which people were instructed to self-isolate, shield and socially distance. Schools, universities and many workplaces closed. The team discussed the impact of this in terms of recruitment to the study and decided to pause further recruitment. The study sponsor was informed as advised by the HRA Covid-19 Guidelines. Participants who had returned the postal reply slip prior to the university closing were contacted and offered a telephone interview if they wished.

In late April, one of the recruitment sites, the Complex Cancer Late Effects Clinic in Bath, contacted JA to say they had identified some participants and would like to start recruiting to the study again. This required a change to the protocol. In the original protocol, participants expressed interest in the study by returning a postal slip. As participants were likely to be shielding and therefore not going outside of their homes, they may not have been able to go to a post box to post the reply. Furthermore because of the university closure, replies could not be collected. Therefore, the postal slip was replaced by an email or telephone call. A protocol amendment was submitted to the sponsor, approval was granted on 30.04.20 and the HRA were informed as per HRA Covid-19 Guidelines.

On discussion with the supervisory team, it was decided against recruiting further participants from the public. The rationale for this was both methodological and pragmatic:

- The interview data collected was rich, complex and, as advocated by Braun and Clarke (2019) "burst with potential" (Braun and Clarke, 2019b, p.10). Braun and Clarke (2019b) recommend that researchers should make an "*in-situ* decision" about final sample sizes, based on the quality of the data for addressing the research question. These decisions can only be made within the process of data collection, reviewing data adequacy during the process and recognising that sample size is not the only important factor
- The timepoints early monitoring 1 and 2 plus late monitoring had recruited well. The only timepoint that was underrepresented in the sample was rehabilitation. As those people were closest to their cancer diagnosis and treatment and most likely to be shielding, arguably, any interviews may be distorted and fears and anxieties may be exacerbated in those self-isolating and at risk of Covid-19

- The pause from the Covid-19 situation meant a delay to further data collection, which in turn would have delayed analysis, which would have resulted in a delay to the overall PhD timescales

No further recruitment took place through HORIZONS or Penny Brohn as teams were remote working and access to participant data and resources were not available.

It was important to recognise in the analysis that some of the interviews were conducted pre Covid-19 and some during the Covid-19 pandemic. As the study was about experiences of chronic pain after cancer treatment, people's experiences (or fears or anxieties) may be altered due to social distancing and alike. The interviews were semi-structured and the interview schedule in the protocol allowed for some flexibility and probing. Interview questions such as can you tell me more? can you describe? what do you think? what do you feel? can you reflect? what else is of importance? provided scope to ask a question about how participants felt about the world situation surrounding Covid-19 at the time.

Public and patient involvement

Two public contributors, who are cancer survivors living with chronic pain after cancer treatment, were involved with the development, design and conduct of the study. Their involvement followed the UK Standards for public involvement in research (UK Public Involvement Standards Development Partnership, 2019; National Institute for Health Research, 2014). Feedback from public contributors resulted in modifications to the methods of the study including informing General Practitioners (GP) about participant involvement, wording of the recruitment poster and interview schedule, and including patient groups within the plans for dissemination. An evaluation of the impact of the public contributors is described in chapter six.

Reflexivity

Reflexivity refers to the process of critical reflection on the production of knowledge through research and is essential for high quality qualitative research (Braun and Clarke, 2013). Wilkinson (1988) articulates two types of reflexivity, personal and functional. Personal refers to how the researcher's beliefs, experiences and assumptions can shape the research and functional reflexivity refers to how research tools and processes may have influenced the findings of the research (Wilkinson, 1988). To assist with reflexivity and to enable a continuous process of critical thought and reflection, a reflexive journal was kept throughout the research. This enabled the researcher to document her experiences and thoughts, plus have the time and space to reflect on the development of the study. Key moments of reflection included the recruitment and evaluation of the involvement of the public contributors, the journey through ethics, communication with recruiting sites, data collection, data analysis, writing up the study and the impact of Covid-19. Further, supervisory meetings were used as an opportunity to critically discuss and reflect upon the research and detailed supervisory meeting notes were kept throughout the study.

Rigour and Trustworthiness

Quality is an essential component of research. In quantitative research, reliability, validity, and generalisability are considered the hallmarks of quality assessment, however, these are not aligned with qualitative research (Korstjens and Moser, 2018; Rolfe, 2006). In qualitative studies, the focus is trustworthiness (can the findings be trusted?) and rigour (were the data collection methods and analysis rigorous and transparent?) (Korstjens and Moser, 2018). To do this, Lincoln and Guba (1985) advocated the need for credibility, transferability, dependability and confirmability from their work on grounded theory as ways of demonstrating rigour and trustworthiness (Lincoln and Guba, 1985). Some authors have used this framework to demonstrate trustworthiness for studies using thematic analysis (Nowell *et al.*, 2017). Others advocate being sensitive to the context of the research, commitment and rigour, transparency and coherence and impact and importance (Yardley, 2015, 2017).

Member checking refers to the practice of checking analysis with participants (Braun and Clarke, 2013). Supporters of member checking suggest it is a method of ensuring findings are not misrepresenting the participants' views and consider it to provide a 'credibility check' (Lincoln and Guba, 1985). However, as Braun and Clarke (2013) explain, qualitative research can not simply 'represent' participants' experiences as the process of analysis and interpretive activity is informed by the researchers' assumptions, beliefs, values and experiences. They also highlight some practical considerations with member checking such as willingness and availability of participants, power and authority of the researcher, issues of contradictory feedback and time and resources. An alternative way, suggested by Tracy (2010) is 'member reflections'. This is an opportunity to engage in dialogue and share with participants about the study's findings and have opportunity to question, critique, feedback, affirm and collaborate with the researchers during the analysis. This study had two public contributors, who are cancer survivors living with chronic pain after cancer treatment, actively engaged with and committed to the study. On agreement with the supervisory team and public contributors, the public contributors were involved in the 'member reflections' to see if the findings resonated with their experiences. During this process the public contributors read interview transcripts and a summary of the findings produced by JA. They reflected on their own experiences and discussed with JA how their experiences aligned with the findings. The public contributors reported the findings mirrored their experiences and they recognised the issues raised by participants.

An audit trail of analysis has been kept electronically. All coded data and lists of codes are stored within Nvivo and electronic copies of all thematic maps developed throughout the analysis, including theme definitions, content of themes and candidate themes have been saved.

3.5: Findings

Sample

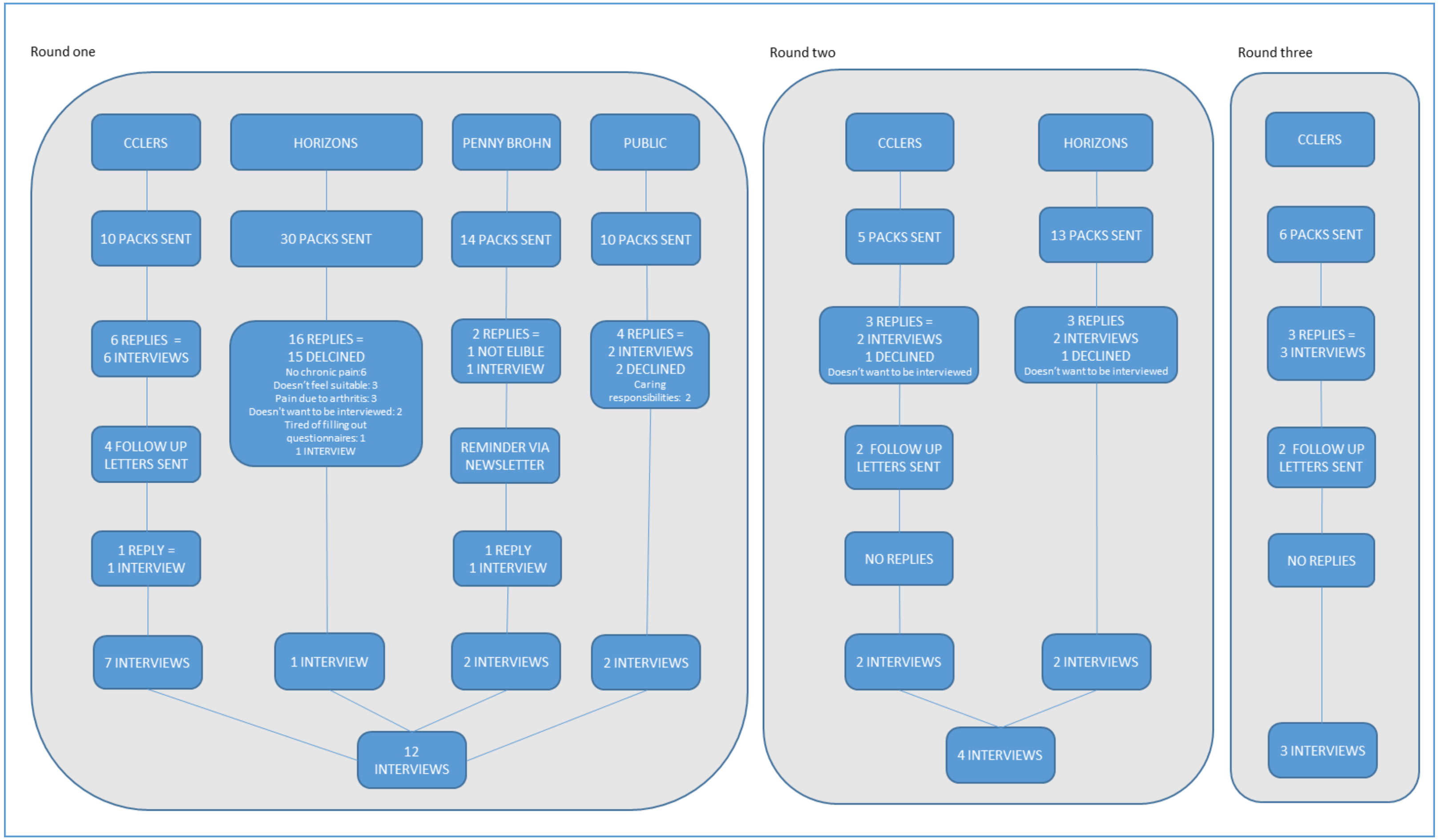
Across the four recruiting sites 82 potential participants were invited to participate in the study. 39 responded to the invitation (47.6%) of whom 20 agreed to be interviewed. During screening, one was identified as ineligible for the study, this was because they experienced long-standing chronic pain that pre-dated their cancer treatment, resulting in 19 participants. Of the 19 who declined to be interviewed, the reasons cited were: they did not feel suitable (n = 11), they did not want to be interviewed (n = 5) or they had too many caring responsibilities (n = 2). Figure 4 describes recruitment from each site during round one, two and three. Table 11 outlines overall recruitment from each site.

Table 11: Recruitment numbers from each site

Round	CCLERS	HORIZONS	Penny Brohn	Public	Total
1	7	1	2	2	12
2	2	2	-	-	4
3	3	-	-	-	3
Total	12	3	2	2	**19**

The final sample (n = 19) consisted of 14 females and 5 males, with a mean age of 62.4 years at time of interview and a mean age of 46 years at diagnosis. Eight tumour groups were represented. Participants were between 18 months and 48 years since diagnosis. All participants were currently living with chronic pain after cancer treatment and six participants (31.6%) developed chronic pain more than ten years after finishing cancer treatment (whole sample range 0-25 years) (table 12). All interviews took place on the telephone and ranged from 43 to 86 minutes with a mean of 67 minutes. Fourteen interviews took place before Covid-19 (January and February 2020) and five within two months of the first UK lockdown (i.e., during March and April 2020)

Figure 4: Recruitment from each site during rounds one, two and three of recruitment



CCLERS - The Pain-related Complex Cancer Late Effects Rehabilitation Service

Table 12: Sample characteristics (n=19)

Demographic		Data
Gender	Male	5
	Female	14
Age at cancer diagnosis	Mean	46 years
	Range	19-74 years
Age at interview	Mean	62.4 years
	Range	38-78 years
Cancer	Breast	10
	Head and neck	2
	Head and neck (1st diagnosis)/Non-Hodgkins Lymphoma (2nd diagnosis)	1
	Non-Hodgkins Lymphoma	1
	Endometrial	1
	Ovarian	1
	Testicular	1
	Hodgkins Disease	1
	Multiple myeloma	1
Time since end of cancer treatment	< 1 years	1
	1-5 years	5
	5-10 years	4
	>10 years	9
	Range	–8 months - 48 years
Time from end of cancer treatment to developing chronic pain after cancer treatment	< 1 year	11
	1-5 years	1
	5-10 years	1
	>10 years	6
	Range	0 – 25 years after cancer treatment

Themes

Five themes were generated which highlighted the experience of chronic pain after cancer treatment for cancer survivors:

1. Hear me… believe me…. Please
2. Expectation versus reality
3. They don't understand…. We don't understand
4. Negotiating the maze
5. Validate my pain, validate me

1. Hear me….believe me…please

This theme centred around the overwhelming sense that people living with chronic pain after cancer treatment did not feel listened to or heard by healthcare professionals. Participants expressed that, when they had tried to talk to healthcare professionals about their pain, they had not been listened to:

"I don't feel that I've been listened to ….it still wasn't really addressed…. no-one would actually listen to the fact that I was still in a lot of pain" (Charlotte)

And *'finding somebody who wants to hear or wants to listen' (Charles)* was a significant challenge for them. Furthermore, alongside not being listened to about their chronic pain after cancer treatment, when they tried to talk to healthcare professionals about it, at times, they felt healthcare professionals did not believe that chronic pain after cancer treatment was a genuine ailment:

"There are a lot of healthcare professional's who don't believe that half these things (chronic pain after cancer treatment) exist… I still bump into people (with chronic pain

after cancer treatment) who've been told, by their GPs and doctors, 'just pull yourself together. there's nothing wrong here. There's nothing actually happening here'" (Thomas)

"And the consultant I saw at the pain clinic didn't believe me …. He said, 'Oh, I don't think you could have that. Not after all this time'" (Olivia)

Participants expressed that they had needed to broach the subject of chronic pain after cancer treatment with healthcare professionals many times. This led to them having the impression that healthcare professionals were exasperated by them and, at times, this felt personal:

"I have felt like I'm annoying, and that's really hard" (Louise)

"I feel a pest if I go to the doctors', because I don't think they know what to do…. I've got a bit of dread …. they'll think, 'Oh, my God, this bloke looks like a nightmare to deal with'" (William)

Similarly, they thought healthcare professionals might have suspected they were making up how hard it was for them:

"My GP is a very good GP, but I think he got to the point where he was almost thinking, 'This is a hypochondriac'" (Thomas)

"I feel as if quite a few medical professionals have thought, 'Oh for god's sake. This has got to be in the brain or something. Psychosomatic or whatever or attention seeking, or whatever you want to say'" (Fiona)

When participants tried to highlight or discuss chronic pain after cancer treatment with healthcare professionals, they were often met with resistance:

(when a participant asked the doctor if it could be chronic pain after cancer treatment) "he said.. 'You prove it to me and I'll look into it'" (William)

It seemed to participants that some healthcare professionals did not want to, or could not, make the connection between the pain that participants were experiencing and their previous cancer treatment:

"*I knew that the pain was there because of what I'd had in the past, but I don't feel there was that correlation between the two… " (Charlotte)*

Some felt healthcare professionals ignored their chronic pain, dismissed their concerns and said *"Well, you know, you should be lucky, you're still here" (Charlotte)* or compared them to others with different side effects of cancer as Sarah explained *an 'oncologist said, "Well you're the lucky ones'* (to live and not have long term side effects to your continence or bowels) but she *'didn't feel lucky – I live in such pain!'.*

The sense that they were not listened to, or believed, left participants feeling both frustrated and desperate. Participants were frustrated for not being taken seriously and explained that they were *'banging their head against the wall' (Charlotte).*

2. Expectations versus reality

This theme centred around the dichotomy of expectation of recovery after cancer treatment versus the reality of living in chronic pain after cancer treatment.

Many participants spoke at length about their cancer diagnosis and treatment and the challenges that time had brought, however, they also expressed that they had understood it was going to be a difficult time. Participants expected acute side effects, but they felt utterly unprepared for the risk of long-term effects. They had not anticipated having chronic pain after cancer treatment, or how hard their life would be. They struggled with making sense of a life-saving treatment having such negative and long-lasting consequences and found it challenging to comprehend '*I didn't dream that by taking a cancer treatment to save my life would leave me in agony all the time. Just that seems ludicrous to give you something that's going to make you feel like this" (Gillian).*

Anticipated recovery after cancer was influenced by personal, cultural and societal factors arising from participants, their families, their social communities and the healthcare professionals they encountered. On a personal level, patients assumed and anticipated they would fully recover after cancer treatment. Participants expressed cultural expectations from themselves and their communities to behave, think and act in 'positive' ways and felt societal pressure to think positively. They explained that sometimes their friends 'forgot' about their chronic pain and would lean in to hug them, even if participants had explained that touch gave them shooting pains. They felt at times their friends and family were frustrated with them: *'And my mum had been very supportive all through my cancer treatment, and as far as she was concerned it (cancer) had gone. So she wasn't very understanding of me having this problem (chronic pain after cancer treatment) and just thought I'd get over it, I think' (Olivia).* Louise explained healthcare professionals had said she *'should be over this by now' (Louise)* and this was hard *'I think the worst thing is when someone is telling me how I should feel or how I should be further along than I am, rather than just listening. I think that's been the most awful thing'.*

The expectations of participants, and those around them, were contrary to the reality of living with chronic pain after cancer treatment. In reality, living with chronic pain after cancer treatment negatively impacted and shaped all aspects of participants' daily lives:

physical, emotional, social, sexual, spiritual and economic. William encapsulated this when saying *"I think it affects every aspect of my life really. It's who you are. It's who I am, going into the world…I don't think there's a part that's not touched by that".* Participants expressed that living with chronic pain after cancer treatment was hard, relentless and felt endless. It felt as if their life had shrunk or diminished in some way:

"I feel like my life has got smaller and smaller" (Sarah)

And this really limited their life:

"So many doors have shut to me, you know" (Sandra)

This made them feel isolated, as expressed by Thomas when he said *"There were times when I felt completely isolated"* and by Olivia who said "*You just felt really alone".*

The reality of living with chronic pain after cancer treatment was associated with loss. There was tangible loss of things participants used to do, such as hobbies, driving, or work. Sophie explained the impact of this as *"My hands can't cope with doing too much and then I'm in extreme pain with my hands afterwards…. So, it does impact on my leisure time, the things I normally do to relax, which is annoying"*. Many participants had needed to stop working, and mourned the loss of their job*:*

"I used to have a very physical job. I used to work outside. I was a gardener…. It was my life, it was my job; it was my everything" (Emily)

Alongside loss of physical function, for many there was loss and change to their appearance. Harry articulated the impact of this when he said:

"I've actually lost four inches in height… it's psychologically so difficult to look at somebody in the chest when you used to look at them in the eye… you do feel a little bit inferior"

Loss was also embodied in other aspects of their lives, for example financial loss and loss of enjoyment as Sandra explained that '*Everything that I've enjoyed, I've lost'.* Participants also discussed lost relationships:

"It (chronic pain after cancer treatment) has totally, utterly ruined my life and my family's and my marriage. Everything….. I mean my relationship with my husband has I would say virtually broken down…. It's (chronic pain after cancer treatment) destroyed a person. It's destroyed a person's marriage. It's destroyed a person's family. It's destroyed a person's friendship group" (Fiona)

Furthermore, there was a lost sense of self, existential identity and who they are since living with chronic pain after cancer treatment:

"*You know, I, sort of, feel like I've lost my identity" (William).* This resulted in loss of confidence, "*It's like basically my confidence is shot – and by 'confidence' I mean physically, socially, professionally, sexually, and spiritually" (Louise)* and a loss of independence. Charlotte highlighted the impact of such loss, by explaining "*My whole life isn't my own. That's how I feel"*. For some, the loss of sense of self meant how they viewed themselves and the way they lived their lives was very unfamiliar to them and different from before. This was epitomised when Louise said *"I don't recognise my life"* and this was at utter odds from the recovery they had expected after cancer. Many still lived with a sense of a Sword of Damocles over their heads regarding anxiety and fear relating to the risk of cancer recurrence:

"That fear is horrendous. It's still there. Five years down the line or six years down the line, I'm still… Every time I get a particular bad pain that suddenly appears from nowhere, you

go down the same… Your brain takes you down that same road of, 'It's back again.'" (Gillian)

And the fear of cancer recurrence limited their enjoyment of day to day living:

"You can't get happy about anything because uhm you're frightened in case the worst is going to happen if you know what I mean?.....You don't want to look forward to anything…It's very emotional. You don't want to build your hopes up too much" (Ben)

This theme demonstrates the challenges surrounding the expectation of recovery after cancer treatment versus the reality of living in chronic pain after cancer treatment. Participants, and their perceptions of their families, social communities and healthcare professionals, had expected full recovery from cancer. Yet in reality, living with chronic pain after cancer treatment was really hard. It negatively impacted and shaped all aspects of participants' daily lives: physical, emotional, social, sexual, spiritual and economic. It felt relentless and endless and embodied loss of function and sense of self. For many, reconciling those differences was difficult.

3. "They don't understand…. We don't understand"

The central organising concept for this theme focused on chronic pain after cancer treatment being an unknown phenomenon. The lack of knowledge and understanding about chronic pain after cancer treatment threaded through all the interviews. Participants felt that they were not told about the risks, causes, symptoms or management of chronic pain after cancer treatment. Furthermore, it seemed that healthcare professionals did not have any knowledge about chronic pain after cancer treatment, nor understanding of the true impact that living with chronic pain after cancer treatment had on participants. There were two subthemes within this theme: ‘an unexpected experience’ and ‘grappling in the dark’.

3a. An unexpected experience

Participants felt unprepared for chronic pain after cancer treatment. Almost all participants felt they had not been told about the risk of chronic pain after cancer treatment at the time of cancer diagnosis or during their cancer treatment:

“I don’t think I’d ever had one single conversation with anyone about pain at all…I started my chemo and nothing was ever said about pain at all” (Charlotte)

However, the complexity about information recall was acknowledged as Nicole explained:

“Well I may have been (told about the risk of chronic pain after cancer treatment) to be honest, but you know, when you’re going through all that, you don’t sort of uhm… I can’t honestly remember”

Furthermore, because they had not been informed about chronic pain after cancer treatment, they did not know what to expect *“There was no mention of any permanent damage. So it was a bit of a shock really” (Olivia)* and thus, when symptoms started to appear, they did not understand them:

“The arm was getting weaker all the time, which I didn’t understand…. I couldn’t understand it all” (Dawn)

They also recognised that not understanding or expecting chronic pain after cancer treatment made it harder to manage and cope with:

“That's a difficult thing to manage, if you expect one thing and something else is happening” (Thomas)

"If you're forewarned about something then I think you deal with it better. And I wasn't informed of that, so I suppose I didn't deal with it as well as I wanted to" (Olivia)

Moreover, the lack of discussion about long term side effects, including chronic pain after cancer treatment, made it harder for them to come to terms with living with pain:

"It's (cancer treatment) taken away more than it should have done, and I was led to believe that it wouldn't have taken away anything…. I grieve deeply about what I had and I'm finding it, as time goes on, I'm finding it harder and harder and harder to come to terms with what things are now" (Fiona).

3b. Grappling in the dark

Many participants were searching to understand chronic pain after cancer treatment. There was a strong sense some participants did not truly understand why they experienced chronic pain after cancer treatment, where it had come from, what caused it or why and *'the lack of understanding of what's happening to your body is real' (Thomas).*

There was a sense of desperation and exasperation from participants who were seeking explanation for the cause of their pain and how to manage it. Participants explained that '*nobody's talked to you about it, you know, [pause] nobody's ever said to me, "Oh this is happening because of whatever…… I don't know, nobody's ever told me." (Sarah).* The feeling of confusion and frustration was clear: *'I would like the support from someone who knows and who's truthful about what's happening to my body. I want to know the facts, and that's it' (William).* This frustration led to desperation to seek answers *because 'no-one has any answers for me, or no-one properly investigate…. I don't know, you know, I really, really don't know…..'.*

This was exacerbated as they perceived healthcare professionals also had little understanding or knowledge. It seemed that healthcare professionals did not have any knowledge about chronic pain after cancer treatment, nor understanding of the true impact that living with chronic pain after cancer treatment had on participants. Many felt they had encountered healthcare professionals who "*didn't know anything about it" (Olivia)* and this culminated in the feeling that *"They (healthcare professionals) don't understand" (Fiona).* Sarah ruefully expressed her frustration about healthcare professional lack of knowledge and understanding, and the impact this had on survivors' experiences *'they don't understand… we don't understand!'.*

This theme has highlighted the lack of knowledge and understanding about chronic pain after cancer treatment. Participants did not feel prepared or informed about the risk of chronic pain after cancer treatment and struggled to understand what chronic pain after cancer treatment was, why it had happened and how to manage it. Further, they felt healthcare professionals lacked knowledge about it and failed to understand the impact chronic pain after cancer treatment had on them.

4. Negotiating the maze

The central organising concept in this theme was that support for chronic pain after cancer treatment is hard to identify. Routes to support were messy and confusing and a lack of support started soon after cancer treatment had finished. Participants reported how they felt abandoned by acute cancer services at the end of treatment:

"They basically say, 'Right, you've finished your treatment. Off you go. Goodbye…' it is the feeling of being discarded" (Gillian)

However, some also mentioned a similar feeling in relation to pain services, particularly if pain management interventions had been seemingly ineffective:

"It's been quite… I use the word 'fleeting', as in you're sent to see someone for, like, six sessions, and then if you don't seem to make the progress that they want, then that's it. You're back on your own. So, that's quite hard really" (Charlotte)

One participant summarised this by explaining that she had not felt *"accompanied" (Louise)* after her cancer diagnosis and subsequent diagnosis of chronic pain after cancer treatment.

When their chronic pain symptoms started, it was evident that participants found it difficult to identify and access services to help support them. Participants had to learn about chronic pain after cancer treatment themselves and seek their own support:

"I had to go and search myself where I could get support…. it was quite a frustrating time. You felt you had to really stick by your guns and stick up for yourself…I just had to get on with it and just find out as much as I could" (Olivia)

This was often because they did not feel they were provided with the information and support from healthcare professionals that they needed:

"Then my problem was finding out what it was…. I did a load of investigation… because no doctor tells you there's an option or there's somebody you can talk to…. nobody is there to tell you at all" (Gillian)

However, participants found this difficult to do and it took its toll on their wellbeing:

"It's been very time-consuming…It's taken a huge amount of time and writing letters and emails and phoning people and trying to decide what to do and making decisions all on by yourself…. I had to think of all this stuff for myself" (Felicity)

"I do feel a bit like I was a floundering fish at times because I just didn't know where to turn…. I didn't know where to go for help …. I feel like I've had to go out and find things for myself, which hasn't been easy with being in pain 24/7" (Charlotte)

Furthermore, there was an apparent inequality regarding identifying support services. For example, some participants had only heard of specialist support because of connections in their personal life, such as playing golf with an oncology consultant, or having a neighbour whose daughter was a specialist nurse.

It was evident that some participants had needed to use their own personal drive and determination to identify specialist services and get referred to them, yet many participants complained that once they had been able to identify a support service, it was difficult to access it. This could be because of the delays involved with referral to a specialist support programme:

"That took two-years to get to (specialist support), by the way – not easy. You need referrals….It was a lot….. I had to get a letter from my GP, blah, blah, blah. You have to jump through a lot of hoops" (Louise)

Similarly, the challenge of having to travel to access support not provided locally was reported:

"That's quite a long way to go for me. But unless you went online there isn't anything local that you can go and join…that is a bit frustrating" (Olivia)

Consequently, some people did not go, or ceased attending, because as Sophie explained *"It was just impractical".* Furthermore, there were financial implications of travel and the costs of supportive treatment:

"You had to pay for it yourself … but unless you've got money to go to somebody, you can't" (Sarah)

Many participants explained that they felt they had spent a lot of time bouncing between clinical services searching for support with their chronic pain after cancer treatment. William explained "*it was a bit like being a ping-pong ball… ".* They felt like there was conflict and confusion about whether their care needs fell under cancer services, pain services or primary care:

"I can go to the (primary care) doctor and say, 'I'm in pain' but it's not their area of expertise, you know, the GP… there's no point going back to an oncology team, because they're really busy" (Sophie)

" (I) actually ended up in the Pain Clinic uhm and uh the guy that I saw wasn't too sure why I was there" (Nicole)

It felt to participants that healthcare professionals did not know how to manage or relieve their chronic pain after cancer treatment and thus, simply referred them to another service:

"I think, generally, people just want to put you onto somebody else, don't they, really? Your GP wants you to go to the pain clinic, and the pain clinic try everything they can and then you're back at your GP's, aren't you, really?" (Emily)

Consequently, participants were trapped in a cycle of endless referral:

"A lot of my life is spent waiting to go to different people, and then you go to the person, and they'll say, 'Well, sorry, we can't help you'. So, you can end up waiting six months and getting nowhere fast" (Charlotte)

Participants felt unsure about where to go for help:

"He (the GP) was telling me to go to talk to them at oncology about everything … They were telling me to go to him, basically, and I was there, stuck in the middle, not knowing what to do…. Basically, you're stuffed because nobody really wants to know…" (Emily)

This contributed to a sense of hopelessness regarding their pain and a belief that nothing can be done to help them:

"There's nothing they (doctors) can do. So, you know, I just think to myself, 'Well what's the point of going?'" (Sarah)

This theme has shown that participants found it hard to identify and access services to support them with their chronic pain after cancer treatment. They felt trapped in an endless cycle of referral whereby most healthcare professionals wanted to refer them on to someone else rather than help them. This resulted in participants feeling lost and alone.

5. Validate my pain, validate me

The power of a diagnosis of chronic pain after cancer treatment was the central organising concept for this theme. There was a lot of emotional turmoil for participants who had not had their pain adequately diagnosed, or the reasons behind it explained: *'it's like having a disability and not being able to satisfactorily diagnose it and have a way* *forward, you know, you're, sort of, just- it's like a ship with no sails or rudder, you're just getting blown around' (William).*

For participants who had received a diagnosis of chronic pain after cancer treatment, there was an overwhelming sense of relief. They took comfort in an actual diagnosis and relief in it being identified. They held an enormous value to the validation of their pain. This helped them manage their pain and is encapsulated by Louise:

"They give me the name for it (chronic pain after cancer treatment)…. I just cried. It was like it was so amazing to have it understood that these particular kinds of pain associated with going through cancer were known and treatable in some ways, that they were not necessarily curable but that there were things that could help. It was amazing…. In a funny way, nothing's changed. I still have those things, but the fact that I know I'm not crazy, and that I know that they happen, and I know that they're common side effects from complex cancer (treatment), it's very reassuring. It's very, very reassuring. It doesn't technically make it less painful, but it, sort of, does, if that makes sense".

Many mentioned the relief at being diagnosed:

"(When I) was told I did have it (chronic pain after cancer treatment), that was a big relief" (Olivia)

Some explained that they had met healthcare professionals who did not appreciate the value or importance on the diagnosis of chronic pain after cancer treatment, as they thought a diagnosis would not make any clinical difference:

"He (the GP) would say, 'Well, it may be (when asked if the pain was related to cancer),'but we can't prove it. There's no connection. Even if it was, what difference does it make now?'" (Thomas)

And some participants speculated that healthcare professionals may not want to discuss or diagnose chronic pain after cancer treatment as they would then be attributing the pain to treatment they had prescribed, given or recommended:

"They're basically not really interested in taking – well, not responsibility, but you know what I mean" (Emily)

"None of them really want to put their name to it" (William)

The value of a diagnosis of chronic pain after cancer treatment, and the subsequent validation of their experiences, could not be overestimated. It helped participants to manage and cope with the situation:

"But now that I know this is just normal for this condition (chronic pain after cancer treatment)… I can cope. I think it was just having more enlightening about the whole thing about pain and about my particular type of pain. I think that was the greatest thing ever" (Dawn)

Having their pain explained to enabled them to understand it, made a difference to how they lived:

I would say that I'm, on the whole, more positive…and I think that's because I probably understand my pain a bit more' (Nicole)

The sense of relief, and even joy, at chronic pain after cancer treatment being identified and, most importantly, explained and believed, was palpable in interviews in those participants who had experienced it. As Dawn explained, *'it changed my life'.*

3.6: Discussion

This study has generated new and important knowledge regarding the experiences of cancer survivors living with chronic pain. It demonstrated survivors did not feel informed or prepared for the risk or reality of chronic pain after cancer treatment and this compounded the difficulties of coping with and managing their pain. Survivors felt they had not been listened to when they tried to talk about their chronic pain after cancer treatment, nor at times, believed. They felt healthcare professionals lacked knowledge and understanding regarding chronic pain after cancer treatment. Survivors encountered unclear and limited pathways for support and often bounced from one support team to another. Identifying and accessing services was a challenge, and the responsibility of this was often left to the survivor. However, palpable relief and benefit was felt when healthcare professionals diagnosed and acknowledged chronic pain after cancer treatment and this validation was essential to help manage and cope with the pain. It is important to address these issues in order to improve the experiences of those living with chronic pain after cancer treatment.

In this study, no participant felt they had, or could remember being informed about the risk of chronic pain after cancer treatment. Without knowledge of the risks of chronic pain, participants in the current study did not understand their symptoms when they started, and this made the experience of pain more anxiety provoking and harder to manage. Information recall at a time of cancer diagnosis is known to be poor (Ector, Hermens and Blijlevens, 2020) and many cancer survivors report being unaware of their risk of late effects of cancer treatment (Rosenberg, Butow and Shaw, 2022). Digesting information at diagnosis and early cancer treatment is complex, as there is a balance between the need for and the fear of information (Aunan, Wallgren and Sætre Hansen, 2019). However, it has long been recognised that people living with and beyond cancer have information needs about long term and late effects of cancer (Kotronoulas et al., 2017) and individuals' desire for knowledge about cancer late effects varies (Rosenberg, Butow and Shaw, 2022). In a global call to action, Howell (2021) stressed the importance of preparing cancer patients and survivors for active involvement in their care; however, this is difficult if people are not equipped with knowledge regarding risks. Further, healthcare professionals have a duty to fully inform patients of risks. For many years, research, policy and clinical practice have advocated the importance of informed consent and it is a legal and ethical requirement to discuss side effects associated with treatments during the informed consent procedure (General Medical Council, 2020).

Participants in this study felt healthcare professionals did not listen to them when they described their pain. They felt like a nuisance to healthcare professionals. At times they felt healthcare professionals did not believe them when they spoke of their pain experiences, and some healthcare professionals did not know or agree that cancer treatments could cause long term pain. This is echoed in the chronic pain literature, whereby not feeling believed, or heard, regarding the experience of living with chronic pain can lead people to feel invalidated, with lost personal credibility and a lack of dignity (Toye et al., 2021). Further, recent research has found that some healthcare professionals believe chronic pain is related to a cancer survivor's personality and they can exaggerate their pain or "are complainers" (Slaghmuylder et al., 2022, p.8). Slaghmuylder and colleagues also found healthcare professionals can underestimate the prevalence, severity and impact of pain in cancer survivors. This supports the findings and assertions made within the current study.

This research demonstrated there was an unclear and limited pathway for support for participants living with chronic pain after cancer treatment. Participants felt abandoned by healthcare professionals and said they were bounced between support services. They reported healthcare professionals did not know what to do with them so were keen to refer them on to a different clinical team. This is reflected by Slaghmuylder et al. (2022) who found healthcare professionals can feel powerless and frustrated when they cannot help cancer survivors to be pain free, thus they cope with these feelings by transferring tasks to their colleagues.

Furthermore, in the current study, participants had difficulties identifying and accessing services to support them with their chronic pain after cancer treatment, and often they had to identify support services themselves or needed to have a personal connection to healthcare professionals. In the UK, there has been significant change to post-cancer follow-up over the past decade with the introduction of personalized stratified follow-up care and supported self-management (Foster, 2022; NHS England, 2020). UK Policy has sought to improve communication between primary and secondary care and the NHS Long Term Plan (Department of Health, 2019b) stresses the importance of creating genuine partnerships and engaging patients in decisions about their health and wellbeing. However, these ambitions have not yet been fully realized and there continue to be problems with communication and follow up within cancer services (Maher et al., 2018; Walter et al., 2015).

This study is the first to include both men and women when exploring the experiences of chronic pain after cancer treatment and thus provides important insights into variations of experiences. However, despite actively seeking male participants, this study only included five men (approximately 25% of the total sample). It can be challenging to recruit men to qualitative studies that rely solely on verbal articulation such as using semi structured interviews (MacDonald et al., 2010). Men's experiences have sometimes been overlooked when examining emotionally complex topics and some researchers have reported a lack of emotional expression among male research participants as a challenge (Affleck, Glass and Macdonald, 2013). However, this was not apparent in the current research and the male participants spoke freely and eloquently. The mean length of time for the male interviews was slightly shorter compared to the female interviews, however their responses were articulate, thoughtful and emotional. Both male and female participants expressed how living with chronic pain after cancer treatment shaped and impacted their lives physically, emotionally and socially. Whilst being mindful of the complexities of a female researcher interviewing and analysing data from male participants (Lefkowich, 2019), gender did not appear to have a considerable impact on the reported experiences of living with chronic pain after cancer treatment, and the themes generated within the study were reflective of both male and female participants. Although all participants were offered a face-to-face interview (pre-covid), a video call or a telephone interview, all participants chose to have a telephone interview. Braun and Clarke (2013) acknowledge virtual interviews can be convenient and empowering for participants as they can be conducted from the comfort of their own home or in a location of their choosing. This may have been particularly apt for participants living with chronic pain.

This study is one of the first to include cancer survivors at later stages of survivorship. It is important to give voice to these participants because effects of cancer treatment can emerge years after treatment has concluded (Macmillan Cancer Support, 2013). Interestingly, the broad sample characteristics, including time from cancer diagnosis, did not appear to impact level of chronic pain acceptance and understanding. Rather than length of time, more influential was survivors' perceptions of the information, support and interaction they had had with healthcare professionals. The quality of the interaction with healthcare professionals, whereby they felt informed of the risks of chronic pain, listened to, believed, and validated through a diagnosis of chronic pain after cancer treatment was key.

3.7: Study limitations

Participants were limited to England thus they received their treatment predominately in the NHS healthcare system and this may limit the transferability of the findings to other countries. Survivors of childhood cancer were not included in the sample due to additional and unique concerns relating to the transition from paediatric to adult cancer services. However, it would be helpful to include childhood cancer survivors who experience chronic pain after cancer treatment in future research.

As this doctoral work has progressed, the researcher has gained considerably more insight into the experiences of those who encounter painful symptoms following cancer treatment. On reflection, aspects of the design of this study, and the language used, may have resulted in reduced recruitment. For example, the patient information sheet explained participants were selected for the study because 'you have had cancer treatment and your cancer has gone but you are living with persistent pain as a consequence of your treatment'. In hindsight, this may not have been as inclusive as intended. Firstly, participants might have been confused or discouraged by the description of their cancer as being 'gone' as their cancer may have been described to them as being in remission, or they may have been on maintenance therapy. Secondly, the wording of the participant information sheet did not acknowledge that pain language can be emotive, and the term 'pain' can be value laden. Björkman, Arnér and Hydén (2008) noted that cancer survivors themselves did not label or acknowledge their experiences as 'pain' and the authors commented that "it was striking how they (the women in the study) initially steered clear of or directly avoided calling their sensations pain, even though the sensations could cause them some discomfort" (Björkman, Arnér and Hydén, 2008, p.1021). Thus, participants may not have recognised themselves as having 'pain' and/or 'persistent pain'. Hovind and colleagues (2013) found most cancer survivors in their study did not view their persistent pain as 'chronic' as they believed it was going to get better. Therefore, if this study were to be repeated, it would be helpful to change the participant information sheet wording to reflect aspects of the complexity of pain language. Finally, whilst the recruitment strategy included four strands of recruitment, additional late effects organisations could have been approached, such as the Pelvic Radiation Disease Association (https://www.prda.org.uk/).

Chapter two of this thesis demonstrated that research into the experience of cancer survivors living with chronic pain after cancer treatment has focused exclusively on breast cancer survivors (Armoogum *et al.*, 2020). Efforts were made during recruitment to this study to include participants with a multiplicity of different cancers, however, over half of the final sample included women with breast cancer. Reasons for this may include that people with breast cancer equate to the highest proportion of people living in chronic pain after cancer (Van Den Beuken-Van Everdingen *et al.*, 2016) and less than 1% of breast cancers are in men (Ali Jad Abdelwahab, 2017). Furthermore, cancer survivors were required to self-identify as having chronic pain after cancer treatment to participate in this study. Gendered norms may have contributed as male patients can be seen as stoic and more likely to deny pain (Samulowitz *et al.*, 2018). Therefore, male cancer survivors might not have considered this study relevant to them. Also, in this study, recruitment was strongest from centres who saw more women with breast cancer compared to other cancers or men.

3.8: Conclusions

This study has demonstrated that living with chronic pain after cancer treatment has detrimental effects on many aspects of people's lives. Survivors did not feel informed or prepared for the risk or reality of chronic pain after cancer treatment and this compounded the difficulties of coping with and managing their pain. Survivors felt that they had not been listened to when they tried to talk about their chronic pain after cancer treatment, nor at times, believed. They felt healthcare professionals lacked knowledge and understanding regarding chronic pain after cancer treatment. Survivors encountered unclear and limited pathways for support and often bounced from one support team to another. Identifying and accessing services was a challenge, and the responsibility of this was often left to the survivor. However, palpable relief and benefit was felt when healthcare professionals diagnosed and acknowledged chronic pain after cancer treatment.

This study highlighted that cancer survivors do not feel healthcare professionals are very knowledgeable about chronic pain after cancer treatment or have understanding of the impact of living with chronic pain. Further research is needed to better understand healthcare professionals' knowledge, understanding and confidence to support people with chronic pain after cancer treatment. Healthcare professionals need to acknowledge and diagnose chronic pain after cancer treatment because, as this study has demonstrated, this can provide considerable support, relief and benefit to those affected. The following chapter describes a study that explores healthcare professionals' knowledge and understanding of chronic pain after cancer treatment.

Chapter 4: Healthcare professionals' views regarding chronic pain after cancer treatment in cancer survivors: knowledge, understanding, experience and confidence.

4.1: Introduction

The previous chapter demonstrated that living with chronic pain after cancer treatment has detrimental effects on many aspects of cancer survivors' lives. Yet they felt they had not been informed or prepared for the risk or reality of chronic pain after cancer treatment by healthcare professionals. Nor had it seemed to them that healthcare professionals had sufficient knowledge and understanding regarding chronic pain after cancer treatment. Cancer survivors explained that they had not felt listened to or believed when talking to healthcare professionals about their pain and had encountered resistance from them to talk about it. Many felt abandoned at the end of treatment and ill-informed about the risks and signs of chronic pain after cancer treatment and found it challenging to identify and receive support. These experiences were from the perspectives of the cancer survivors. It is important to give healthcare professionals a 'right to reply' and investigate this from the view of the healthcare professionals. To do this, a study was conceptualised, designed, and conducted to explore healthcare professionals' knowledge, understanding and confidence about chronic pain after cancer treatment.

Limited literature has been identified examining healthcare professionals' knowledge and understanding of chronic pain after cancer treatment. A research team from Belgium recently conducted a qualitative study with 22 healthcare professionals, split into four focus groups, exploring healthcare providers perceptions regarding the prevention and treatment of chronic pain in breast cancer survivors (Slaghmuylder *et al.*, 2022). They found insufficient knowledge about chronic pain in breast cancer survivors to be a common hindering factor in breast care follow up. In a systematic review of 12 studies, with 3,574 participants, Bouya *et al.* (2019) found oncology nurses had poor levels of cancer-related pain knowledge. In primary care, lack of knowledge in long term cancer care can be a barrier to implementing a cancer care review (Gopal *et al.*, 2022). Walter *et al.* (2015) asked 500 GPs about their current practice and views of cancer survivorship care in England, UK, and only just over a quarter (29%) felt very confident about managing treatment related side effects. In a scoping review of barriers to primary care led cancer survivorship care, lack of knowledge was the barrier cited in the most papers (Hayes *et al.*, 2022). Similarly, many practice nurses do not feel confident supporting the management of pain as a side effect of cancer treatment (Dyer and Dewhurst, 2020). Whilst this demonstrates a lack of confidence from nurses and doctors, research has shown that cancer survivors seek advice and support from a range of healthcare professionals during their cancer treatment and beyond, including nurses, doctors, allied health professionals and support workers (NHS England, 2019; Macmillan Cancer Support, 2017a, 2017b). Thus, it is important to establish different healthcare professionals' knowledge, understanding, experience and confidence about chronic pain after cancer treatment as this will impact on the information and support they give to people living with and beyond cancer.

This chapter describes a quantitative study aiming to investigate healthcare professionals’ knowledge, understanding and experience of chronic pain after cancer treatment. Furthermore, it will determine their levels of confidence regarding discussing chronic pain after cancer treatment with people living with and beyond cancer.

4.2: Research questions

Primary research question:

- What understanding and experience do healthcare professionals have about chronic pain after cancer treatment and how confident do they feel to inform, listen and signpost people living with and beyond cancer about it?

The secondary research questions are:

- What awareness do healthcare professionals have about the prevalence, risk, impact, and experience of cancer survivors living in chronic pain after cancer treatment?
- Where, when and by whom do healthcare professionals think people living with and beyond cancer should be informed about the potential of chronic pain after cancer treatment?
- What factors may prevent healthcare professionals from discussing chronic pain after cancer treatment with those living with and beyond cancer?

4.3: Methodology

Research Design

Quantitative research uses numerical data to answer research questions or test hypotheses with an aim to generalise the findings to the wider population (Green and Thorogood, 2018; Bowling, 2014; Cresswell and Plano Clark, 2007). Survey research is a research design often employed within quantitative research (Cresswell and Plano Clark, 2007). The majority of survey questionnaires consist of closed questions whereby participants select a response from a fixed number of options (O’Cathain and Thomas, 2004). It is not uncommon for surveys to include one or more open questions where participants are invited to provide information in a free text format, for example ‘is there anything else you would like to say?’ (O’Cathain and Thomas, 2004). Use of such questions can provide participants with opportunity to expand on their answers or voice an opinion and can help identity issues not covered by the closed questions (Singer and Couper, 2017; O’Cathain and Thomas, 2004). However, open ended questions in a quantitative survey can cause problems with respect to analysis as they are ‘strictly neither qualitative or quantitative data’ (O’Cathain and Thomas, 2004, p.2). Mixed method research combines qualitative and quantitative approaches and focuses on collecting, analysing and mixing both qualitative and quantitative data (Cresswell and Plano Clark, 2007). Whilst it is acknowledged that ‘merely adding an open-ended qualitative question to an otherwise quantitively designed questionnaire does not constitute mixed method research’ (McKenna, Copnell and Smith, 2021, p.582) and thus such an approach does not qualify as mixed method research, it is recognised that including a small qualitative component to a quantitative survey can afford participants opportunity to provide supplementary information and additional insights (Leufer and Cleary-Holdforth, 2020).

When designing quantitative surveys that include open ended questions it is important to have a strategy for analysis based on the depth of responses received. If the responses corroborate or slightly elaborate upon the answers to the closed questions, it may not be appropriate to conduct any formal analysis, however, O’Cathain and Thomas (2004) state that it is good practice within publications and reports to acknowledge if free text questions did not provide additional information. They recommend that if new insights are given by the responses to the closed questions then formal analysis should take place and content analysis is an appropriate strategy in such circumstances.

4.4: Method

A 19 question online survey was distributed to healthcare professionals working with people living with and beyond cancer. The survey was distributed via the online platform Qualtrics.

Development of survey tool

The development of the survey stemmed from findings from the previous two chapters of this thesis. The studies outlined in chapters two and three demonstrated that cancer survivors perceive healthcare professionals do not have appropriate knowledge and understanding of chronic pain after cancer treatment. To investigate this assertion, it was decided to develop a survey to specifically identify healthcare professionals' knowledge and understanding of chronic pain in cancer survivors. No standardised, validated tools exist to measure this and therefore a tool needed to be developed. Thus, an online survey was developed based on the existing published literature, findings from the qualitative evidence synthesis outlined in chapter two, the qualitative study described in chapter three, and discussions with experts in the field. To increase reliability and validity, the survey was extensively piloted with relevant healthcare professionals. Their feedback (see Appendix 18) informed the final survey text and format.

To identify knowledge about chronic pain after cancer treatment, participants were asked a series of factual questions about prevalence rates, timing, causes and risks of chronic pain after cancer treatment. These included a multiple-choice question about the percentage of cancer survivors who experience chronic pain after cancer treatment has ended. Participants could select a range of answers such as ‘up to 10%’, ‘between 10-20%’, ‘between 30-40%’, ‘between 40-50%’, ‘between 50-60%’, ‘over 60%’ and ‘I don’t know’. Based on literature, in this study, the percentage of cancer survivors experiencing chronic pain after cancer treatment was taken to be 30-40% (Jiang et al., 2019; Van Den Beuken-Van Everdingen et al., 2016). Multiple choice questions were also posed for severity of chronic pain, when chronic pain arising from cancer treatment can occur, what cancer treatments can cause chronic pain after cancer treatment, and which cancers can lead to chronic pain after cancer treatment.

To identify knowledge about the risks of chronic pain after cancer treatment, participants were given factual statements about risks associated with gender, age, Body Mass Index (BMI), pre-existing anxiety and timing of pain, and were asked to select if they felt they were true or false (Lim et al., 2022; Cramer, Johnson and Nilsen, 2018; Hamood et al., 2018; Leysen et al., 2017; Wang et al., 2016; Bruce et al., 2014; Schreiber, 2014).

The survey also sought to identify healthcare professionals’ understanding of the impact of living with chronic pain on cancer survivors’ lives. Much consideration was given to how best to capture this. Based on recommendations from the supervisory team, twenty direct patient statements, taken from the interview transcripts from the cancer survivor study, were quoted in the survey. Participants were invited to select if they thought the statements were from cancer survivors living with chronic pain after cancer treatment, people living with non-malignant chronic pain, or both. As the statements were taken directly from the interview data described in chapter three, all statements came from cancer survivors living with chronic pain after cancer treatment. The questions were designed in that way to determine if participants understood the breadth of impact that living with chronic pain after cancer treatment can have on cancer survivors.

To identify variation in participants' clinical experiences of chronic pain after cancer treatment, the same cancer survivor statements were given, and participants were asked to move a slider to indicate the extent they have come across the patient experience in their clinical practice. It was important to capture confidence levels and thus slider questions were included asking participants to rank their confidence regarding talking, signposting and listening to cancer survivors living with chronic pain after cancer treatment. A multiple choice question was included to identify barriers to talking to people about chronic pain after cancer treatment. Responses were garnered from the literature, expertise within the team and free text responses given by participants in the pilot studies. The final question was an open question with a free text response option. Participants were asked 'Is there anything else you feel is relevant or important about this area of research? Please comment'. A copy of the survey can be found in appendix 19.

A good survey is carefully crafted for a specific purpose with a focus on content, questions, wording, order and format and is then pretested and revised (Jacobsen, 2021). Decisions regarding the look and feel of a survey, including the types of questions, the answer categories and ordering of questions, can have a profound effect on the data obtained (Toepoel, 2017). A range of questions were used to engage participants including multiple choice, true or false, Likert scale and sliding scale (Pallant, 2020). Most questions were closed ended as these are quicker to complete, and the answers are easier to analyse, however, this meant there was no opportunity to probe the answers. The main disadvantage of closed questions is that they may force the participants to select a response that does not truly express their status or opinions (Jacobsen, 2021). To minimise this risk, the question responses were extensively piloted and participants were given the choice to opt for an ‘I don’t know’ answer or a free text choice of ‘other’, if they wanted to add an additional comment. Jacobsen (2021) suggests adding an ‘I don’t know’ option may increase the percentage of participants who complete the whole survey rather than quit mid-way through. Circular tick boxes, known as ‘radio buttons’ were used for multiple choice questions as these can be seen to be more visually appealing compared to boxes (Toepoel and Funke, 2018) and were the standard approach used by the software. Clear instructions were given to explain to participants if they could select one or more answer. To minimise accidental non-completion, participants were reminded if they missed a question and asked if they wanted to return to answer the question or proceed. Jacobsen (2021) cautions against this as participants may leave the survey if forced to answer all questions. In this survey, a forced response was only requested once, for consent (see below).

Pilot testing

Pilot testing a survey enables researchers to check the wording, clarity and order of survey questions, the ability and willingness of participants to answer the questions, the responses given (and if these match the intended types of responses), and the amount of time it takes to complete the survey (Jacobsen, 2021). The survey was piloted with 48 people including:

- 26 healthcare professionals studying an MSc module in advancing practice in long term conditions
- Six final year undergraduate nurses with experience and interest in cancer care
- Three hospital based cancer nurses
- A community cancer nurse
- Four nursing and allied healthcare professional educators (one based in an Intensive Care Unit, three based in a university setting)
- A hospice manager and registered nurse
- A GP
- Four PhD supervisors with expertise in nursing and/or health psychology
- Two public contributors, who are cancer survivors living with chronic pain

The pilot studies were conducted in a variety of ways:

- Two focus groups whereby healthcare professionals (n=26) or final year nursing undergraduate nurses (n=6) completed the survey online and then discussed the content and questions as a group facilitated by JA
- Three PhD supervisory meetings in which the supervisors completed the survey online and then gave written feedback and discussed as a group with JA
- Two public contributors completed the survey online and gave written feedback and discussed this feedback in a group with JA

- Ten healthcare professionals were emailed the survey and gave JA either written or verbal feedback

After each pilot study, the survey was revised based on the recommendations. A summary of amendments is in appendix 18. Feedback from the pilot studies demonstrated that the questions were deemed very relevant, the survey was easy to navigate with a good range of question types, was a suitable length, and was enjoyable to do.

Inclusion criteria

- Healthcare professionals working in the UK with and/or caring for people living with and beyond cancer who may experience, or be at risk of, chronic pain after cancer treatment
- Able to communicate in the English language

Cancer survivors seek advice from a range of healthcare professionals (NHS England, 2019; Macmillan Cancer Support, 2017a, 2017b) therefore anyone working with people living with and beyond cancer in a health-related supportive role was eligible for the study e.g., nurse, doctor, allied health professional, cancer support worker. Participants were asked to verify which area of the UK they worked in during the demographic section of the survey.

Size of sample

The survey was open for six weeks with active advertising and recruitment continuing throughout this time. There was no limit to the sample size, but if there had been less than 50 respondents, the recruitment window would have been extended by three weeks. These time restraints were selected due to time available within the PhD and other work commitments. It is acknowledged that time is a resource limitation many PhD students face, as they have a certain time to complete their thesis, and often conduct multiple lines of enquiry simultaneously (Lakens, 2022).

Recruitment

The NCRI Living With and Beyond Cancer Group, the British Pain Society, the Pain Nurse Network, the UK Oncology Nursing Society (UKONS) and the General Practice Nurse Education Network all agreed to distribute the survey on their social media platforms. Furthermore, a number of Cancer Alliances, Macmillan GPs and Lead Cancer Nurses shared the survey with their staff. Charities such as Penny Brohn UK, Maggie's, Action Radiotherapy and Pelvic Radiation Disease Association (PRDA) shared the survey on their social media platforms. The survey was shared on the researcher's and PhD supervisors' Twitter feeds.

Consent

The welcome screen briefly outlined the aims of the survey and participants were asked to read and download a Participant Information Sheet (Appendix 20) and Privacy Notice. Participants were asked to select either 'Yes, I do consent' or 'No, I do not consent'. Participants were forced to answer this question before they proceeded and depending on their answer, they were either taken to the survey or to a thank you page.

Analysis

Quantitative data were exported from the Qualtrics platform, entered into the statistical analysis software programme SPSS (version 28.0.1.1 (15)) and analysed using descriptive statistics. Chi squared tests for independence is a non-parametric test suitable for when there are two categorical variables with two or more categories in each (Pallant, 2020). Chi squared tests for independence were used to look for associations within the data where appropriate including:

- To establish if there was an association between participants who thought the patient statement came from a cancer survivor with chronic pain, person with non -malignant pain or both, and demographic groups
- To establish if there was an association between participants who thought it was their role to talk to people living with and beyond cancer about the potential of chronic pain after cancer treatment, and demographic groups
- To establish if there was an association between talking, listening and signposting about chronic pain, and demographic groups

A Kruskal-Wallis non-parametric test was applied when there are two variables, one categorical independent variable with three or more categories and a continuous dependent variable (Pallant, 2020). This test was used to establish if there was an association between confidence levels and demographic groups.

Free text comments were analysed using inductive content analysis to provide a descriptive analysis (Elo and Kyngäs, 2008). Content analysis is a suitable method of analysis when free text questions are used in a quantitative survey (O'Cathain and Thomas, 2004). Inductive qualitative content analysis involves three phases: preparing, organising and reporting (Elo *et al.*, 2014; Elo and Kyngäs, 2008; Graneheim and Lundman, 2004). During the preparation phase, units of analysis were selected, and the researcher strived to make sense of the data and obtain a sense of the whole. The organising phase involved open coding, grouping and categorisation of the data followed by abstraction (formulation of a general description of the topic through generated categories). Final categories were then reported (Elo *et al.*, 2014; Elo and Kyngäs, 2008; Graneheim and Lundman, 2004).

Patient and public involvement

Two public contributors, who are cancer survivors living with chronic pain after cancer treatment and who had commented on previous research in this PhD were involved with the development of this study. They commented on research aims, research questions, inclusion criteria and piloted the survey. An evaluation of the impact of their role on the research is described in chapter six.

Ethical and regulatory considerations

A full UWE risk analysis (Reference R4707), UWE Research Governance Record (Reference 833) and Data Management Plan were all completed and maintained throughout the study. Ethical approval from UWE Research Ethics Committee was granted on 7th May 2021 (UWE REC REF No: HAS 21.02.109, Appendix 21). The study was sponsored by the University of the West of England, Bristol and was covered by the University's Professional Indemnity Insurance.

4.5: Results

Key findings

This study found healthcare professionals had limited knowledge and understanding of chronic pain after cancer treatment. Whilst many thought it was, or might be, their role to talk to people living with and beyond cancer about chronic pain after cancer treatment, almost a quarter reported they rarely or never did. Healthcare professionals lacked confidence to talk to people about chronic pain after cancer treatment and viewed their lack of knowledge as a barrier.

Study participants

A total of 135 healthcare professionals submitted responses to the online survey (table 13) comprising 51.9% (n=70) nurses, 26.7% (n=36) allied health professionals (AHP), 14.8% (n=20) doctors and 6.9% (n=9) other healthcare professionals (educators, cancer support workers and clinical fellows). Most worked in a hospital setting (79.3%, n=107), 17.0% (n=23) in the community and 3.17% (n=5) in education. Almost half, (49.6%, n=67) were involved with people living with and beyond cancer (LWBC) for more than 75% of their main professional role and most had worked with people living with and beyond cancer for over 11 years (56.3%, n=76). Participants mainly worked in England (83.0%, n=112) but the other countries of the UK were also represented: Scotland (11.1%, n=15), Northern Ireland (3.0%, n=4) and Wales (2.2%, n=3).

Fifty-two participants (38.5%) provided 70 separate free text comments within the online survey. Of these, 28 (53.8%) were nurses, 14 (26.9%) were AHPs, eight (15.4%) were doctors and two (3.4%) were other professionals. 41 (78.8%) worked in a hospital setting, nine (17.3%) worked in the community and two (3.8%) in educational settings. This was reflective of the overall study sample.

Twenty-nine participants (21.5%) submitted incomplete responses to the whole survey: they completed the sections about knowledge including prevalence, severity, risks and timing, but did not answer the questions about understanding or reflections on their own practice. The demographics were broadly similar between those who completed the whole survey and the attrition group. Differences in demographics between the whole sample (n=135) and the 'attrition' sample (n=29) are presented in table 14.

Table 13: Sample demographics

Group or setting		n	%
Professional group	Nurse	70	51.9
	AHP	36	26.7
	Doctor	20	14.8
	Other	9	6.7
	Total	135	100.0
Workplace setting	Hospital	107	79.3
	Community	23	17.0
	Education	5	3.7
	Total	135	100.0
Proportion of main professional role involving people who are LWBC	More than 75%	67	49.6
	50-75%	23	17.0
	About 50%	14	10.4
	25-50%	11	8.1
	Less than 25%	20	14.8
	Total	135	100.0
Length of time working with people who may be LWBC	Up to 5 years	33	24.4
	6-10 years	26	19.3
	Over 11 years	76	56.3
	Total	135	100.0
Area of the UK	Northern Ireland	4	3.0
	Scotland	15	11.1
	Wales	3	2.2
	England	112	83.0
	No response	1	0.7
	Total	135	100.0

Table 14: Demographics of whole sample (n=135) compared to attrition sample (n=29)

Group or setting		Whole sample (n = 135)		'Attrition' sample (n = 29)	
		N	%	N	%
Professional group	Nurse	70	51.9	14	48.3
	AHP	36	26.7	6	20.7
	Doctor	20	14.8	6	20.7
	Other	9	6.7	3	10.3
	Total	135	100.0	29	100.0
Workplace setting	Hospital	107	79.3	22	75.9
	Community	23	17.0	6	20.7
	Education	5	3.7	1	3.4

	Total	135	100.0	29	100.0

Knowledge of chronic pain in cancer survivors

Participants were asked about the prevalence, severity, risks and timing of chronic pain after cancer treatment.

Knowledge of prevalence and severity

Participants were asked, in their opinion, what percentage of cancer survivors experience chronic pain after their cancer treatment has ended. 20% (n=27) identified a prevalence rate of 30-40%. Similar levels of identification of prevalence were seen across professional groups, workplace settings and proportion of role involving people living with and beyond cancer (table 15).

Table 15: Identification of prevalence of chronic pain in cancer survivors

Group or setting		Total number of participants	Identified that 30-40% of cancer survivors experience chronic pain*	
		n	n	%
Professional group	Nurse	70	16	22.9
	AHP	36	8	22.2
	Doctor	20	1	5.0
	Other	9	2	22.2
Workplace setting	Total	135	27	20.0
	Hospital	107	20	18.7
	Community	23	6	26.1
	Education	5	1	20.0
	Total	135	27	20.0
Proportion of role involving people LWBC	More than 75%	67	13	19.4
	50-75%	23	3	13.0
	About 50%	14	4	28.6
	25-50%	11	1	9.1
	Less than 25%	20	6	30.0
	Total	135	27	20.0

*= Prevalence rate identified in the literature (Jiang *et al.*, 2019; Van Den Beuken-Van Everdingen *et al.*, 2016)

Participants were asked how many cancer survivors living with chronic pain would describe their pain as moderate or severe and 21.5% (n=29) stated 20-30% of cancer survivors living in chronic pain would describe their pain as moderate or severe (table 16). A fifth (20.9%, n=14) of those working with people living with and beyond cancer for more than 75% of their main professional role identified that 20-30% of cancer survivors living with chronic pain would describe it as moderate or severe (table 16).

Table 16: Identification of severity of chronic pain in cancer survivors

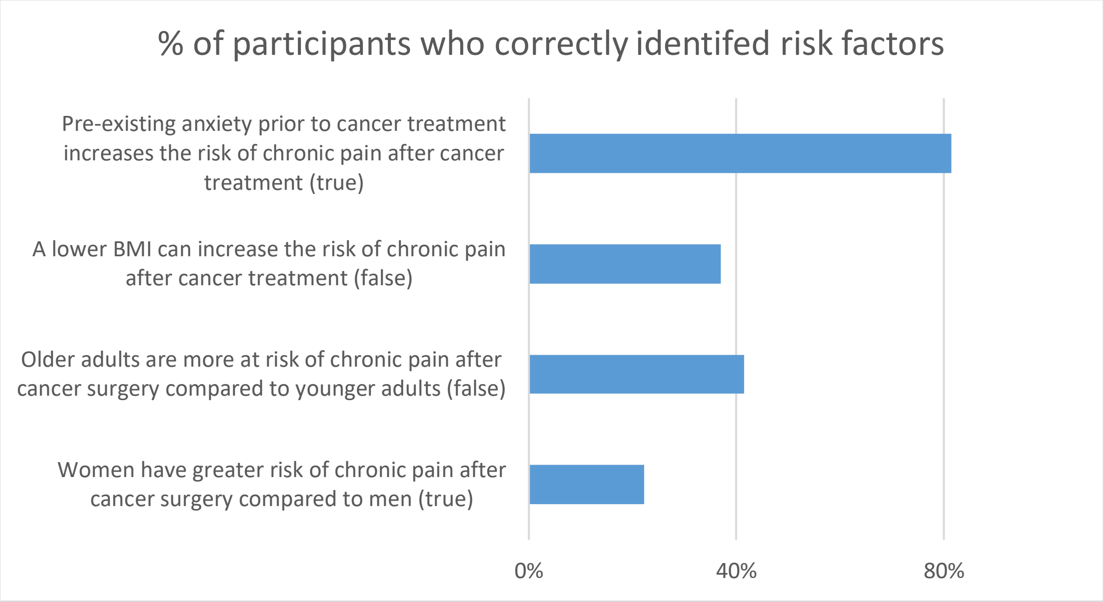
Group or setting		Total number of participants	Identified that 20-30% of cancer survivors would describe their pain as moderate to severe*	
		n	n	%
Professional group	Nurse	70	17	24.3
	AHP	36	4	11.1
	Doctor	20	7	35.0
	Other	9	1	11.1
	Total	135	29	21.5
Workplace setting	Hospital	107	24	22.4
	Community	23	3	13.0
	Education	5	2	40.0
	Total	135	29	21.5
Proportion of role involving people LWBC	More than 75%	67	14	20.9
	50-75%	23	9	39.1
	About 50%	14	2	14.3
	25-50%	11	1	9.1
	Less than 25%	20	3	15.0
	Total	135	29	21.5

*= severity rate identified in the literature (Van Den Beuken-Van Everdingen *et al.*, 2016)

Knowledge of risk factors

Participants were presented with factual statements relating to risks associated with chronic pain after cancer treatment. Figure 5 highlights the percentage of participants who correctly identified if the factual statements were true or false. 81.5% (n=110) identified that pre-existing anxiety increases the risk of chronic pain after cancer treatment. 41.5% (n=56) knew older adults are not more at risk of chronic pain after cancer treatment and 37.0% (n=50) knew that a lower BMI does not increase the risk of chronic pain after cancer treatment. 77.8% (n=105) did not know women are at greater risk of chronic pain after cancer surgery compared to men (Lim *et al.*, 2022; Cramer, Johnson and Nilsen, 2018; Hamood *et al.*, 2018; Leysen *et al.*, 2017; Wang *et al.*, 2016; Bruce *et al.*, 2014; Schreiber, 2014).

Figure 5: % of participants who correctly identified factual statements to be true or false



Knowledge of timing

Over three quarters of participants (77%, n=104) identified that chronic pain that starts years after cancer treatment has ended can be related to previous cancer treatment, 18% (n=24) did not know and 5% (n=7) said it could not. This was broadly reflected across professional groups and workplace settings (table 17) however, a greater proportion of doctors (85%, n=17) and those working in the community (82.6%, n=19) identified that it can be related. 25.4% (n=17) of those whose main professional role involves people living with and beyond cancer for more than 75% of the time, either did not know chronic pain that starts years after cancer treatment has ended can be related to previous cancer treatment or stated it could not.

Table 17: Awareness that chronic pain after cancer treatment that starts years after cancer treatment has ended can be related to previous cancer treatment

Group or setting		Participants who stated that chronic pain that starts years after cancer treatment has ended can be related to previous cancer treatment	
		n/total in sample	%
Professional group	Nurse	53/70	75.7
	AHP	27/36	75.0
	Doctor	17/20	85.0
	Other	7/9	77.8
Workplace setting	Hospital	81/107	75.7
	Community	19/23	82.6
	Education	4/5	80.0
Proportion of role	More than 75%	50/67	74.6
	50-75%	18/23	78.3
	About 50%	9/14	64.3
	25-50%	9/11	81.8
	Less than 25%	18/20	90.0

Differences in knowledge between whole sample and 'attrition' sample

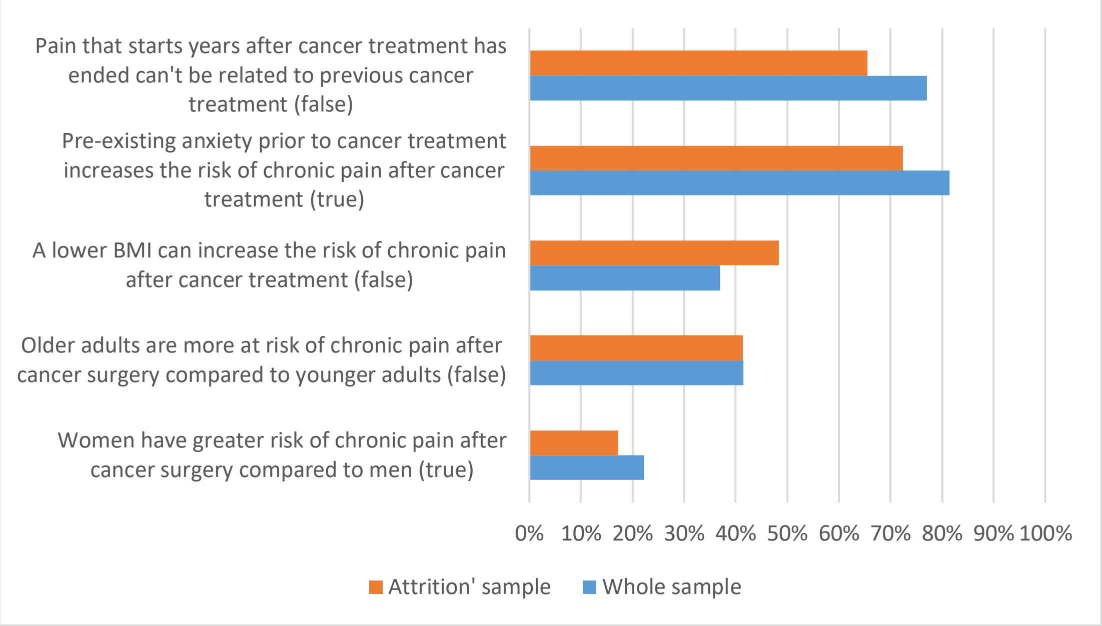
Some participants did not complete the whole survey (n=29). Differences in responses to the knowledge questions between the whole sample (n=135) and the 'attrition' sample (n=29) are presented in tables 18 and figure 6.

Table 18: Identification of prevalence and severity of chronic pain in cancer survivors by whole sample and 'attrition' sample

Fact	Whole sample (n = 135)		'Attrition' sample (n = 29)	
	n	%	n	%
Identified that 30-40% of cancer survivors experience chronic pain*	27	20.0	6	20.7
Identified that 20-30% of cancer survivors would describe their pain as moderate to severe*[1]	29	21.5	11	37.9

*= Prevalence rate identified in the literature (Jiang *et al.*, 2019; Van Den Beuken-Van Everdingen *et al.*, 2016) *[1] = Severity rate identified in the literature (Van Den Beuken-Van Everdingen *et al.*, 2016)

Figure 6: Comparison of responses to factual statements between whole sample and 'attrition' sample



Understanding of experiences of cancer survivors living with chronic pain

A hundred and six participants responded to the survey questions exploring their understanding of the experience of living with chronic pain after cancer treatment. Participant responses to individual statements are reported in table 19. Nearly all participants recognised the statement *'It's like basically my confidence is shot – and by 'confidence' I mean physically, socially, professionally, sexually, and spiritually'* could have originated from a cancer survivor living with chronic pain after cancer treatment (n=25, 23.6%) or both a cancer survivor and a person living with non-malignant pain (n=74, 69.8%). Almost a third (n-32, 30.2%) thought the statement *'You feel as if you're a liar. It's as if they (healthcare professionals) don't believe you'* did not come from a cancer survivor living with chronic pain after cancer treatment. Approximately a fifth thought '*Nobody (healthcare professionals) really, when it happened to me, wanted to know about it'* (n=23, 21.7%) and *'Nobody is there to tell you at all about where to go for help'* (n=20, 18.9%) were from cancer survivors living with chronic pain after cancer treatment.

Table 19: Participants' views on the source of patient statements

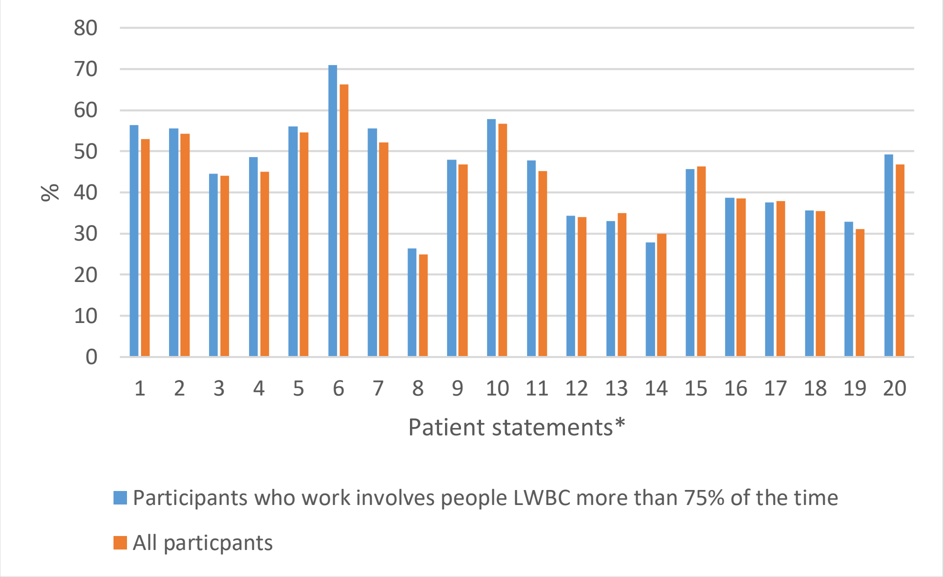
Patient statement	**Statement source**									
	CS*		NMP*		Both		NR*		Total	
	n	%	n	%	n	%	n	%	n	%
1. Living in chronic pain affects every aspect of my life	4	3.8	7	6.6	95	89.6	0	0	106	100
2. You just feel really alone	10	9.4	5	4.7	88	83.0	3	2.8	106	100
3. My life has got smaller and smaller	8	7.5	5	4.7	89	84.0	4	3.8	106	100
4. Everything I have enjoyed, I've lost	10	9.4	6	5.7	85	80.2	5	4.7	106	100
5. It's like basically my confidence is shot – and by 'confidence' I mean physically, socially, professionally, sexually, and spiritually	25	23.6	2	1.9	74	69.8	5	4.7	106	100
6. That fear is horrendous. It's still there. Five years down the line or six years down the line, I'm still… Every time I get a particular bad pain I think "the cancer, it's back again"	96	90.6	5	4.7	5	4.7	0	0	106	100
7. It is rough. It's rough every single day. When I wake up in the middle of the night, I think, "Oh, my God, this is going to go on forever. It's always going to be the same. I'm never going to not be in any pain	13	12.3	15	14.2	73	68.9	5	4.7	106	100
8. I've actually lost four inches in height… it's psychologically so difficult to look at somebody in the chest when you used to look at them in the eye. .. you know, it's very very silly… but erm, you do feel a little bit inferior	23	21.7	27	25.5	51	48.1	5	4.7	106	100
9. I mean I now feel that to me, the cancer was much less bad than the after effects because …. I can no way lead a fairly normal life because I'm in pain constantly. So it's worse	89	84.0	12	11.3	5	4.7	0	0	106	100
10. The alternative was not very good, so I would have had all of the treatment anyway. I would rather be alive and in pain than not	91	85.8	10	9.4	5	4.7	0	0	106	100
11. The pain has taken away the joy and the pleasures of life that I had	3	2.8	19	17.9	79	74.5	5	4.7	106	100
12. I don't think I'd ever had one single conversation with anyone about pain at all…nothing was ever said about pain at all. I didn't have one single conversation with anyone about pain	52	49.1	11	10.4	38	35.8	5	4.7	106	100
13. You feel as if you're a liar. It's as if they (healthcare professionals) don't believe you	6	5.7	32	30.2	63	59.4	5	4.7	106	100
14. Nobody (healthcare professionals) really, when it happened to me, wanted to know about it	22	20.8	23	21.7	56	52.8	5	4.7	106	100
15. They say to you, basically, "We treat your cancer. Anything else, you have to go your GP." Then you go to your GP and they say, "ask them in oncology." Basically, you're stuffed because nobody really wants to know	93	87.7	1	0.9	7	6.6	5	4.7	106	100
16. An awful lot of it is you have to figure it out yourself	13	12.3	17	16.0	71	67.0	5	4.7	106	100
17. It is the feeling of being discarded and not having that, having somebody to discuss things with, I found difficult	29	27.4	15	14.2	57	53.8	5	4.7	106	100
18. Nobody seems to listen	2	1.9	10	9.4	89	84.0	5	4.7	106	100
19. Nobody is there to tell you at all about where to go for help	6	5.7	20	18.9	75	70.8	5	4.7	106	100
20. Then they (healthcare professionals) give me the name for it.. I just cried. It was like it was so amazing to have it understood that these particular kinds of pain associated with going through cancer were known and treatable in some ways, that they were not necessarily curable but that there were things that could help. It was amazing	82	77.4	3	2.8	16	15.1	5	4.7	106	100

CS* Cancer survivor living with chronic pain, NMP* Person with non-malignant chronic pain, NR* No response

No statistically significant associations were found between who the participant thought had said the statement (cancer survivor with chronic pain, person with non -malignant pain or both) and professional groups, workplace settings, length of time working with those living with and beyond cancer and proportion of role involving those living with and beyond cancer.

For 14 out of 20 statements, less than half of the participants had come across people living with and beyond cancer in their clinical practice who had experienced similar problems to those in the statements, including those whose role involves working with people living with and beyond cancer for more than 75% of the time (figure 7).

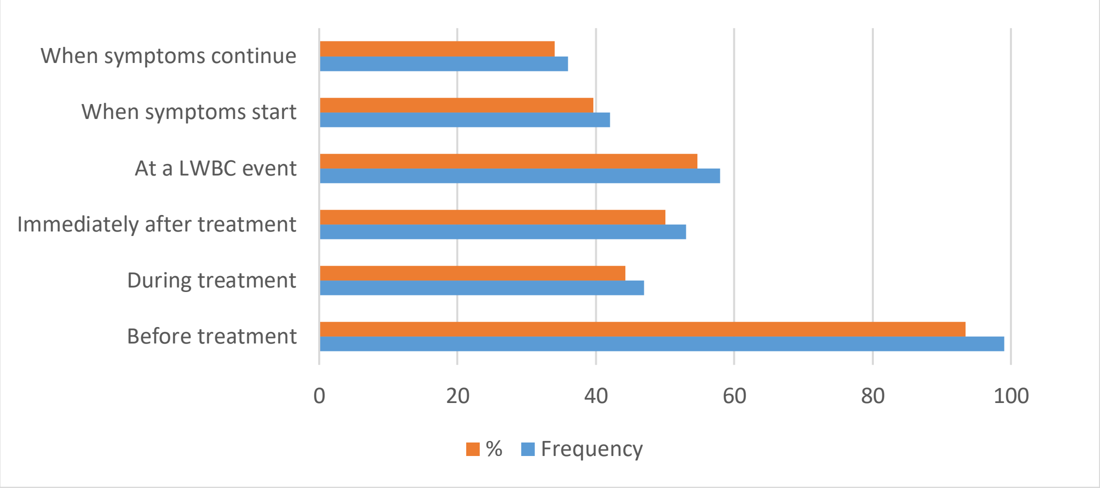
Figure 7: Extent participants had come across people living with and beyond cancer experiencing the patient statements in their clinical practice



Views on information and support

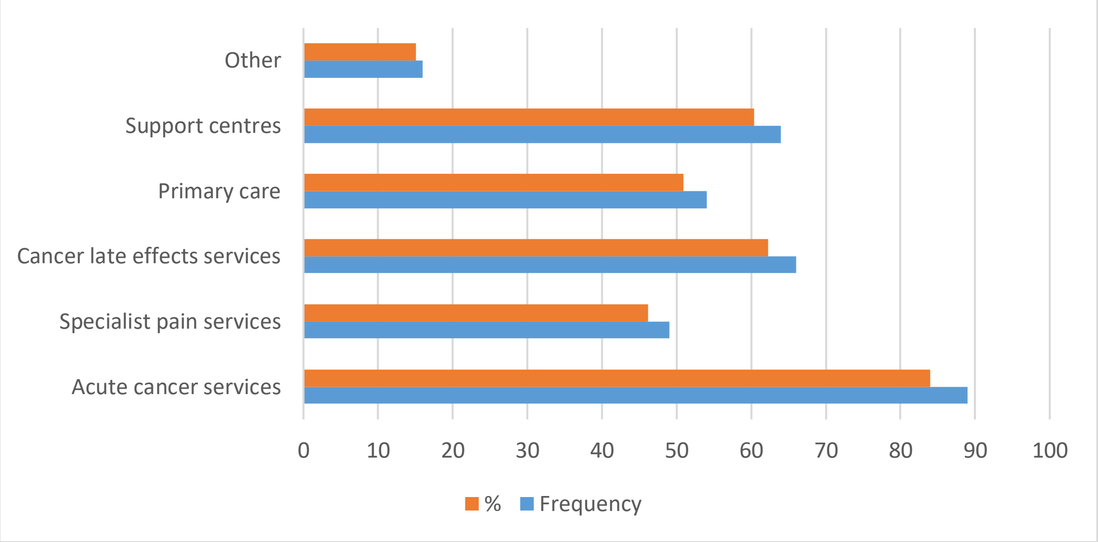
Almost all participants (93.4%, n=99) thought people living with and beyond cancer should be informed about the potential for chronic pain after cancer treatment before cancer treatment (n-99, 93.4%) and 54.7% (n=58) thought it should be at a living with and beyond cancer event (figure 8).

Figure 8: Timepoints participants thought people living with and beyond cancer should be informed about the potential of chronic pain after cancer treatment



Over 80% (n=89) said it was the role of acute cancer services to provide this information, 62.3% (n=66) thought it was the role of cancer late effects clinics, and 60.4% (n=64) said support centres. 46.2% (n=49) thought it should be specialist pain services (figure 9).

Figure 9: Clinical services participants thought should inform people living with and beyond cancer about the potential of chronic pain after cancer treatment



Within the free text comments, the main category for when information should be offered was 'Throughout the pathway but definitely before treatment'. Examples of comments include:

‘Prior to treatment… but everyone should be involved subsequently’ (Doctor, hospital setting)

‘We all play a role, however informed consent means discussing the potential chronic pain issue BEFORE treatment’ (Doctor, community setting)

‘Those undertaking or prescribing the treatments that cause the pain, everyone’s!’ (Nurse, hospital setting)

However, some thought it was not appropriate to discuss pain prior to treatment:

‘Often when someone is receiving treatment or facing a new diagnosis and isn't experiencing pain, discussing risks of chronic pain feels like an unnecessary burden to impose on the patient’ (Doctor, hospital setting)

‘(radiotherapy) doesn't feel like the right time…. to discuss it’ (AHP, hospital setting)

It was acknowledged that patients have a lot of information to take in before treatment, and they may not remember it all:

‘Sometimes these things aren’t discussed or sometimes they are but there is so much to take in that the patient doesn’t take it in (Doctor, community setting)

The importance of repeated information throughout the pathway was paramount:

‘if it is discussed (prior to treatment) but the information is so overwhelming that the patient doesn’t take it in….(it should be) during follow ups and discussions with Specialist cancer nurses’ (Doctor, community setting)

Reflection on own roles regarding people living with and beyond cancer and chronic pain

Over half of participants (54.7%, n=58) thought it was their role to talk to people living with and beyond cancer about the potential for chronic pain after cancer treatment and 39.6% (n=42) thought it might be. This was reflective across professional groups, workplace settings and those whose role involves working with people living with and beyond cancer for more than 75% of the time (table 20).

Table 20: Participants who think it is their role to talk to people living with and beyond cancer about the potential for chronic pain after cancer treatment

Group or setting		Yes		Maybe		No		NR*		Total	
		n	%	n	%	n	%	n	%	n	%
Professional group	Nurse	29	52.7	23	41.8	1	1.8	2	3.6	55	100
	AHP	18	60.0	10	33.3	2	6.7	0	0.0	30	100
	Doctor	8	57.1	6	42.9	0	0.0	0	0.0	14	100
	Other	3	42.9	3	42.9	1	14.3	0	0.0	7	100
	Total	58	54.7	42	39.6	4	3.8	2	1.9	106	100
Workplace setting	Hospital	43	52.4	34	41.5	3	3.7	2	2.4	82	100
	Community	12	60.0	8	40.0	0	0.0	0	0.0	20	100
	Education	3	75.0	0	0.0	1	25.0	0	0.0	4	100
	Total	58	54.7	42	39.6	4	3.8	2	1.9	106	100
Proportion of role involving people LBWC	More than 75%	29	56.9	20	39.2	2	3.9	0	0.0	51	100
	50-75%	8	47.1	6	35.3	2	11.8	1	5.9	17	100
	About 50%	6	54.5	5	45.5	0	0.0	0	0.0	11	100
	25-50%	4	40.0	5	50.0	0	0.0	1	10.0	10	100
	Less than 25%	11	64.7	6	35.3	0	0.0	0	0.0	17	100
	Total	58	54.7	42	39.6	4	3.8	2	1.9	106	100

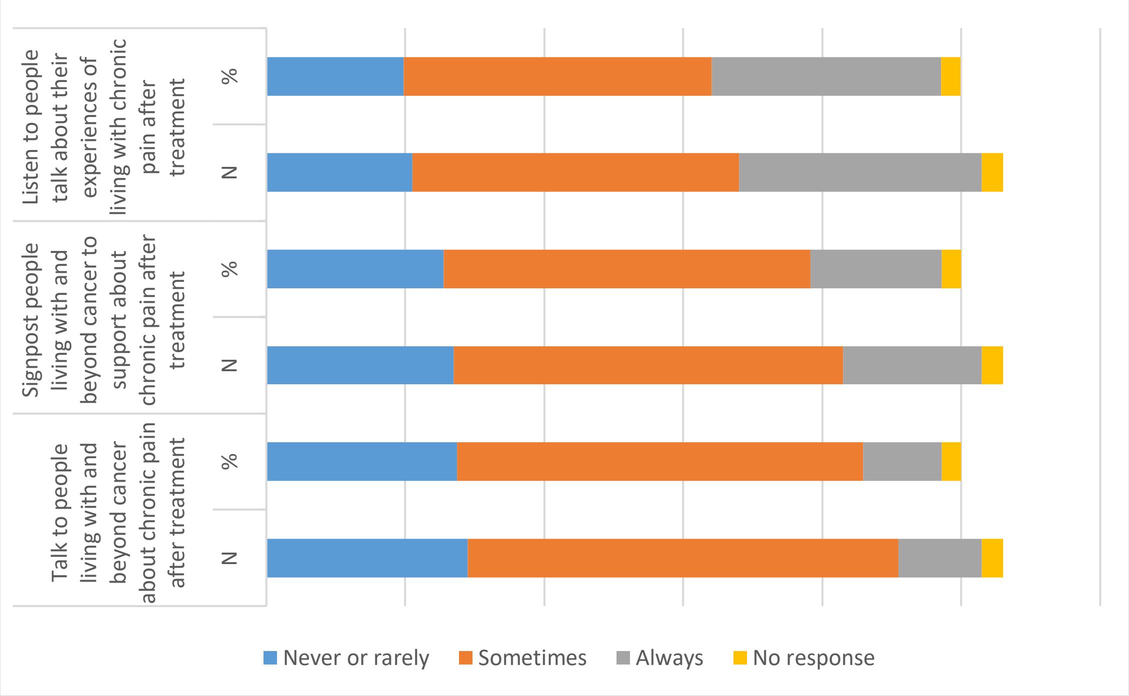
*NR – No response

There were no statistically significant associations between participants thinking it was their role to talk to people living with and beyond cancer about the potential of chronic pain after cancer treatment and professional groups, workplace setting, length of time working in cancer, nor proportion of role working with people living with and beyond cancer.

Participants were asked if they talk, signpost or listen to people living with and beyond cancer about chronic pain after cancer treatment:

- Talk: 58.5% (n=62) of participants reported they sometimes talk to people living with and beyond cancer about chronic pain after treatment, 27.4% (n=29) reported they never or rarely do, 11.3% (n=12) reported they always do and 2.8% (n=3) did not answer
- Signpost: 52.8% (n=56) reported they sometimes signpost people living with and beyond cancer to support about chronic pain after cancer treatment, 25.5% (n=27) reported they never or rarely do, 18.9% (n=20) reported they always do and 2.8% (n=3) did not answer
- Listen: 44.3% (n=47) reported they sometimes listen to people talk about their experiences of living with chronic pain after treatment, 33.0% (n=35) reported they always do, 19.8% (n=21) reported never or rarely do and 2.8% (n=3) did not answer (figure 10).

Figure 10: How often participants reported they talk, signpost or listen to people living with and beyond cancer about chronic pain after cancer treatment



Talking to people living with and beyond cancer about chronic pain after cancer treatment

Over a quarter (27.3%, n=15) of nurses, 50% (n=10) of healthcare professionals working in the community and 23.5% (n=12) of those working with people living with and beyond cancer for more than 75% of their role reported they rarely or never talk to people living with and beyond cancer about chronic pain after cancer treatment (table 21).

Table 21: How often participants reported they talk to people living with and beyond cancer about chronic pain after cancer treatment

Group or setting		Never/ Rarely		Sometimes		Always		NR*		Total	
		n	%	n	%	n	%	n	%	n	%
Professional group	Nurse	15	27.3	32	58.2	6	10.9	2	3.6	55	100
	AHP	8	26.7	18	60.0	4	13.3	0	0.0	30	100
	Doctor	3	21.4	9	64.3	2	14.3	0	0.0	14	100
	Other	3	42.9	4	57.1	0	0.0	0	0.0	7	100
	Total	29	27.4	63	59.4	12	11.3	2	1.9	106	100
Workplace setting	Hospital	18	22.0	51	62.2	11	13.4	2	2.4	82	100
	Community	10	50.0	9	45.0	1	5.0	0	0.0	20	100
	Education	1	25.0	3	75.0	0	0.0	0	0.0	4	100
	Total	29	35.4	63	59.4	12	11.3	2	1.9	106	100
Proportion of role	More than 75%	12	24.4	30	58.8	9	17.6	0	0.0	51	100
	50-75%	4	23.5	12	70.6	0	0.0	1	5.9	17	100
	About 50%	4	36.4	6	54.5	1	9.1	0	0.0	11	100
	25-50%	3	30.0	5	50.0	1	10.0	1	10.0	10	100
	Less than 25%	6	35.3	10	58.8	1	5.9	0	0.0	17	100

Signposting people living with and beyond cancer for support about chronic pain after cancer treatment

The majority of healthcare professionals reported they sometimes or always signpost people living with and beyond cancer for support about chronic pain after cancer treatment. Almost a third of allied health professionals (30%, n=9) and a quarter of nurses (n=14, 25.5%) reported they rarely or never signpost, neither do 22% (n=18) who work in the community or 19.6% (n=10) of those who work with people living with and beyond cancer for more than 75% of their main professional role (table 22)

Table 22: How often participants reported they signpost people living with and beyond cancer to support about chronic pain after cancer treatment

Group or setting		Never/ Rarely		Sometimes		Always		NR*		Total	
		n	%	n	%	n	%	n	%	n	%
Professional group	Nurse	14	25.5	31	56.4	8	14.5	2	3.6	55	100
	AHP	18	30.0	15	50.0	6	20.0	0	0.0	30	100
	Doctor	1	7.1	9	64.3	4	28.6	0	0.0	14	100
	Other	3	42.9	2	28.6	2	28.6	0	0.0	7	100
	Total	27	25.5	57	53.8	20	18.9	2	1.9	106	100
Workplace setting	Hospital	18	22.0	46	56.1	16	19.5	2	2.4	82	100
	Community	7	35.0	10	50.0	3	15.0	0	0	20	100
	Education	2	50.0	1	25.0	1	25.0	0	0	4	100
	Total	27	25.5	57	53.8	20	18.9	2	1.9	106	100
Proportion of role	More than 75%	10	19.6	30	58.8	11	21.6	0	0.0	51	100
	50-75%	6	35.3	9	52.9	1	5.9	1	5.9	17	100
	About 50%	3	27.3	5	45.5	3	27.3	0	0.0	11	100
	25-50%	2	20.0	6	60.0	1	10.0	1	10.0	10	100
	Less than 25%	6	35.3	7	41.2	4	23.5	0	0.0	17	100
	Total	27	25.5	57	53.8	20	18.9	2	1.9	106	100

Listening to people living with and beyond cancer talk about their experiences of chronic pain after cancer treatment

Most healthcare professionals reported they listen to people living with and beyond cancer talk about their experiences of chronic pain after cancer treatment sometimes or always. Over a fifth of nurses (21.8%, n=12), almost a fifth of those working with people living with and beyond cancer for more than 75% of their role (17.6%, n=9) and 85% (n=17) in the community reported they rarely or never do (table 23).

Table 23: How often participants reported they listen to people talk about their experiences of living with chronic pain after cancer treatment

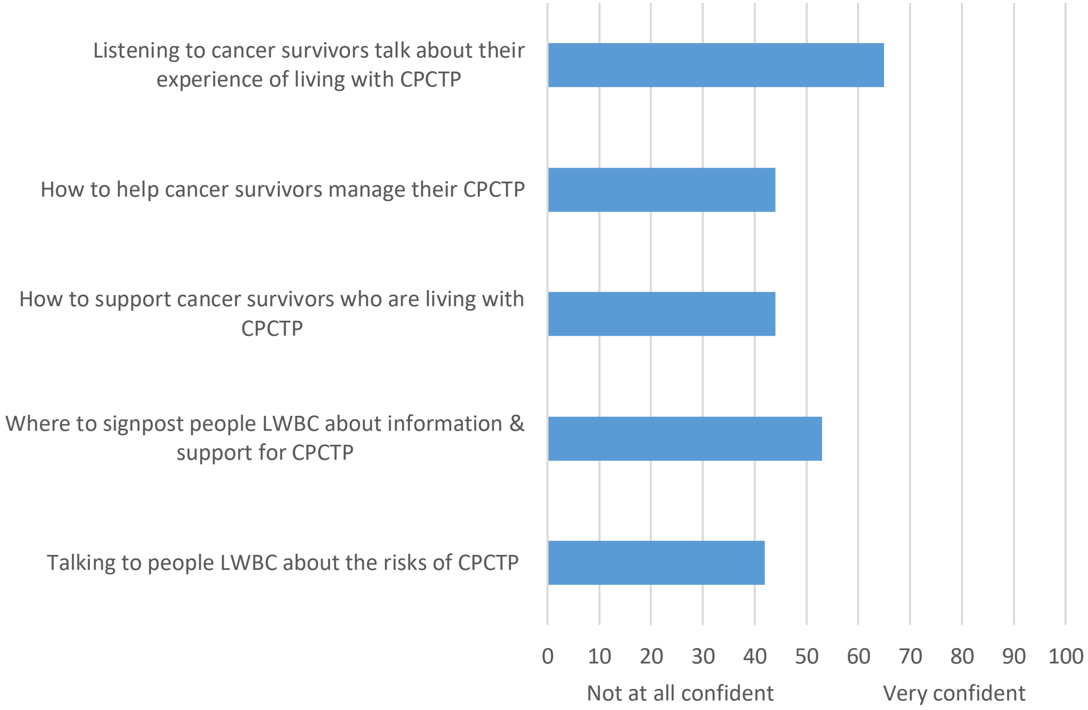
Group or setting		Never/ Rarely		Sometimes		Always		NR*		Total	
		n	%	n	%	n	%	n	%	n	%
Professional group	Nurse	12	21.8	25	45.5	16	29.1	2	3.6	55	100
	AHP	7	23.3	12	40.0	11	36.7	0	0.0	30	100
	Doctor	1	7.1	8	57.1	5	35.7	0	0.0	14	10
	Other	1	14.3	3	42.9	3	42.9	0	0.0	7	100
	Total	21	19.8	48	45.3	35	33.0	2	1.9	106	100
Workplace setting	Hospital	17	20.7	37	45.1	26	31.7	2	2.4	82	100
	Community	3	15.0	9	45.0	8	40.0	0	0.0	20	100
	Education	1	25.0	2	50.0	1	25.0	0	0.0	4	100
	Total	21	19.8	48	45.3	35	33.0	2	1.9	106	100
Proportion of role	More than 75%	9	17.6	24	47.1	18	35.3	0	0.0	51	100
	50-75%	4	23.5	7	41.2	5	29.4	1	5.9	17	100
	About 50%	3	27.3	5	45.5	3	27.3	0	0.0	11	100
	25-50%	0	0.0	3	30.0	6	60.0	1	10.0	10	100
	Less than 25%	5	29.4	9	52.9	3	17.6	0	0.0	17	100
	Total	21	19.8	48	45.3	35	33.0	2	1.9	106	100

There were no statistically significant associations between the different groups and talking, listening and signposting about chronic pain including professional groups, workplace settings, length of time working with people with cancer and proportion of role involving people living with and beyond cancer.

Reflection on confidence regarding people living with and beyond cancer and chronic pain

Participants were asked how confident they felt about supporting cancer survivors living with chronic pain after cancer treatment. Mean scores (0-100) for confidence in helping = 44 (SD=21, range 0-85), supporting = 45 (SD=22, range 0-85), signposting = 53 (SD=23, 1-85), talking = 43 (SD=26, range 0-85) and listening = 65 (SD=32, 3-85) to people living with and beyond cancer about chronic pain after cancer treatment are presented in figure 11.

Figure 11: Confidence in listening, helping, supporting and talking about chronic pain after cancer treatment (Scale 0-100)



No statistically significant associations were found between confidence levels and professional groups, workplace settings or proportion of role involving people living with and beyond cancer. Data are presented in table 24.

Table 24: Confidence levels by professional group, workplace setting and proportion of role working with people living with and beyond cancer

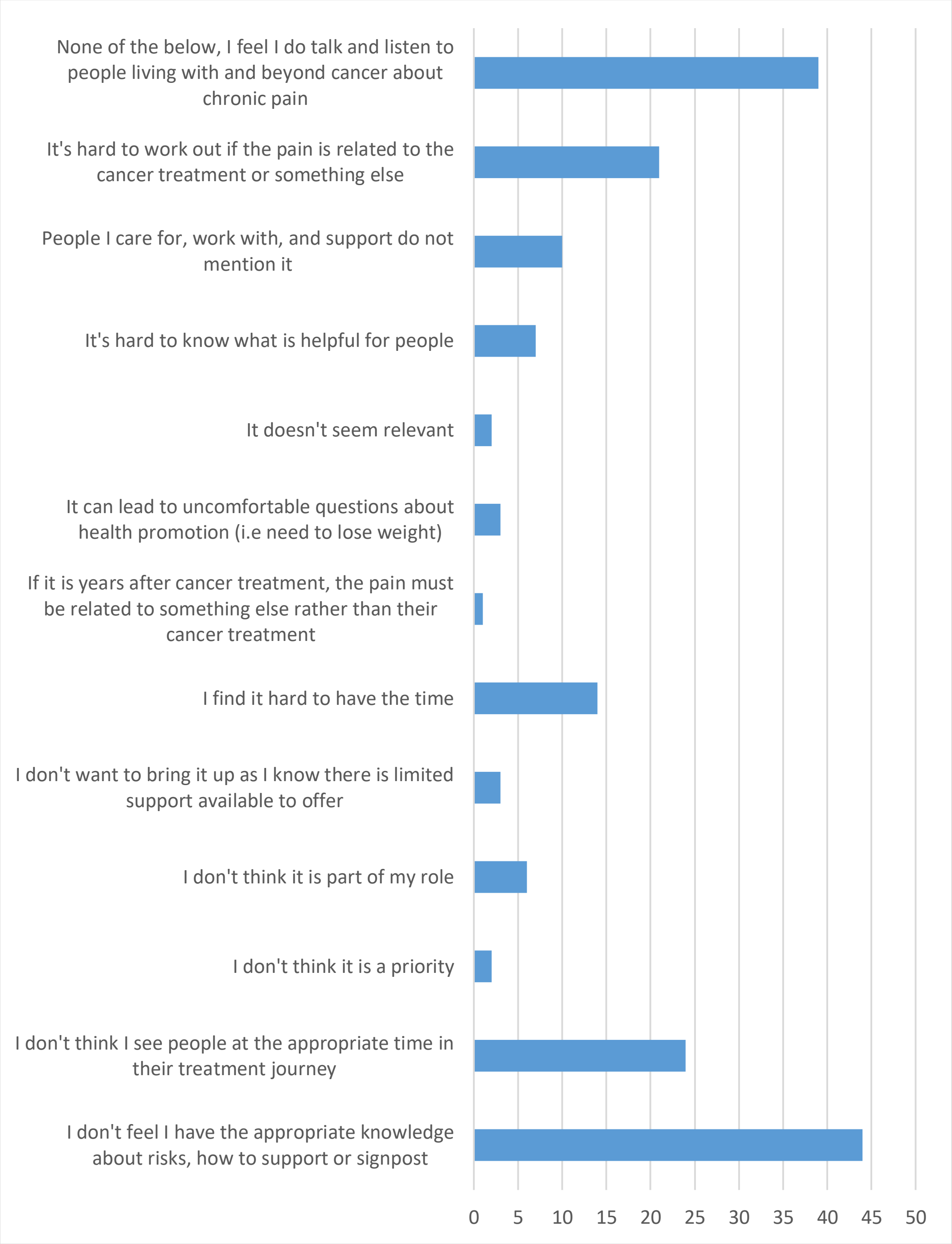
Group or setting		Talking to people LWBC about the risks of chronic pain after cancer treatment		Where to signpost people LWBC about informat-ion and support for chronic pain after cancer treatment		How to support cancer survivors who are living with chronic pain after treatment		How to help cancer survivors manage their pain		Listening to cancer survivors talk about their experien-ce of living with chronic pain after treatment	
		n	m*	n	m*	n	m*	n	m*	n	m*
Professional group	Nurse	28	47	28	54	28	53	28	48	28	48
	AHP	14	53	14	47	14	62	14	53	14	44
	Doctor	51	53	51	52	51	49	51	53	50	53
	Other	7	40	7	35	7	30	7	35	7	47
	Total	100		100		100		100		99	
Workplace setting	Hospital	76	54	76	54	76	52	76	53	75	51
	Community	20	39	20	39	20	48	20	46	20	49
	Education	4	40	4	41	4	44	4	30	4	44
	Total	100		100		100		100		99	
Proportion of role	More than 75%	49	53	49	54	49	55	49	55	49	52
	50-75%	15	42	15	45	15	47	15	46	15	45
	About 50%	11	56	11	50	11	38	11	46	10	55
	25-50%	8	52	8	40	8	47	8	60	8	56
	Less than 25%	17	46	17	51	17	51	17	41	17	42
	Total	100		100		100		100		99	

m* mean rank

Barriers to listening, talking and signposting people living with and beyond cancer about chronic pain after cancer treatment

Participants were asked what prevented them from talking to people living with and beyond cancer about chronic pain after cancer treatment. 96 answered the question and 45.8% (n=44) cited lack of appropriate knowledge about risks of chronic pain after cancer treatment, or how to support and signpost. 25% (n=24) felt they did not see people at the appropriate time in their treatment journey and 21.9% (n=21) said it was hard to work out if the pain is related to the cancer treatment or something else. 40.6% (n=39) felt there were no barriers, and they did talk, listen, and signpost (figure 12)

Figure 12: Barriers to talking to people living with and beyond cancer about chronic pain after cancer treatment



Within the free text comments, the desire for more education to increase knowledge about chronic pain after cancer treatment was evident:

'(We need) better online resources for healthcare professionals to be able to read up on how to help patients and also where to signpost patients too for further support and advice' (AHP, community)

'Would be useful to have a better understanding for different cancer types on the degree of the problem' (Nurse, hospital setting)

and a recognition that there is *'Much misunderstanding and misconceptions about chronic pain, its cause and treatment' (nurse, hospital setting)*

Analysis of the free text comments highlighted some additional barriers including 'Limited service provision', 'Conflict between services', 'Not my role' and 'Challenges in diagnosing chronic pain in cancer survivors'.

Limited service provision

Participants commented on the lack of services available to support people living with and beyond cancer with chronic pain after cancer treatment:

'There are some excellent services for post cancer side effects…but they are few and far between' (Doctor, community setting)

'I see patients from many different regional areas and not all support is available to everyone' (Nurse, hospital setting)

This resulted in healthcare professionals feeling they should not signpost to services:

'I feel unable to refer anyone but the most severe cases' (AHP, hospital setting)

And the limited services available often change, which makes signposting difficult:

'Often there are so many changing options for signposting people for support that these can get confusing and change rapidly' (Nurse, hospital setting)

Conflict between services

The frustration and conflict participants felt between different services was evident, with primary care staff particularly feeling secondary care was not doing enough:

'As much as I try to do my best for my patients, I do not think that acute services should disregard these symptoms to primary care, at least set up and refer to cancer late effects service' (Doctor, community setting)

'More needs to be done in secondary care to advise patients and services set up for this… it shouldn't always fall on the GP' (Doctor, community setting)

'GP's need to stop being so hit and miss, and Palliative Specialist Nurses need to support DN's (district nurses) to give the best to patients, all very disjointed services, especially acute to community no –communication - shocking!' (AHP, community setting)

Not my role

Some participants felt that they did not see people living with and beyond cancer who experienced chronic pain, or felt that information giving was not their role:

'These type of conversations not appropriate to radiotherapy treatment sessions… not really our remit' (AHP, hospital setting)

Or they had not considered it to be part of their role:

'*Honestly haven't thought about it as much previously' (AHP, community setting)*

Challenges in diagnosing chronic pain in cancer survivors

Participants working in the community stressed their frustration that acute services appeared unwilling or hesitant to diagnose chronic pain after cancer treatment:

'I do think sometimes when consulting the patient they have been told by their cancer team to speak to me as their GP, regarding their symptoms/side effects, which is clearly related to their cancer treatment but the team have asked me to exclude other causes… it just delays things for the patient and I end up doing a lot of tests to exclude things to then conclude it's related to their treatment' (Doctor, community setting)

'Sometimes, when the patient finally comes to see me as their GP, they are frustrated and anxious why they have this pain as secondary care may have told them it's not related to their cancer treatment but after I have tested for various other conditions I find it is related' (Doctor, community setting)

Ultimately, this was *'not fair on the patient or the GP' (Doctor, community setting).*

4.6: Discussion

This study achieved a varied sample of healthcare professionals with a good range of nurses, AHPs and doctors. The sample were experienced with looking after people living with and beyond cancer. Most worked with people living with and beyond cancer for more than 75% of their main professional role and had been doing so for more than 10 years. Yet despite being an experienced sample, there was a lack of knowledge about prevalence, severity, and risks of chronic pain after cancer treatment and mixed levels of understanding of the impact of chronic pain on cancer survivors' lives.

Healthcare professionals' knowledge of prevalence and severity rates of chronic pain after cancer treatment was low, as only a fifth identified the prevalence rates of 30-40% calculated by Van den Beuken-van Everdingen *et al.* (2016) and Jiang *et al.* (2019). However, this needs to be taken in the context of differing prevalence rates within different cancer tumour sites and treatment modalities (Dugué *et al.*, 2022; Karri *et al.*, 2021; Hamood *et al.*, 2018) and thus a prevalence rate of 30-40% may not be reflective of participants' experiences depending on the groups of people living with and beyond cancer they work with. However, in their recent research into the perceptions of healthcare providers of chronic pain in breast cancer survivors, Slaghmuylder *et al*. (2022) also found healthcare providers underestimated prevalence rates and severity of chronic pain in cancer survivors. With respect to risk factors, in the current study most healthcare professionals identified pre-existing anxiety as a risk of chronic pain after cancer treatment but fewer recognised age or BMI and only a fifth recognised gender as a risk factor. Almost a quarter of participants either did not know or incorrectly stated that chronic pain that starts years after cancer treatment has ended cannot be related to previous cancer treatment.

Concerns about lack of knowledge about chronic pain after cancer treatment start at undergraduate level, where there are issues regarding even the broader topics of pain, cancer, cancer pain and late effects. There is currently little or no evidence of pain, cancer, or cancer-related pain education within pre-registration healthcare programmes. A review of 71 undergraduate nursing programmes in the UK found pain was only present in 6 (8.5%) (Mackintosh-Franklin, 2017). Similarly, in a sample of 19 UK higher education institutions delivering 108 medical and health programmes, pain education accounted for less than 1% of programme hours for some disciplines (Briggs, Carr and Whittaker, 2011).

This is reflected across Europe whereby pain teaching in many European medical schools falls far short of what might be expected given the prevalence and public health burden of pain (Briggs *et al.*, 2015). There are also concerns regarding the quantity of cancer specific education within nursing and allied health professional pre-registration programmes in the UK (ACCEND, 2023). Furthermore, in a recent review of the inclusion of cancer-related pain across seven cancer care competency and knowledge frameworks, no specific mention of cancer-related pain was found across all documents (Galligan, 2022b).

When education surrounding pain and cancer pain is scant within undergraduate programmes, and there is no direction from cancer competency and knowledge frameworks to include cancer pain, it is unsurprising that healthcare professionals graduate with little knowledge of it. This is borne out in studies exploring healthcare professionals' knowledge of cancer-related pain whereby a systematic review of 12 studies, with 3,574 participants, found oncology nurses had poor levels of cancer-related pain knowledge (Bouya *et al.*, 2019) and there is lack of knowledge about cancer pain management amongst oncologists and other medical specialists (Breuer *et al.*, 2015).

Evidence from this current study highlights that healthcare professionals do not fully understand the impact of living with chronic pain after cancer treatment. Some participants did not recognise cancer survivors as the authors of some of the experience statements and this rose to almost a third when the statements focused on healthcare professionals believing or acknowledging cancer survivors when they say they have pain. It is recognised that higher levels of empathy in healthcare professionals may make it more likely to understand pain experiences, which, in turn, may help them to evaluate and manage their patients' pain (Dağ *et al.*, 2022). Dag *et al.* (2022) found levels of cognitive and affective empathy were positively correlated with pain knowledge and attitudes in nursing students.

Almost all healthcare professionals thought it was, or might be, their role to talk to people living with and beyond cancer about the potential for chronic pain after cancer treatment. However, approximately a quarter reported they never or rarely *did* this in practice – neither talking, listening or signposting people living with and beyond cancer to support and information about chronic pain after cancer treatment. This was reflected across different professional groups, in both the hospital and community setting, including from those who work with people living with and beyond cancer for more than 75% of their main professional role. This is mirrored in the literature, whereby in a study of 310 haematology nurses in Australia, Chan *et al.* (2018) found participants generally agreed that survivorship care was part of their role, however the mean frequency scores for performing items of survivorship care ranged between 2.34 and 3.86 (1 = never, 5 = all the time). Chan and colleagues (2018) did not ask about pain specifically, however, there were high levels of agreement that discussing long term side physical effects and linking to appropriate support services were part of the nurse's role. However, they found it was less common to actually perform an item or intervention to support: for discussing long term physical effects, the mean perception of responsibility was 4.42 (total disagreement on responsibility = 1 and total agreement on responsibility = 5), the frequency of performing the intervention was 3.12 (1 = never, 5 = all the time) and the confidence to do it was 7.2 (0 = cannot do at all and 10 = highly certain can do). For linking to appropriate support services, the mean perception of responsibility was 4.45 (total disagreement on responsibility = 1 and total agreement on responsibility = 5), the frequency of doing it was 3.25 (1 = never, 5 = all the time) and the confidence was 7.69 (0 = cannot do at all and 10 = highly certain can do). Chan and colleagues (2018) found being older, having more years of experience, a post graduate qualification and working in a non-metropolitan area were associated with higher levels of perceived responsibility for survivorship care and greater confidence. However, similarly to the current study, they did not find a statistically significant association with years of experience and the frequency of activities involving survivorship interventions (Chan *et al.*, 2018).

Findings from this study highlight that healthcare professionals' confidence about chronic pain after cancer treatment is low. Working with people living with and beyond cancer for longer or for more than 75% of their main professional role, did not increase confidence about chronic pain after cancer treatment. This is reflected in the wider literature surrounding nurses and allied health professionals (Faithfull *et al.*, 2016) and doctors (Ellison *et al.*, 2021, 2022). A survey of 618 healthcare professionals (368 specialist cancer nurses in oncology and the community and 250 cancer allied health professionals), who provided services for adults a year post cancer therapy in the UK, found many self-reported confidence deficits regarding long term and late effects (Faithfull *et al.*, 2016). Within the sample, many reported confidence in managing general pain (66%, n-=278) yet this dropped to 27.3% (n=109) when it came to providing complex symptom management for severe symptoms and 29.6 % (n=118) when reviewing medications and advising patients on potential medication effects. Community nurses felt less skilled in managing adult cancer patients long-term (Faithfull *et al.*, 2016). This is reflected in the findings from the current study, whereby those working in the community were least confident to talk and signpost about chronic pain after cancer treatment. Similar findings are found in studies of confidence for doctors, whereby in a survey of 133 medical graduates, mean scores for self-reported confidence in knowledge and skills regarding pain in general was rated as ‘low’ and only 15.8% reported feeling ‘confident’ (Ellison *et al.*, 2021, 2022). However, interestingly, only 7/21 of ‘confident’ participants also passed a pain knowledge survey within the study. Therefore, confidence to manage pain and performance may not correlate (Ellison *et al.*, 2022). Many healthcare professionals worry that pain management is a difficult and complex aspect in follow-up care after cancer and do not always know how to respond to pain problems or ‘do not dare to start a conversation about pain’ (Slaghmuylder *et al.,* 2022, p.7).

Participants expressed their desire for more education to increase knowledge about chronic pain after cancer treatment in the free text comments section of the survey. This is reflected in the literature whereby almost 70% (n=246) of nurses, both in the hospital and community setting, and allied health professionals, considered knowledge of long term health effects of cancer treatment to be a training priority (Faithfull *et al.*, 2016). Similarly, medical graduates reported their current pain education is inadequate (Ellison *et al.*, 2022) and most GPs would like further education to improve their knowledge and expertise about the management of cancer treatment-related side effects (Gopal *et al.*, 2022; Walter *et al.*, 2015), as would general practice nurses (Dyer and Dewhurst, 2020). In the current study, the perceived lack of knowledge about risks of chronic pain after cancer treatment, or how to support and signpost, was cited as the largest barrier to talking to people living with and beyond cancer about chronic pain after cancer treatment. This is reflected in a global survey of 1,639 physicians and nurses, from 56 countries, that found the barriers to improve cancer pain management included a lack of appropriate training and education at all levels. Inadequate knowledge among healthcare workers was considered a ‘‘highly significant’’ barrier by 46.60% of respondents and at least ‘‘moderately significant’’ by 36.14% of respondents (Silbermann *et al.,* 2022).

In addition to knowledge barriers, this study also identified organisational barriers, whereby there were limited services available, and there was conflict between primary and secondary care regarding who should support, how and when. This issue is not unique to the UK and represents a global problem (Jefford *et al.*, 2022; Slaghmuylder *et al.*, 2022; Lynch *et al.*, 2021; IJsbrandy *et al.*, 2020). A qualitative study of healthcare professionals’ perspectives of barriers and facilitators to implementing physical activity programmes for cancer survivors in the Netherlands found cooperation between primary and secondary care was not optimal. There was insufficient communication, GPs felt they were not involved or were involved too late and there was no consensus over roles (IJsbrandy *et al.*, 2020). Similarly, a qualitative study from Australia found GPs can feel excluded from the cancer team when patients are receiving new and unfamiliar treatments and that patients may not present to them until they are unwell or experiencing side effects, at which time the GP may not have any information from the cancer team about what treatment the patient was on or the expected side effects (Lynch *et al.*, 2021). As cancer care increasingly moves away from specialist led care, it is imperative that appropriate support is in place for non-oncologist care providers (Jefford *et al.*, 2022). However, this is a challenge when healthcare professionals believe that their colleagues have limited knowledge regarding chronic pain (Slaghmuylder *et al.*, 2022; Allemani *et al.*, 2018).

4.7: Limitations

This study achieved a sample size of 135, which is in keeping with similar studies looking at training needs analysis (Dyer and Dewhurst, 2020), and found some relevant and interesting findings. However, within the sample, there were smaller numbers of the individual groups, such as profession, workplace setting and time working in cancer. This may have impacted on the statistical analysis between groups. There were no statistically significant findings within the results, however it is unclear if this is because there were no clear differences between the groups, or the numbers had been too low to identify the differences.

One of the ways the survey was distributed was via social media. Whilst this enabled promotion of the survey, it was limited to the researcher's followers, the majority of whom are nurses from the cancer community. Thus, those who work in non-cancer services may have either not been aware of the survey, or not thought it was relevant to them. To mitigate against this risk, the survey was tweeted to various primary care organisations such as @rcgp (Royal College of General Practitioners), @PACTGP (Primary care academic collaborative), @RCNGPN (Royal College of General Practice Nursing Forum) and @WeGPNs (We General Practice Nurses) and pain groups, such as @BritishPainSoc (British Pain Society) and @RNPAinNET (Pain Nurse Networks). However, promotion via Twitter does not have the same credibility as distribution through recognised professional organisations. Such organisations could have been contacted directly to see if the survey could be distributed in additional ways, such as bulletins or newsletters. Further, whilst the researcher's 'tweets' about the survey made over 92,000 impressions, it was not clear if Twitter actually resulted in increased completion of the survey. In the days in which there were over 125 re-‘tweets’ of the survey, only a handful of surveys were completed.

The introduction to the survey said it was about ‘healthcare professionals’ understanding, experience and confidence surrounding chronic pain after cancer treatment’. In hindsight, this was a very brief explanation and it may have been better to include more detail about the meaning of ‘chronic pain after cancer treatment’. There may have been some self-selection bias because it is possible that healthcare professionals who did not feel knowledgeable about chronic pain after cancer treatment, or did not think it was relevant to their clinical role, did not engage with the survey (Lavrakas, 2008).

The demographic questions omitted to ask how much of a participant’s role involved pain management. This inhibited investigating relationships and associations between pain management expertise and a participant’s knowledge and confidence regarding chronic pain after cancer treatment. Also, the questions on prevalence needed a binary answer, however, in practice, prevalence rates are more nuanced and vary between tumour types and cancer treatments received. This may have resulted in an over or underestimation of healthcare professional’s knowledge about prevalence of chronic pain after cancer treatment.

The researcher selected the cancer survivor statements for the questions that included direct quotes. If this study was to be repeated, it would be preferable if two or more researchers independently selected quotes and a consensus was agreed on the most appropriate quotes to include.

The survey relied on self-reported data about participants’ awareness and understanding of chronic pain after cancer treatment. Participants may have overstated their understanding of chronic pain after cancer treatment to appear more knowledgeable or empathic and thus be at risk of social desirability bias (Bowling, 2014; Lavrakas, 2008). Just over a fifth (n=29, 21.5%) of participants did not complete the whole survey and this could have indicated a non-response bias (Bowling, 2014; Lavrakas, 2008). However, it was noted during the analysis that demographics and knowledge levels of those who completed the whole survey, and those that did not, were broadly similar.

4.8: Conclusion

This study aimed to investigate healthcare professionals' understanding of patients' experience of chronic pain after cancer treatment and confidence to inform, listen and signpost people living with and beyond cancer about it. The research found limited knowledge and understanding of chronic pain after cancer treatment by healthcare professionals. Whilst many thought it was, or might be, their role to talk to people living with and beyond cancer about chronic pain after cancer treatment, almost a quarter reported that they rarely or never did. Healthcare professionals lacked confidence to talk to people about chronic pain after cancer treatment and viewed their lack of knowledge as a barrier. Limited availability of services to support people with chronic pain after cancer treatment and lack of care co-ordination were also cited as barriers. Healthcare professionals expressed a wish for more education to increase knowledge about chronic pain after cancer treatment.

The following chapter seeks to address the concerns raised within this study and to offer some recommendations for researchers, policy makers, educators and healthcare professionals in clinical practice.

Chapter 5: Development of key findings and clinical recommendations

5.1: Introduction

The previous three chapters have described the new knowledge that has been generated within this thesis. Each study addressed one of the objectives of the PhD and the findings from each study informed the development of the next study. Collectively, they have provided key findings to address the overall aim of the PhD*: What are the experiences of cancer survivors living with chronic pain after cancer treatment and how can their experiences be improved?* This chapter describes the development of the key findings from across the studies and the clinical recommendations to improve patient experiences relating to chronic pain after cancer treatment for people living with and beyond cancer.

5.2: Development of key findings and draft recommendations

Thomas (2016) recommends highlighting key findings within a PhD and stresses the importance of making an informed decision concerning what to include and what to exclude. To assist with the process of summarising the key findings across all the studies, the following activities took place:

- A review of the findings of each study
- A critical review of the similarities and differences between the findings generated by each study
- A critical review of the strength of each finding across the studies

- A critical reflection of the dissemination activities undertaken to share the findings over the course of the PhD (Appendix 17) and the response and feedback from the different audience members (healthcare students, healthcare professionals attending cancer or pain conferences, patient representatives at Patient Public Involvement Events, healthcare professionals attending clinical education sessions, the PhD supervisor team, the PhD public contributors)
- Revisitation of the PhD aim and objectives

The key findings, supported by evidence from across the studies, were drawn together and clinical recommendations to address the key findings were drafted.

5.3: Expert peer review of key findings and clinical recommendations

The National Institute for Health and Care Excellence (NICE) (2022) state that consultation with stakeholders is an integral part of the process of guideline and recommendation development. External expert peer review may take place during guideline development or during consultation on the draft guideline (NICE, 2022). Within the development of these key findings and clinical recommendations expert peer review took place in two phases:

Phase 1) Initial review

Phase 2) A series of targeted engagement exercises (NICE, 2022), called ‘Expert review panels’, to obtain a range of views, experiences and expertise.

Phase 1: Initial review

Initial review of the key findings and recommendations were undertaken by the academic PhD supervisory team. The public contributors participated in phase 2. JA emailed the supervisory team a copy of the draft findings and recommendations alongside her reflections on points of discussion regarding each recommendation (Appendix 22). During an online supervision meeting, JA chaired a discussion on the key findings and recommendations and asked for feedback from the team.

Findings from the initial review

All academic members of the PhD supervisory team were present for the online meeting. There was consensus that the key findings represented the findings from across the individual studies. The team said the way the table was presented helped to strengthen the key findings because the evidence for each finding from across the PhD studies was clearly laid out. The new data generated by the studies played an important contribution to knowledge about how to support people affected by chronic pain after cancer treatment. It was suggested the title of the table was changed from ‘Key concerns and recommendations’ to ‘Key findings and clinical recommendations’. It was recognised that the issues and points for discussion that were raised acknowledged the complexity of implementing the recommendations.

Phase 2: Expert Review Panels

The aim of the expert review panels was to share the key findings and recommendations with experts in the field, discuss how the recommendations could be met in practice and provide a qualitative description of the outcomes of the discussion.

Methodological design

When seeking to provide a comprehensive summary of events, a qualitative descriptive design is a method of choice (Sandelowski, 2000). Whilst often cited as ‘basic’ or 'fundamental', compared to the more theoretically driven approaches, this does not mean that qualitative descriptive studies are atheoretical (Bradshaw, Atkinson and Doody, 2017; Sandelowski, 2000, 2010). Thus it is important to address philosophical, epistemological and ontological assumptions within qualitive descriptive designs (Bradshaw, Atkinson and Doody, 2017). From an ontological perspective, qualitative description research strives for in-depth understanding but with emphasis first on literal description and then on the analysis and interpretation of the meaning that people ascribe to events (Bradshaw, Atkinson and Doody, 2017; Sandelowski, 2010). Epistemologically, qualitative description acknowledges that many interpretations of reality exist, it is a subjective interpretation of events and knowledge of reality is socially and contextually constructed by participants and researchers (Bradshaw, Atkinson and Doody, 2017).

Method

The composition, format and content of the expert review panels was informed by NICE and WHO guidelines (NICE, 2022; Fretheim, Schünemann and Oxman, 2006), recommendations for qualitative fieldwork and running group interviews (Green and Thorogood, 2018; Ritchie *et al.*, 2014) and research using consultation workshops in palliative care (Evans *et al.*, 2020; Gysels *et al.*, 2013; Higginson *et al.*, 2013).

Composition of the expert review panel

Care and consideration should be given to the composition of a review group and participants need sufficient experience, knowledge and expertise to comment on the topic under review (NICE, 2022; Green and Thorogood, 2018; Fretheim, Schünemann and Oxman, 2006). Green and Thorogood (2018) recognise a common strategy is to identify, from the literature and pilot work, the key demographics that are likely to have an impact on participants' knowledge, experiences or views on a topic. These can then be used to form a 'sampling grid' and groups can be recruited to reflect various combinations of variables. The key variables for this work include experience of chronic pain and/or experience of cancer care either through clinical practice, research, education, and teaching or a lived experience lens. These variables were added to a sampling grid (table 25) and participants were recruited from each group.

Table 25: Sampling grid

	Experience of chronic pain	Experience of cancer care/ cancer late effects/ cancer survivorship
Clinical practice	X	X
Research	X	X
Education/Teaching	X	X
Lived experience	X	X

Review panels and groups can be homogeneous and thus share the same variables (for example all participants work in clinical practice or are people with lived experience) or heterogeneous (a mix of participants with different variables) (Green and Thorogood, 2018). Whilst there are advantages to homogenous groups, such as being a 'safe' space in which people share similar experiences, it was decided that a heterogenous group would be more appropriate because it would enable a discussion from a range of views, experiences and perspectives (Green and Thorogood, 2018). Thus, each expert review panel comprised participants from across the sampling grid.

Recruitment of participants

Based on the desired variables identified in the sampling grid, participants were identified via:

- The UK Oncology Nursing Society (UKONS) committee members

- The Pain-related Complex Cancer Late Effects Rehabilitation Service (CCLERS)
- The UK Cancer Pain Nurses Group
- The Aspirant Cancer Career and Education Development programme (ACCEND) steering group committee
- The Radiotherapy Late Effects Special Interest Group, the Society of Radiographers
- Authors of relevant published literature
- Participants of previous research who had agreed to be approached for future research on this topic
- PhD public contributors

Individuals were invited to join an expert review panel via a personalised email. The email explained why they had been approached and briefly outlined what would be involved. If they were interested in participating, they gave their availability via an online poll or requested a one-to-one meeting with JA.

Format of the expert review panel

Participants could choose to be part of a group online meeting, run via MS Teams or have a one-to-one phone call or MS Teams meeting. MS Teams was selected as a practicable approach to enable participants to join from across the UK. All group and one-to-one meetings were facilitated by JA. JA is a university lecturer who is experienced at facilitating group meetings in an online setting. All meetings were recorded and transcribed.

Content of the expert review panel

Richie *et al.* (2014) recommend 'enabling techniques' to stimulate thinking and enable participants to reflect and discuss a topic more deeply. Providing information, before or during discussions can be a method to aid expression, refine views, tease out difference in views, explore priorities and look at how abstract concepts can be applied in practice. To this end, a summary was sent to all expert review panel members via email in advance of the meetings. This included a summary of the PhD aims and objectives, PhD studies, findings and recommendations and questions for the expert review panel discussion (Appendix 23). As recommended by Ritchie *et al.* (2014) and Green and Thorogood (2018), consideration was given to the language and terminology used, the content, layout, formatting, and the length when designing the summary. The summary was used as a topic guide during the expert review panels. It was not an exact prescription of the order or coverage of each discussion item, but steered the data collection to key questions (Ritchie *et al.*, 2014).

Each expert review panel started with a round of introductions and JA gave a brief overview of the PhD, the key findings and recommendations. The discussion broadly focused on the following questions:

a) To meet these recommendations, what would 'good' look like?
b) How would it be measured?
c) What could enable this?
d) What are the challenges and barriers?

At the end of each expert review panel JA summarised the discussion, explained the next steps in the PhD process, offered a copy of final findings to members, confirmed consent for inclusion of names within the list of participants and thanked everyone for their time and contribution.

Analysis

Qualitative content analysis is the analysis strategy of choice in qualitative descriptive studies (Sandelowski, 2000). The aim of qualitative content analysis is to provide a condensed and broad description of phenomenon, and the outcome of the analysis is concepts or categories describing the phenomenon (Elo and Kyngäs, 2008). Inductive qualitative content analysis was used to describe the discussions within the expert review panels thus the analysis was data driven, compared to a concept driven approach of deductive analysis (Graneheim, Lindgren and Lundman, 2017).

Inductive qualitative content analysis involves three phases (Elo *et al.*, 2014; Elo and Kyngäs, 2008; Graneheim and Lundman, 2004):

- Preparation phase: This phase consists of collecting suitable data, making sense of the data and selecting the unit of analysis.
- Organisation phase: This phase involves open coding, creating categories and abstraction.
- Reporting phase: The content of the categories is described and reported.

Preparation phase

The first decision to be made in inductive qualitative content analysis is the unit of analysis. Graneheim and Lundman (2004) suggest a suitable unit of analysis are data that are large enough to be considered whole but small enough to be kept in mind during the analysis process (i.e. a whole interview transcript). In this study, each expert review panel recording and transcript was considered to be a unit of analysis. Each expert review panel recording was re-listened to and Teams-generated transcripts were downloaded and read to get a sense of the whole. Recordings and transcripts were uploaded to NVivo to help manage the data. As described by Graneheim and Lundman (2004, 2010), the transcribed text was then organised into five content areas, reflecting the research questions posed in the summary for expert review panel members, namely:

- To meet these recommendations, what would ‘good’ look like? (Content area: Components for best practice)
- How would it be measured? (Content area: Measurement strategies)
- What could enable this? (Content area: Enablers)
- What are the challenges and barriers? (Content areas: Challenges, Barriers)

To manage this within Nvivo, each content area was named as a parent node (QRS International, 2022). Finally, it was decided that both manifest (visible) and latent (underlying meaning) content would be analysed (Elo and Kyngäs, 2008; Graneheim and Lundman, 2004).

Organisation phase

During the organisation phase, firstly, open coding took place whereby headings were attributed to sections of the text and categories were freely generated. After open coding, the lists of categories were grouped under higher order categories. The aim of the creation of higher order categories was not simply to bring together text that was similar or related, but rather to classify text that ‘belonged’ together. The purpose was to describe the phenomenon and increase understanding (Elo and Kyngäs, 2008). Finally, abstraction took place. During this process, re-organisation and re-contextualisation of categories took place as codes were compared and grouped into sub-categories and categories moved from closeness to distance from the text (Lindgren, Lundman and Graneheim, 2020). Within the Nvivo platform, this was achieved by organising the coded text into hierarchical nodes (Lumivero, n.d.).

Reporting phase

Providing a full description of the sample, analysis and creation of categories is essential to increase trustworthiness of qualitative content analysis findings (Lindgren, Lundman and Graneheim, 2020; Elo *et al.*, 2014; Graneheim and Lundman, 2004).

Trustworthiness

The concept of trustworthiness (can the findings be trusted?) and rigour (were the data collection methods and analysis rigorous and transparent?) (Korstjens and Moser, 2018) are important in qualitative research. Elo *et al.* (2014) explain that the most used criteria to assess trustworthiness in qualitative content analysis was developed by Lincoln and Guba (1985) and includes credibility, transferability, dependability and confirmability. Elo *et al*. (2014) recommend that in the preparation phase, researchers consider their data collection method and sampling strategy to ensure the data collected will reflect their aims and the sample is appropriate and includes who would be the best informants for the study. For the expert review panels, much consideration and thought was given to the most suitable data to collect, how to do this and who to recruit to participate; details of the process are provided within this chapter. To increase trustworthiness in the organisation phase, it is recommended to include a table to summarise the analysis so readers can see the development of codes, sub categories and categories (Lindgren, Lundman and Graneheim, 2020; Graneheim, Lindgren and Lundman, 2017; Elo *et al.*, 2014; Timlin, Riala and Kyngäs, 2013). For the reporting phase, effort was made to report the results systematically and logically, with the use of quotations, as recommended by Elo *et al.* (2014).

5.4: Findings

Composition of expert review panel

In total, 16 participants contributed to the Expert Review Panels. Details of the participants are in appendix 24. All participants have consented to be named in this thesis. There were four group Expert Review Panels and two one-to-one discussions. All were via MS Teams apart from a one-to-one discussion which took place over the telephone at the participant's request. Each group Expert Review Panel took approximately 1.5 hours and the one-to-one discussions were between 20 and 45 minutes. Each group Expert Review Panel consisted of between two and five participants (5, 4, 3 and 2 respectively) plus the facilitator, and included a mix of participants with lived experience and/or clinical, education or research expertise. All professionals who were approached agreed to participate. Two patient representatives did not respond to the invitation and one agreed but was away during the time the expert review panels occurred.

Summary of findings from expert review panels

Participants thought the summary document and key findings and recommendations table were clear and provided a good summary. Participants commented that they *'love it, love it, love it' (Patient representative, expert review panel no.2)* and that it '*summed it* *up very nicely' (Researcher, one to one discussion)* and they *'love the way it's presented. It's very simple. It's a very clear message' (Clinician, expert review panel no.4).*

The process of preparing and organising the data of the expert review panels resulted in four categories:

1) Validating cancer survivors' experiences of chronic pain is essential to best practice'
2) Well informed patients and healthcare professionals making good decisions together
3) Not seeking a perfect system, but an improved system
4) Make the recommendations fly

The development of the categories is outlined in table 26.

Validating cancer survivors' experiences of chronic pain is essential to best practice

Across all expert review panels, when discussing what 'good' looked like, it was clear that listening, validation and communication are at the heart of best practice. Clinicians recalled the impact it has on patients when patients are given opportunity to share their experiences and are communicated with in a compassionate, informed and supportive manner. One explained '*people have been brought to tears because it's the first time somebody listens and acknowledges that they have got pain' (Clinician, expert review panel no.1).* Patient representatives spoke of the benefit they encountered when they had felt listened to, and conversely the harm experienced when they had not, and expressed '*having people listen to you and hear what you say and believe what you're saying is fundamental' (Patient representative, expert review panel no.1).* The importance of validating and acknowledging the experience of chronic pain was regarded as key and this was seen as the cornerstone of what best practice ('good') would look like. It was acknowledged that the *'artistry'* of communication was central to this *(Educator, expert review panel no.3)*.

Well informed patients and healthcare professionals making good decisions together

One participant eloquently described what 'good' would look like by explaining *'good would be well informed patients and healthcare professionals that are making good decisions together (Patient representative, expert review panel 1)'.* To enable this, the value of *'shared decision making' (Clinician, expert review panel 1)* was highlighted by many and the importance of people having '*ownership' (Patient representative, expert review panel 1).* The concept of ownership was considered in two ways. Firstly, by people affected by cancer being able to take 'ownership' of their symptoms and the factors that influenced them such as knowledge about the risks of chronic pain and a sense of agency to seek help. A clinical diagnosis of chronic pain after cancer treatment and an explanation of the aetiology of their pain was essential to this. Secondly, ownership was mentioned in relation to healthcare professionals. It was said that *'we (healthcare professionals) all need to take responsibility' (Clinician, expert review panel 2)* and chronic pain after cancer treatment is '*everyone's business' (Clinician, expert review panel 2).*

The central tenant for shared decision making was the importance of informed patients and healthcare professionals. Patient information, alongside reinforcement of the information, was discussed including the use of creative technologies such as podcasts, videos and interactive symptom detection websites. It was highlighted that some patients have *'gone googling'* to find information or support services but people cannot do that without being relatively well informed because *'it's only if you know the term 'late effects' that you can go looking for it…. So that in itself is a barrier'* (Researcher, expert

Table 26: Codes, sub-categories and categories of analysis arising from expert review panels

Codes	Sub-categories	Categories
Importance of listening	Listening and validation are at the heart of best practice	Validating cancer survivors' experiences of chronic pain are essential to best practice
Validating pain experiences		
The way healthcare professionals communicate	Communication is paramount	
Holistic needs assessment	Shared decision making	Well informed patients and healthcare professionals making good decisions together
Patients having ownership of their symptoms		
Patients having sense of agency over care and pathway		
Link role in primary care		
Tailor information to stage of cancer pathway	Introduce and reinforce information over time using different ways to educate	
Reinforce risks of chronic pain over time		
Use of multimedia patient information	Use technology to create and develop patient and healthcare professionals' information and education	
Develop accessible learning for healthcare professionals		
Be realistic about your responsibilities as researcher	You have highlighted issue, future work to implement change and evaluate	Not a perfect system, but an improved system
How much can you change the world?		
Move the dial bit by bit	One encounter can make a difference	
improve the encounter for a patient		
Role of national education strategies	Clearer pathways for education and career progression	
New advanced practice roles emerging		
Connect to policy	Align recommendations to policy and priorities	Make the recommendations fly
Align with funders' priorities		
Approach funders	Be ambitious and brave with scope of recommendations	
Highlight transferability of findings		
Components of quality	Assess against quality indicators	
What happens if they are not met	Create a sense of urgency	

review panel 3). From a healthcare professional perspective, it was proposed that everyone involved with people's care should know about the reality of chronic pain after cancer treatment, including those involved with providing treatments: '*it's really important that (the reality of living with chronic pain after cancer treatment) gets back To the surgeon…. otherwise they don't have an idea of the burden of the problem or what's happening further down the line' (Clinician, expert review panel 2)*. An holistic needs assessment was considered by many as an approach to identify concerns and a way *to 'improve person centered care, holistic care and provide higher quality cancer care' (Researcher, one to one discussion).* However, it was recognised that assessment is *'not a quality measure, it's not a quality of life outcome measure' (Researcher, one to one discussion)*. It was also acknowledged that, before a holistic needs assessment can take place, healthcare professionals need to *'realise that there's a big gap and that people are– falling through - that needs to be first' (Clinician, expert review panel 2)* and without knowledgeable healthcare professionals having awareness of the risks and impact of chronic pain after cancer treatment, the potential benefits of a holistic needs assessment are limited. Furthermore, whilst the benefits of shared decision making and assessment were appreciated, there was a sense of frustration that *'we spend a lot of time doing holistic needs assessments and asking people about this and about that. But actually the patients I see, they want someone to sort their problems out' (Clinician, expert review panel 2).*

Not a perfect system, but an improved system

The complexity of the issues surrounding healthcare professional and patient education, and patient pathways was acknowledged in all expert review panels. Ambitious suggestions were made for new roles and services, including a chronic cancer service to mirror acute oncology services. However, the significant challenges facing this were also identified such as issues of commissioning, education, access, and communication. At the conclusion of these discussions, many participants gave a wry smile and acknowledged it is '*hugely challenging' (Patient representative, expert review panel 3).* However, it was also acknowledged that *'every person… in the NHS, whatever, who's awareness is moved (about chronic pain after cancer treatment) would improve the encounter in the life experience for a patient' (Patient representative, expert review panel.1)* and that any healthcare professional who *'sits down with one patient and says the right things, then you've improved the system' (Patient representative, expert review panel 1).* Participants questioned *'how much you can change the whole world through your work' (Patient representative, expert review panel 1)* but reassured that improving the experience of one person was a worthwhile outcome. How to measure this was discussed and the clinical limitations of quality of life measures such as the EQ-5D was highlighted, as were the challenges of developing and realistically implementing a pain-specific measure or metric. Data collection has a *'massive burden to clinical staff to generate and pull out that data and report it' (Researcher, one to one discussion)* and questions were raised such as 'W*ho's that going to report to? Who's going to be responsible for it? And who's going to fund it?' (Researcher, one to one discussion).* A suggestion was made to collect it with a *'whole load of other… data' (Researcher, one to one discussion)* and canvass the National Cancer Patient Experience survey to include a question relating to pain or possibly to cluster pain with other chronic symptoms such as fatigue.

The complexity and 'messy' nature of where these services sit was acknowledged by all expert review panels. There was agreement that communication needs to improve across services, there is inconsistent provision across the UK, and referral pathways need to open up, but it was acknowledged that commissioning makes that extremely challenging. There was no consensus about where a support service should be based. Across the expert review panels *'acute services', 'as an adjunct to acute oncology services' 'treatment centres' , 'late effect clinics', 'specialist pain clinics', 'pain services' 'general practice', 'primary care', 'palliative services' 'hospices'* and *'a hybrid between hospital and community'* were all raised separately as the place it could or should sit. However, it was also acknowledged, that within my role of researcher*, 'you can't solve all of that' (Patient representative, expert review panel 1)* and *'it's not your responsibility, as a researcher (to educate all healthcare professionals and patients) about it' (Researcher, one to one discussion)* but to say to yourself *'I have responsibility for publishing it (the findings) and to do my best to disseminate it'* but then it's the *'business of'* others to take it forward in practice *(Researcher, one to one discussion).*

Make the recommendations fly

Many participants remarked on the importance of the findings and recommendations and mentioned how it provided evidence in an arena where there is little research. Some participants expressed their appreciation for the work and their relief and satisfaction that chronic pain after cancer treatment was receiving the attention of researchers. There was lots of enthusiasm, encouragement and advice to ensure the recommendations were taken forward.

It was acknowledged that cancer care and services are a *'noisy'* place *(Patient representative, expert review panel 3)* and *'one of the challenges is making it a priority (Patient representative, expert review panel 1)'.* The value of being *'really ambitious'* and connecting with individuals in organisations of influence was encouraged as well *(Clinician, expert review panel 4)* as creating a sense of urgency about the work. Many expert review panels mentioned the importance of aligning the work with current government policy and the way to *'get people to pay attention to it is to look at the NHS long term plan' (Researcher, one to one discussion).* Also, to highlight the work to relevant and influential organisations and funders *'to get their interest'* and show the work '*answers a question….that's on the(ir) mind' (Researcher, expert review panel 4)*. For example, it is currently *'on the mind of HEE (Health Education England)'* to develop the role of the advanced clinical practitioner, and this work provides a *'really good example of how that could work'* as it presents *'a real opportunity for an advanced clinical practitioner in cancer to work between and across the services to provide that ongoing support' (Educator, expert review panel 3).*

It was suggested that providing a framework of quality indicators and being explicit about the impact of not acting on the recommendations, could increase the likelihood of the recommendations being taken forward. It was acknowledged that the recommendations seek to improve the *'quality of cancer care' (Researcher, expert review panel 3)* and the key indicators of quality of cancer care are *'effectiveness, efficiency and patient experience' (Researcher, one to one discussion)*. It was suggested that the recommendations need to address one or more of these components and the question was posed that *'if they don't (for example, have access to rehabilitation and support services), then what's going to be the outcome' (Researcher, one to one discussion)* and it was acknowledged that *'the outcome is in your findings, because they don't at the moment' (Researcher, one to one discussion).*

Whilst participants thought the overall summary document was excellent, some suggested the wording of the recommendations themselves could be strengthened and tightened. It was warned that ambiguous recommendations might mean that commissioners may see an opportunity to under resource activities and services. There was discussion about the ‘chicken and egg’ nature of the recommendations, but without raising healthcare professional awareness, they will not inform and educate people living with and beyond cancer about chronic pain after cancer treatment, nor lobby for improved services.

In summary the findings from the expert review panels highlight that the way healthcare professionals communicate is central to a positive patient experience and that well informed patients and healthcare professionals making good decisions together would exemplify a ‘good’ service. It was highlighted that if this work raises the awareness of chronic pain after cancer treatment, and that impacts on the experience of patients, then it has been a worthwhile endeavour. Suggestions were given to increase the likelihood of the recommendations being successful, these included: reordering them in priority, reworking some of the recommendations, and aligning the work to policy and funder priorities.

5.5: Amendments made to the clinical recommendations following the expert review panels

After further critical reflection of the key findings from the PhD, and the discussions from the expert review panels, some amendments were made to the key findings and clinical recommendations.

Wording of key findings

Discussions within the expert review panels re-emphasised the importance of communication. Listening to, and validating people's pain experiences, was seen as key to best practice. This was also the central finding in the patient study (chapter 3). It was shown in the healthcare professional study (chapter 4) that many healthcare professionals did not listen to people talk about chronic pain after cancer treatment, and many did not fully recognise the impact chronic pain had on cancer survivors' lives. Within the development of the draft key findings and recommendations (Appendix 22) this was initially encompassed in:

Concern
Chronic pain after cancer treatment is not discussed with people living with and beyond cancer *(incorporating 'not listened to', 'not believed', 'resistance to talk')*

However, in the summary sent to the expert review panel members (Appendix 23), the text saying *(incorporating 'not listened to', 'not believed', 'resistance to talk')* had been removed:

Key finding
Chronic pain after cancer treatment is not discussed with people living with and beyond cancer

Thus, the recommendation had been diluted. It had moved away from the importance of listening to people living with and beyond cancer and providing them with the opportunity to talk about their experiences of chronic pain after cancer treatment and validating their experiences as real. Critical reflection of these points resulted in the wording in the final key findings changing to:

Key finding

People living with and beyond cancer do not feel heard or believed when talking to healthcare professionals about their chronic pain after cancer treatment

After critical reflection on the discussions within the expert review panels and the findings from the studies, it became clear that the importance of validating cancer survivors' experiences and explaining the aetiology of their pain needed to be emphasised within the key findings and recommendations. Therefore, an additional key finding and recommendation was included:

Key finding
Cancer survivors who have received a clinical diagnosis and explanation of the aetiology of their chronic pain after cancer treatment feel better able to manage their pain

Clinical recommendation
Chronic pain after cancer treatment should be accurately diagnosed and explained to cancer survivors living with chronic pain after cancer treatment

Wording of recommendations

Discussions within the expert review panels highlighted that ambiguous and vague recommendations can be challenged and dismissed by commissioners and funders. 'Raise awareness of chronic pain after cancer treatment' was considered vague so was rewritten to be more specific: *'Raise awareness, knowledge and understanding of chronic pain after cancer treatment among the healthcare workforce to increase their confidence to listen, acknowledge and address it with people living with and beyond cancer'.*

Aligning the recommendations to policy and funders was stressed as important within the expert review panels. Thus, it was decided to use the same terminology to help demonstrate how the recommendations address policy concerns. Therefore, the wording ‘healthcare staff’ was changed to *‘healthcare workforce’.*

As discussed above, the finding ‘Chronic pain after cancer treatment is not discussed with people living with and beyond cancer’ was amended to ‘People living with and beyond cancer do not feel heard or believed when talking to healthcare professionals about their chronic pain after cancer treatment’. Thus, on reflection, the corresponding recommendation needs to be as clear and unambiguous as the finding. Thus, this was changed to ‘People living with and beyond cancer who experience chronic pain after cancer treatment should have their concerns listened to, acknowledged and addressed’.

Amalgamation of key findings and clinical recommendation

After critical thought and reflection, it was decided to combine two of the key findings to support one of the recommendations. The original key finding and recommendation was:

Key findings
1. Living with chronic pain after cancer treatment affects physical, psychological, social, emotional, financial, and social wellbeing

Clinical recommendation
People living with and beyond cancer should have access to rehabilitation and support services

However, it was considered that the key finding alone did not fully provide a rationale for the clinical recommendation. It was decided to add ‘yet cancer survivors have difficulty accessing support for their chronic pain after cancer treatment’ so the consequence of chronic pain after cancer treatment was apparent within the finding. During the expert review panels, it was noted that the finding and recommendation about ‘pathways for support’ was unclear. On reflection, it was considered that this was incorporated in the new wording of the access to rehabilitation and support recommendation, and thus they were combined.

A summary of the changes to the findings and recommendations after the expert review panels are listed in table 27.

Table 27: Summary of amendments to key findings and clinical recommendations following the expert review panels

Draft key finding and recommendations	Final key finding and recommendations
Key finding: Chronic pain after cancer treatment is not discussed with people living with and beyond cancer	Key finding: People living with and beyond cancer do not feel heard or believed when talking to healthcare professionals about their chronic pain after cancer treatment
Key finding: Living with chronic pain after cancer treatment affects physical, psychological, social, emotional, financial, and social wellbeing	Key finding: Living with chronic pain after cancer treatment affects physical, psychological, social, emotional, financial, and social wellbeing yet cancer survivors have difficulty accessing support for their chronic pain after cancer treatment
Recommendation: Raise healthcare professional awareness, knowledge and understanding of chronic pain after cancer treatment and increase confidence to acknowledge and address it	Recommendation: People living with and beyond cancer who experience chronic pain after cancer treatment should have their concerns listened to, acknowledged and addressed
Recommendation: Raise awareness of chronic pain after cancer treatment amongst healthcare staff	Recommendation: Raise awareness, knowledge and understanding of chronic pain after cancer treatment among the healthcare workforce to increase their confidence to listen, acknowledge and address it with people living with and beyond cancer
Recommendation: Identify pathways for support and communicate pathways with healthcare professionals and people living with and beyond cancer	Amalgamated with the recommendation: ‘People living with and beyond cancer should have access to rehabilitation and support services’

Reordering of findings and recommendations

The ‘chicken and egg’ nature of the recommendations was discussed across all expert review panels. However, on reflection, it was decided to change the order of the recommendations to mirror the strength of findings across the PhD. Thus, as being listened to (or not), believed and having their pain validated had the biggest impact on people living with and beyond cancer, these findings were put first. It was acknowledged that without an increase in healthcare professional knowledge about chronic pain after cancer treatment, the other recommendations could not be implemented therefore, increasing healthcare professional knowledge was listed next. This was followed by the need for information, services and pathways.

The final key findings and recommendations will be presented and discussed in next chapter.

5.6: Limitations of the expert review panels

Refining the key findings and recommendations via expert review panels enabled an opportunity to 'sense check' the recommendations, test how they might be received by the healthcare community and bring the PhD work to a close for the purpose of this thesis. However, the depth of the stakeholder engagement was limited as there was not scope within this PhD to conduct detailed stakeholder analysis. If more time and resource were available, more extensive engagement could have been utilised, for example, consensus methodology to identify areas of prioritisation.

The development of these key findings and recommendations followed evidenced based guidelines recommended by NICE, the World Health Organisation and researchers (NICE, 2022; Fretheim, Schünemann and Oxman, 2006). There was excellent recruitment and participation from educators, clinicians, researchers and patient representatives. However, if this exercise were to be repeated, it would be advisable to include policy, charity, primary care representatives and commissioners. All professionals approached agreed to take part. This demonstrates the enthusiasm and support for this subject and was enabled by the researchers strong connections across the cancer, pain and education communities. However, this could have introduced some potential bias to the review panels. Firstly, all members were either working in, or affected, by cancer and/or pain and therefore were already interested and committed to this field. Attempts were made to address this by including those with a different professional focus (i.e practice, education and research) however, it is acknowledged everyone had a strong association with cancer. Inviting a General Practitioner (GP) or practice nurse, as someone for whom cancer is part of their role rather than the main focus, could have counterbalanced this, however, it is acknowledged they would have been challenging to recruit due to work pressures, particularly during the covid-19 pandemic.

Due to the researchers professional connections, many of the participants were known to the researcher in some professional capacity. The researcher has been a part of the cancer healthcare professional community for almost 20 years, it was inevitable that she would know many of the professionals whose opinions were being sought. This may have meant that people felt obligated to participate or participated primarily to support the researcher personally. To minimise this risk, the researcher stressed that the invite came with no pressure or obligation to attend. Due to professional relationships with the researchers and the other members of the panel, participants may have been less forthcoming with criticisms or critiques of the work. To minimise this, it was explained and reiterated the recommendations were in draft form. To counteract the risk of panel members being ‘too supportive’ to the researcher, when identifying who to invite to the panels, the researcher reflected on times where they have disseminated the work and been challenged by individuals, and actively sought out these individuals to join the panels. However, over and above these mitigating measures, the participants were all professional experts in their field, and would have been able to provide honest and robust feedback regardless of any personal connections.

5.7: Conclusion

This chapter sought to develop and sense check key findings and clinical recommendations from the PhD findings. NICE (2022) recognise that consultation with stakeholders is an integral part of the process of guideline and recommendation development. This process was completed in two phases, firstly initial review and secondly, via a series of targeted engagement exercises called expert review panels. The expert review panels were planned and executed in line with recommendations from NICE and the World Health Organisation (NICE, 2022; Fretheim, Schünemann and Oxman, 2006), and researcher guidelines, thus consideration was given to the methodological design, composition, format and content of the expert review panels (Green and Thorogood, 2018; Ritchie *et al.*, 2014). The expert review panels were conducted using a qualitative descriptive design and were analysed using qualitative content analysis (Sandelowski, 2000). The presentation of the key findings and recommendations was positively received, and the expert review panels resulted in four categories of findings, namely: Validating cancer survivors' experiences of chronic pain are essential to best practice, well-informed patients and healthcare professionals making good decisions together, not seeking a perfect system, but an improved system and, make the recommendations fly. Amendments were made to keys findings and recommendations following the two phases of development. The final key findings and recommendations will be presented and discussed in the next chapter.

Chapter 6: Recommendations, discussion and reflections

This chapter will outline the final key findings and clinical recommendations from this thesis. The evidence for each key finding and clinical recommendation will be provided alongside a discussion of the challenges surrounding each recommendation and suggestions for potential solutions to those challenges. An implementation strategy will be proposed. An evaluation of the impact of the public contributors on the research will be described. A summary of the overall thesis will be given, conclusions provided and limitations discussed. The chapter will conclude with proposals for future research.

6.1: Key findings and clinical recommendations

The key findings and clinical recommendations from this thesis are outlined in table 28. Evidence for these key findings and clinical recommendations has been provided by the qualitative evidence synthesis (chapter 2), the qualitative study of cancer survivors (chapter 3), the healthcare professional study (chapter 4) and the expert review panels (chapter 5).

The key findings and clinical recommendations have been developed through new knowledge gained from original research within this thesis. Thus, each finding is evidence based and each recommendation has been developed with consultation with relevant stakeholders. However, it is acknowledged that there are inherent complexities in realising the recommendations. These complexities will now be discussed.

Table 28: Key findings and clinical recommendations

Key findings	Clinical recommendation	Evidence
People living with and beyond cancer do not feel listened to, heard or believed when talking to healthcare professionals about their chronic pain after cancer treatment	People living with and beyond cancer who experience chronic pain after cancer treatment should have their concerns listened to and acknowledged	1*, 2*, 3*, 4* 5*
Cancer survivors who have received a clinical diagnosis and explanation of the aetiology of their chronic pain after cancer treatment feel better able to manage their pain	Chronic pain after cancer treatment should be accurately diagnosed and explained to cancer survivors living with chronic pain after cancer treatment	2*, 4*, 5*
Healthcare professionals lack knowledge, understanding and confidence about chronic pain after cancer treatment	Raise awareness, knowledge and understanding of chronic pain after cancer treatment among the healthcare workforce to increase confidence to listen about, acknowledge and address pain, with people living with and beyond cancer	1*, 2*, 3*, 5*
People living with and beyond cancer are not prepared for chronic pain after cancer treatment: - They are not informed of risks of chronic pain after cancer treatment at diagnosis and pre-cancer treatment - They are not aware of signs and symptoms of chronic pain when they arise	People living with and beyond cancer should be given accessible information about risks of late effects of cancer, including chronic pain, before - and throughout their cancer pathway	1*, 2*, 3*, 5*
Living with chronic pain after cancer treatment affects physical, psychological, social, emotional, financial, and social wellbeing yet cancer survivors have difficulty accessing support for their chronic pain after cancer treatment	People living with and beyond cancer should have access to rehabilitation and support services	1*, 2*, 3*, 5*

1* Qualitative evidence synthesis, 2* Cancer survivor study, 3*Healthcare professional study, 4* Expert Review Panel, 5* Published literature

Clinical recommendation 1: People living with and beyond cancer who experience chronic pain after cancer treatment should have their concerns listened to and acknowledged

Evidence for recommendation

All studies in this thesis demonstrate that cancer survivors living with chronic pain after cancer treatment do not feel listened to, heard or believed when talking to healthcare professionals about their chronic pain after cancer treatment:

1: Qualitative evidence synthesis:* Women felt their chronic pain after cancer treatment was not recognised or acknowledged by some healthcare professionals and in some instances, when women did tell physicians about their pain, they felt either dismissed or were sent to a psychiatrist. This ‘psychiatrization’ of pain made women feel impotent and guilty because it implied that their pain was not ‘real’.

2*: *Qualitative cancer survivor study:* Participants felt they had not been listened to and thought some healthcare professionals did not believe that chronic pain after cancer treatment was a genuine ailment. Participants needed to broach the subject of chronic pain after cancer treatment with healthcare professionals many times. This led to them having the impression that healthcare professionals were exasperated and irritated by them and to thinking that healthcare professionals might have suspected they were making up how hard it was for them. When participants tried to highlight or discuss chronic pain after cancer treatment with healthcare professionals, they were often met with resistance. It seemed to participants that some healthcare professionals did not want to, or could not, make the connection between the pain that participants were experiencing and their previous cancer treatment. Some felt healthcare professionals ignored their chronic pain and dismissed their concerns.

3: Quantitative healthcare professional study:* Most healthcare professionals thought it was their role to listen to people living with and beyond cancer talk about their experiences of living with chronic pain after treatment. However, approximately a quarter of healthcare professionals reported they never or rarely did so. Almost a quarter either did not know that chronic pain can start years after cancer treatment has ended and can be related to previous cancer treatment, or stated that it could not. Many did not understand the impact chronic pain had on cancer survivors' lives.

4: Expert Review Panels:* It was recognised that validating cancer survivors' experiences of chronic pain are at the heart of best practice.

5: Published literature:* There is a growing body of evidence about the experience of living with chronic pain and over 20 reviews have been published in this area since 2012 (Toye *et al.*, 2021). However, the qualitative evidence synthesis published from work within chapter 2 of this thesis is the only review that has focused on chronic pain in cancer survivors (Toye *et al.*, 2021; Armoogum *et al.*, 2020). Most of the research into the experiences of chronic pain has been in the non-malignant population (Toye *et al.*, 2021). In the non-malignant chronic pain literature, Toye and Colleagues (2017) conducted a *mega*-ethnography using 11 qualitative evidence syntheses with over 5000 international participants. They found 10 of the 11 qualitative evidence syntheses supported the conceptual category of 'lost personal credibility' in which participants described a loss of personal credibility as no one believed their pain was real. This is reflected in a recent published qualitative study exploring the barriers to adequate pain control with 25 breast cancer survivors (Marshall *et al.*, 2022). Marshall and colleagues found cancer survivors with chronic pain after cancer treatment felt questions were made about the validity of their pain by healthcare professionals. Participants expressed that healthcare professionals disregarded their pain and did not believe that after a given time on opioid therapy, they should still experience pain (Marshall *et al.*, 2022). They expressed that healthcare professionals' attitudes and discomfort at managing long-term chronic pain after cancer treatment often made them feel as if they were drug-seeking. Cancer survivors noted not wanting to discuss their discomfort with their healthcare professionals because of fear or concern of not being believed or being labelled as a hypochondriac, manipulating, or demanding of opioid therapy (Marshall *et al.*, 2022).

Collectively, these findings demonstrate that people living with and beyond cancer do not feel heard or believed when talking to healthcare professionals about their chronic pain after cancer treatment. This resulted in the recommendation that people living with and beyond cancer who experience chronic pain after cancer treatment should have their concerns listened to and acknowledged.

Challenges to implementing the recommendation

There is consensus among clinicians, researchers and policy makers that listening to patients is essential and how people are communicated with impacts on their care experience (NHS England, 2021a; Fitch *et al.*, 2020; Street *et al.*, 2019). Communication skills training in cancer care has been advocated for decades (Fallowfield and Jenkins, 1999) and is known to increase levels of healthcare professional empathy (Moore *et al.*, 2018). However, poor communication and lack of empathy from healthcare professionals is still resulting in unmet need in people living with and beyond cancer (Rodrigues *et al.*, 2022). Within the UK, there have been drives to encourage healthcare professionals to ask patients what matters to them and personalise their care (Healthcare

Improvement, 2020; Department of Health, 2019b). This cannot be achieved without listening to patients, yet evidence highlights that this does not always happen in practice. The Cancer Patient Experience Survey (CPES) in England reported that during their hospital stay, almost 70% of respondents said they could always talk to the hospital staff about their worries and fears if they needed to, however when it came to discussing options for managing the impact of any long term side effects, this dropped to just over half (NHS England, 2021b). It is unlikely that healthcare professionals would advocate *not* listening to people living with and beyond cancer talk about their concerns, so it is important to consider the barriers that are preventing them from doing so. Lack of time and skill is often cited as a barrier to effectively communicating with patients (Margariti *et al.*, 2020; Chan *et al.*, 2019). However, attributing this solely to time restraints or lack of communication skills ignores an important nuance highlighted by the findings of this thesis: that participants did not feel *believed* when they spoke about their chronic pain after cancer treatment. Some healthcare professionals can see cancer survivors who experience pain as difficult, “complainers”, with a tendency to exaggerate their pain (Slaghmuylder *et al.*, 2022, p.8) and cancer survivors can fear being considered a hypochondriac or manipulating and demanding (Marshall *et al.*, 2022). This level of judgment and prejudice will prevent healthcare professionals from truly listening and believing what cancer survivors are saying about their pain. No healthcare professional participant in this thesis demonstrated a derogatory judgement to people living with and beyond cancer who experience chronic pain. However, evidence from this thesis highlights that some healthcare professionals do not fully understand the impact that living with chronic pain has on cancer survivors: they did not recognise cancer survivors as the voices behind the patient experience quotes from the qualitative study that they were presented with in the healthcare professional study. Many did not know that chronic pain that starts years after cancer treatment has ended can be related to previous cancer treatment. In clinical practice, if patients try to broach their experiences of living with chronic pain after cancer treatment with healthcare professionals, but those healthcare professionals have a lack of understanding of the impact of living in chronic pain after cancer treatment, that lack of understanding may come across to patients as if they are not being believed.

Potential solutions

Cancer survivor participants in this thesis, who had experienced being listened to, heard and believed by healthcare professionals, felt valued. This acknowledgement led to a sense of relief and a feeling of empowerment and strength to go on. This is reflected in a recent meta-ethnography study synthesizing 195 qualitive studies to understand the process of healing for those living in chronic pain (Toye *et al.*, 2021). Toye *et al.* (2021) found that for people living in chronic pain, finding a voice and being heard by others was a key theme towards a healing journey. To feel that their suffering was given a voice, was understood, that they had time to tell their story, were believed and taken seriously, was lifechanging. It is important that healthcare professionals are reminded of the importance of listening to people living with and beyond cancer and acknowledging their pain. It was evident in the healthcare professional study in this thesis that healthcare professionals perceived a personal lack of knowledge about chronic pain, or limited support services to refer and signpost to, as barriers to talking to cancer survivors about chronic pain after cancer. Some healthcare professionals are *"so programmed to fix things that sometimes we're not hearing what our patients are saying to us"* (Randall-

David *et al.*, 2003, p.664) and as was expressed in the expert review panel discussions in this thesis, they want to '*sort their (patients) problems out*'. However, for many cancer survivor participants in this thesis, the feeling that they had been listened to and thus have their experiences validated, *had* been the difference between feeling supported or not.

Clinical recommendation 2: Chronic pain after cancer treatment should be accurately diagnosed and explained to cancer survivors living with chronic pain after cancer treatment

Evidence for recommendation

In this thesis, cancer survivors who had received a formal diagnosis and explanation for their chronic pain after cancer treatment felt understood and validated by healthcare professionals and better able to manage their pain. Within this thesis, evidence for this comes from:

2: Qualitative cancer survivor study:* The value of a chronic pain diagnosis after cancer treatment, and an explanation of the aetiology of their pain, could not be overestimated for cancer survivors. It helped them manage and cope with their pain and its impact. Having their pain explained enabled them to understand it, and consequently it made a difference to how they lived. The sense of relief, and even joy, at chronic pain after cancer treatment being identified and explained was clear in participants who had experienced it.

4: Expert Review Panels:* A clinical diagnosis of chronic pain after cancer treatment and an explanation of the aetiology of their pain was essential to enable cancer survivors to take ownership of their symptoms and facilitate joint decision making with healthcare professionals.

5* *Published literature:* A recent quantitative study of 549 participants from 13 countries in Europe, aged 18 years or over, with a diagnosis of non palliative cancer and who experienced at least three symptoms of neuropathic pain, found being formally diagnosed with cancer-related neuropathic pain was significantly associated with participants feeling that their healthcare professional understood the impact of their pain on their life (Dupoiron *et al.*, 2022). Further, Dupoiron and colleagues found participants who had been formally diagnosed with cancer-related neuropathic pain expressed they believed healthcare professionals made every effort to find the best treatment for them. Additionally, participants were significantly less likely to state that their healthcare professional made them feel like their cancer-related neuropathic pain was unimportant, and those who had a formal diagnosis were significantly more likely to be satisfied with their pain management treatments (Dupoiron *et al.*, 2022). A diagnosis can provide understanding and comfort to the person living with chronic pain. Toye *et al.* (2021) described having a meaningful and acceptable explanation for chronic pain gave a person a sense of control and made the pain less threatening. The International Association for the Study of Pain (IASP) agrees and proports that correctly identifying the nature and cause of pain in a cancer patient or cancer survivor is important to achieve optimal pain control (Bennett *et al.*, 2019b). The IASP state that an accurate diagnosis and classification of pain can lead to important benefits to patients including referral to tailored treatments, triggering support to promote patient self-management, and more specialist referrals for some patients with complex pain needs (Vaz-Luis *et al.*, 2022; Bennett *et al.*, 2019b).

Participants in the qualitative study by Dupoiron and colleagues (2022), who truly felt they understood their chronic pain after cancer treatment, felt better able to manage it. This is supported by contemporary psychoeducational interventions, known as pain science education, that focus on explaining how pain works and thus reconceptualising the meaning of pain. This has been shown to promote patient agency and autonomy, enabling and empowering patients to evaluate treatment options and make optimal coping decisions (De Groef *et al.*, 2022). Thus, evidence from this thesis, and the literature, support the recommendation that chronic pain after cancer treatment should be accurately diagnosed and explained to cancer survivors living with chronic pain after cancer treatment.

Challenges to implementing this recommendation

Cancer survivors are significantly less likely to receive a diagnosis of cancer-related pain compared to those on active cancer treatment (Dupoiron *et al.*, 2022). It is recognised that it can be difficult to diagnose and determine if the pain is related to cancer or something else. This was a key barrier for healthcare professionals in this thesis when they were talking to people living with and beyond cancer about chronic pain after cancer.

Cancer survivors may have existing or increased co-morbidities (Williams *et al.*, 2016; Elliott *et al.*, 2011). Co-morbidities can complicate attributing chronic pain to cancer treatment and cancer recurrence needs to be excluded. Furthermore, chronic pain after cancer treatment can occur years after treatment has ended but evidence from this thesis shows that up to a quarter of healthcare professionals do not know this, thus, would not be looking to diagnose it. Even if healthcare professionals are aware of the risk of chronic pain after cancer treatment, they may not know that a patient has had a previous cancer diagnosis (Walter *et al.*, 2015) or, if they do, it can be hard to isolate the exact aetiology if patients have been extensively treated for cancer (Bennett *et al.*, 2019c). Collectively, these problems can result in either a lack of diagnosis, or a protracted route to diagnosis. This was expressed as a frustration by both cancer survivors and healthcare professionals within this thesis.

Potential solutions

Without adequate knowledge and understanding of causes, prevalence, risks and timing of chronic pain after cancer treatment, healthcare professionals will not be able to explain it to people living with and beyond cancer. Nor will healthcare professionals know to be looking for chronic pain after cancer treatment as a potential diagnosis and cause of pain. Thus, firstly, healthcare professionals need more knowledge and understanding of chronic pain after cancer treatment. Secondly, clinical guidelines are needed to support healthcare professionals to accurately diagnose chronic pain in cancer survivors. To facilitate this, clinical guidelines and advice are being developed and published to support healthcare professionals to accurately diagnose chronic pain in cancer survivors (Emery *et al.*, 2022; Glare *et al.*, 2022; Bennett *et al.*, 2019c; Paice *et al.*, 2016), however, this needs to be in conjunction with an increase in knowledge and understanding from healthcare professionals.

Clinical recommendation 3: Raise awareness, knowledge and understanding of chronic pain after cancer treatment among the healthcare workforce to increase confidence to listen about, acknowledge and address pain, with people living with and beyond cancer

Evidence for recommendation

Evidence from this thesis demonstrates that healthcare professionals lack knowledge, understanding and confidence about chronic pain after cancer treatment.

2 Qualitative cancer survivor study:* The lack of knowledge and understanding about chronic pain after cancer treatment threaded through all the interviews. It seemed to cancer survivors that healthcare professionals did not have any knowledge about chronic pain after cancer treatment, nor understanding of the true impact that living with chronic pain after cancer treatment had on participants.

3 Quantitative healthcare professional study:* Healthcare professionals had limited knowledge of prevalence and severity rates of chronic pain after cancer treatment and the risk factors. Healthcare professionals exhibited mixed levels of understanding of the impact of chronic pain after cancer treatment on cancer survivors' lives: for half of the patient statements (n=10), more than 10% of healthcare professional participants did not think the statement came from a cancer survivor living with chronic pain after cancer treatment and for some statements it was over 30%. Healthcare professionals lack confidence to talk, help or support people living with and beyond cancer about chronic pain after cancer treatment, with mean scores ranging from 42-44 (0 = not at all confident, 100 = very confident).

4* *Expert review panels:* The central tenant for shared decision making was the importance of informed patients and healthcare professionals. From a healthcare professional perspective, it was proposed that everyone involved with people's care should know about the reality of chronic pain after cancer treatment, including those involved with providing treatments. It was acknowledged that without knowledgeable healthcare professionals having awareness of the risks and impact of chronic pain after cancer treatment, the potential benefits of a holistic needs assessment are limited.

5* *Published literature:* Slaghmuylder and colleagues (2022) found insufficient healthcare professional knowledge can hinder follow up care for breast cancer: healthcare professionals underestimate the prevalence, severity and impact of pain and pain related problems in cancer survivors and feel they lack knowledge in the causes and management of chronic pain. Participants in this thesis wanted more education about chronic pain after cancer treatment. Many authors recognise the need for nurses, doctors and allied health professionals to have more education about cancer late effects and chronic pain (Ellison *et al.*, 2021, 2022; Dyer and Dewhurst, 2020; Faithfull *et al.*, 2016; Breuer *et al.*, 2015; Walter *et al.*, 2015) and that self-perceived gaps in knowledge, skills and confidence can serve as a barrier to healthcare professionals addressing needs about long term effects of cancer with patients (Fauer, Ganz and Brauer, 2022).

These findings demonstrate the need to raise awareness, knowledge and understanding of chronic pain after cancer treatment among the healthcare workforce to increase confidence to listen about, acknowledge and address pain, with people living with and beyond cancer.

Challenges to implementing recommendation

Specialist cancer education can benefit healthcare students and the general and specialist healthcare workforce (Armoogum, 2022; Chan *et al.*, 2022; Watson *et al.*, 2021; Wong *et al.*, 2021; Edwards *et al.*, 2016). Wong *et al.* (2021) found specialist training in cancer care was associated with higher levels of perceptions of responsibilities in providing interventions for the physical and psychosocial consequences of cancer and its treatment as well as coordination of care to ensure that all health needs of cancer survivors are met (Wong *et al.,* 2021). However, the long term impact of cancer education is rarely reported (Campbell, Taylor and Douglas, 2019). Furthermore, whilst literature shows that there are advantages to cancer survivorship education for healthcare professionals, such as increased confidence, knowledge and behaviour change, many papers have methodological bias and weakness (Chan *et al.*, 2022). Thus, whilst it is essential that educational resources are developed to address the knowledge gap relating to chronic pain after cancer treatment among healthcare professionals, these resources must have appropriate pedagogical underpinnings. Their development and evaluation should be informed by the relevant cancer practice and education guidelines, and teaching and learning theory and frameworks.

Potential solutions

Despite the challenges discussed above, there are some very encouraging facilitators to raise awareness, knowledge and understanding of chronic pain after cancer treatment among the healthcare workforce. Within this thesis, there was a good response rate to the survey, including a range of healthcare professionals, and they wanted to increase their knowledge about chronic pain after cancer treatment and asked for more learning resources. This shows a level of enthusiasm and commitment to increase their knowledge. Furthermore, everyone who was asked to participate in an expert review panel agreed and they all stressed the importance of raising awareness of chronic pain after cancer treatment. This is reflected in the literature because despite the challenges, healthcare professionals are highly motivated to address the long term effects of cancer on patients (Fauer, Ganz and Brauer, 2022).

There are also encouraging signs from UK policy to increase nursing and allied health professional knowledge and understanding of cancer. The Aspirant Cancer Career and Education Development programme (ACCEND) is a multiyear funded programme (2022 – 2025) aiming to provide transformational reform in the education, training and career pathways for cancer support workers, nurses and allied health professionals supporting people affected by cancer in the UK (ACCEND, 2023). ACCEND involves five workstreams, each focusing on a level of practice (supportive and assistive, pre-registration, registration, enhanced, advanced and strategic leadership) with an overarching Framework (Appendix 25). The Career Pathway, and the Core Cancer Capabilities and Education Framework was published in January 2023 (ACCEND, 2023). The 'Framework' consists of three components: 1) Career pathway 2) Core cancer capabilities in practice and 3) Education. Within the framework, pain (acute and chronic) is recognised and listed as an example of a common disease and treatment related effect and there are core capabilities in practice related to late effects of cancer (ACCEND, 2023). The educational component of the framework provides specific learning outcomes for each level of practice. The learning outcomes stipulate increasing knowledge and understanding of transitions of the cancer pathway and the late and long-term effects of cancer are specifically cited within the syllabus. The publication of these nationally agreed learning outcomes will enable educators in clinical practice and Higher Education Institutes to design their educational programmes and resources to meet the relevant learning outcomes. Further, to support Higher Education Institutes to increase cancer education in their nursing and allied health professional pre-registration programmes, in Spring 2023, ACCEND will be releasing the Foundations of Cancer Care online modules. This will consist of nine e-learning modules on the nationwide e-learning for health (e-LfH) platform. The modules will be given ‘green’ level access, which means they can be accessed by the general public and any email address will be accepted to log in for access to them. Therefore, they will be able to reach interested audiences without restriction. The modules have been designed and authored by a team of nursing and allied health professional cancer educators, led by JA. Modules include:

- 1. The context of cancer
- 2. The science of cancer
- 3. Personalised treatment and care for cancer
- 4. Understanding the impact of cancer on the individual, families and healthcare professionals
- 5. Living with and beyond cancer
- 6. Palliative and end of life care
- 7. Self care, ethics and clinical leadership in cancer
- 8. Communication and team working in cancer care
- 9. Evidenced based practice and applied research in cancer care

Late and long term effects of cancer, including chronic pain after cancer treatment, have been included in these modules and the resources include interactive written content, videos of people sharing their experiences of living with and beyond cancer, self assessment quizzes plus reflective and work place activities. The chronic pain after cancer treatment content was informed by the published research cited in this thesis and the published qualitative evidence synthesis (chapter 2) was included in the reading list (Armoogum *et al.*, 2020). Implementation guides are being developed to support Higher Education Institutes to include these resources in pre-registration curricula and the University of the West of England (UWE) will be a case study example. Within UWE, the intention is for all pre-registration healthcare students to undertake the e-learning module as a timetabled activity from the academic year 2023/24. The modules cover a broad range of issues related to cancer care and thus, late and long term effects, and chronic pain after cancer, are only included briefly. However, the issue will still be highlighted to pre-registration students and more detailed educational resources, expanding on supporting people living with and beyond cancer treatment with chronic pain after cancer treatment, can be developed in the future.

Clinical recommendation 4: People living with and beyond cancer should be given accessible information about risks of late effects of cancer, including chronic pain, before treatment and throughout their cancer pathway

Evidence for recommendation

People living with and beyond cancer are not prepared for chronic pain after cancer treatment. They are not informed of the risks of chronic pain after cancer treatment at diagnosis and pre-cancer treatment. When chronic pain occurs, they are not aware it may be related to their previous cancer and its treatment. Evidence from this thesis to support this includes:

1 Qualitative Evidence Synthesis:* Many of the women were unprepared for the experience of chronic pain after cancer treatment. They expressed an expectation that they would experience acute pain during treatment, and many of the women felt supported during this time, yet did not recall being given information about possible chronic pain after cancer treatment. When chronic pain after cancer treatment manifested, they felt healthcare professionals avoided addressing it or dismissed their concerns and thus they felt abandoned and alone in the responsibility to manage their pain.

2 Qualitative Cancer Survivor Study:* Participants felt that they were not told about the risks, causes, symptoms or management of chronic pain after cancer treatment. Chronic pain after cancer treatment was an unexpected experience as participants felt unprepared for chronic pain after cancer treatment. Almost all participants felt they had not been told about the risk of chronic pain after cancer treatment at the time of cancer diagnosis or during their cancer treatment. As they had not been informed about chronic pain after cancer treatment, they did not know what to expect and thus, when symptoms started to appear, they did not understand them. They also recognised that not understanding or expecting chronic pain after cancer treatment made it harder to manage and cope with the pain, and the lack of discussion about long term side effects, including chronic pain after cancer treatment, made it harder for them to come to terms with living with pain.

3 Quantitative healthcare professional study:* Almost all participants thought people living with and beyond cancer should be informed about the potential for chronic pain after cancer treatment before cancer treatment. Over half of participants thought it was their role to talk to people living with and beyond cancer about the potential for chronic pain after cancer treatment and almost 40% thought it might be. However, over a quarter (27.4%) never or rarely talk to people living with and beyond cancer about chronic pain after cancer treatment.

4* *Expert Review Panels:* The central tenant for shared decision making was the importance of informed patients and healthcare professionals. Patient information, alongside reinforcement of the information, was fundamental.

5* *Published literature:* Research has shown that cancer survivors have unmet informational needs regarding treatment side effects (Bellas *et al.*, 2022; Fitch, Lockwood and Nicoll, 2021), leaving them with feelings of unpreparedness and isolation (Chambers *et al.*, 2018) and a lack of information can exacerbate side effects in cancer survivorship (Bellas *et al.*, 2022; Philp *et al.*, 2017). Collectively, these findings demonstrate that people living with and beyond cancer should be given accessible information about the potential risks of late effects of cancer, including chronic pain, before treatment and throughout their cancer pathway.

Challenges to implementing recommendation

Information giving in healthcare can be complex and there is little agreement about how, when and by whom information should be given to people living with and beyond cancer. In this thesis, most healthcare professionals thought diagnosis and pre-treatment were the most appropriate times to give information about the risks of chronic pain after cancer treatment. However, there are competing priorities at the pre cancer treatment stage (Fauer, Ganz and Brauer, 2022). Research has demonstrated that at diagnosis and during cancer treatment, patients can find it difficult to understand and act on information and advice about acute, life threatening side effects such as neutropenic sepsis (Oakley *et al.*, 2017). In this context, discussing long term or late side effects that may or may not happen in the future seems of diminished importance. Furthermore, the perceived vast myriad of potential long term side effects can make it challenging to prioritise which to discuss with patients. Some patients can be overwhelmed by the amount of information they receive (Cunningham and Wells, 2017) and can find it hard to absorb everything that is being said, especially close to cancer diagnosis (Tanay and Armes, 2019). With regards to timing, Fauer and colleagues (2022) found some oncologists believe these discussions should be postponed until patients are more receptive to this information, emphasizing the end of treatment as a prime opportunity to provide anticipatory guidance and set realistic expectations with respect to long-term effects. However, as demonstrated by this thesis, there are poor levels of knowledge about chronic pain, and many healthcare professionals do not think it is in their *'remit'* to discuss chronic pain or *'honestly haven't thought about it'*. Therefore, there is a risk that it will be missed or forgotten in practice, with everyone thinking that someone else is picking it up. Whilst there is agreement within the data in this thesis, and the wider literature, that patients should be informed about the risks of chronic pain after cancer treatment, when and by whom continues to be unclear.

Potential solutions

Information recall is known to be challenging at a time of heightened anxiety such as a cancer diagnosis (Nguyen *et al.*, 2019). Information recall by patients can be enhanced by empathetic healthcare professional communication (Westendorp *et al.*, 2021) and verbal information can be supported with supplementary written information (printed or web based) or videos, animations or podcasts. Healthcare professional skills in communication and assessment can enable healthcare professionals to judge when and how to give people living with and beyond cancer information about chronic pain after cancer treatment.

In addition to healthcare professionals giving information, people living with and beyond cancer can benefit from being able to access information when they feel ready. How they choose to do this varies from person to person, therefore a range of information from websites, webinars, podcasts, and written information can be helpful. When creating information, content authors should be mindful of the language used, accessibility of the information and health literacy of the population (Papadakos *et al.*, 2018; Manning and Dickens, 2006). Increasingly, people living with and beyond cancer are co-designing information with healthcare professionals, academics and digital providers to ensure the information is accurate, relevant and user-friendly (Grynne *et al.*, 2021).

Clinical recommendation 5: People living with and beyond cancer should have access to rehabilitation and support services

Evidence for recommendation

Living with chronic pain after cancer treatment is hard. It affects physical, psychological, social, emotional, financial, and social wellbeing. Yet cancer survivors have difficulty accessing support for their chronic pain after cancer treatment. Therefore, people living with and beyond cancer should have access to rehabilitation and support services. Evidence for within this thesis includes:

1 Qualitative evidence synthesis:* The physical and emotional impact of chronic pain on women came across in the studies and living with chronic pain after cancer treatment was hard on the women as it hindered them at work, in physical activities and in their social and personal lives. The physical aspects of the pain caused them difficulties in performing day to day activities, and it frustrated and upset them. However, women felt abandoned by healthcare professionals and alone in managing their pain as they were not given support to manage the pain or its impact.

2 Qualitative Cancer Survivor Study:* Living with chronic pain after cancer treatment negatively impacted and shaped all aspects of participants' daily lives: physical, emotional, social, sexual, spiritual and economic. Participants expressed that living was chronic pain after cancer treatment was hard, relentless and felt endless. It felt as if their life had shrunk or diminished in some way and this made them feel isolated and lost. They were unable to undertake activities such as hobbies or driving. Many participants had needed to stop working, mourned the loss of their job and their sense of identity.

It was clear from the cancer survivor study that pain after cancer treatment is messy, confusing and support is hard to identify. The messiness and lack of support started soon after cancer treatment had finished. Participants reported how they felt abandoned by acute cancer services at the end of treatment and a similar feeling in relation to pain services, particularly if pain management interventions had been seemingly ineffective. When their chronic pain symptoms started, it was evident that participants found it difficult to identify and access services to help support them. Participants had to learn about chronic pain after cancer treatment themselves and seek their own support. They found this difficult to do and it took its toll on their wellbeing. There was an apparent inequality regarding identifying support services and it was evident that some participants had needed to use their own personal drive and determination to identify specialist services and get referred to them. Many participants explained that they felt they had spent a lot of time bouncing between clinical services searching for support with their chronic pain after cancer treatment. William explained "*it was a bit like being a ping-pong ball… "*. They felt like there was conflict and confusion about whether their care needs fell under cancer services, pain services or primary care. It felt to participants that healthcare professionals did not know how to manage or relieve their chronic pain after cancer treatment and thus, simply referred them to another service. Consequently, participants were trapped in a cycle of endless referral and felt unsure about where to go for help.

3 Quantitative healthcare professional study:* Participants commented on the lack of services available to support people living with and beyond cancer with chronic pain after cancer treatment and resulted in healthcare professionals feeling they should not or could not signpost to services. Furthermore, the limited services available were felt to often change, which made signposting difficult. There was also conflict between primary and secondary care. Primary care staff felt frustrated that those in secondary care were not doing enough to support people living with chronic pain after cancer treatment.

4 Expert Review Panels:* The complexity of the issues surrounding clinical pathways was acknowledged in all expert review panels. The significant challenges of commissioning, education, access, and communication were highlighted. The complexity and 'messy' nature of where these services sit was acknowledged by all expert review panels. There was agreement that communication needs to improve across services, there is inconsistent provision across the UK, and referral pathways need to open up, but it was acknowledged that commissioning makes that extremely challenging. There was no consensus about where a support service should be based.

5*: *Published literature* Cancer survivors can have unmet needs regarding the physical consequences of cancer (Bellas *et al.*, 2022), and specifically about chronic pain after cancer (Dupoiron *et al.*, 2022). Yet cancer survivors experience challenges when trying to access and receive support. This mirrors the findings from Fitch and colleagues (2019) study, whereby 35% of cancer survivors found it difficult to obtain help (Fitch *et al.*, 2019). Collectively these findings highlight the importance of the recommendation: People living with and beyond cancer should have access to rehabilitation and support services.

Challenges to implementing recommendation

Whilst it is evidenced in this thesis that increasing access to support and rehabilitation services is essential, there are challenges to this. Findings from this thesis have demonstrated there are issues within the healthcare system for supporting cancer survivors living with chronic pain. Issues include:

1) Cancer survivors encounter unclear and limited pathways to access support. They don't know who to ask, or when to ask, and support is hard to identify. Often, they feel it is left to them as individuals to seek out support systems whilst they 'grapple in the dark'

2) Healthcare professionals state there is a lack of available support services to refer patients to. They consider the limited services available are very stretched and have limited time and capacity and this makes them feel that they cannot, or should not, refer patients to these services. Further, as shown within this thesis, healthcare

professionals may not know about available provision or consider there to be inconsistent provision of support and rehabilitation services across the UK. A recent conference poster of a survey of services to support people living with cancer-related pain in the UK supported this assertion (Galligan et al., 2022). This survey was conducted by the Cancer Pain Nurses Group, a subsection of the Pain Nurse Network, of which the researcher is a member of, and co-author of the poster. The authors found there is varied provision across the UK, with most services in the Northwest (n-22) and Southwest (n-17). Of the 63 services identified, 58.7% (n=37) only accept local referrals and there was inconsistency in referral criteria (Galligan et al., 2022). This presents a challenge, people living with chronic pain after cancer treatment may not be able to receive a successful referral for support or rehabilitation services, be that local or specialist. Participants in the cancer survivor study in this thesis explained that travelling to a rehabilitation service that was far from home was a barrier to attending due to practicalities such as travel and cost but also physical energy levels.

3) Composition of support and rehabilitation services needs consideration. Multidisciplinary team working is regarded as essential for chronic pain rehabilitation in cancer (De Groef et al., 2019) yet Galligan et al. (2022) found that just over half (52.4%, n=33) of services that support people living with cancer-related pain offered people a multi-disciplinary pain assessment.

4) There are ongoing challenges between primary and secondary care with regards to communication and who is responsible for care and when. Poor communication and unclear roles between primary and secondary care result in reduced referral. This is a worldwide challenge. In a review of 97 articles from USA, Canada, Australia, the EU and UK on primary care led cancer survivorship care, interdisciplinary communication was

highlighted as the largest barrier from cancer specialists' perspectives and the second largest barrier from primary care providers' perspective (Hayes et al., 2022).

5) There are nationwide challenges to how services are commissioned, accessed and advertised.

Potential solutions

For cancer survivors generally, and those with chronic pain after cancer treatment specifically, there are potential solutions to the challenges of access to support and rehabilitation and improving the system.

For all cancer survivors, there has been much improvement in cancer survivorship care in recent years, including the introduction of personalised stratified follow up pathways for cancer survivors in the UK (Jefford *et al.*, 2022; Maher *et al.*, 2018; McConnell, White and Maher, 2017). There are various models for how support can be delivered in the months and years following cancer treatment including supportive self-management, patient - initiated follow up, nurse led follow up, oncologist led follow up, follow up by general practitioners, shared care between oncology providers and primary care providers, long term and late effects clinics and comprehensive multidisciplinary rehabilitation (Foster, 2022; Jefford *et al.*, 2022).

It is known that appropriate support can reduce health crises, enhance confidence to manage and improve mental health, quality of life and other health outcomes in cancer survivors (Foster, 2022). There is recognition by healthcare professionals that alternative models of care, such as patient initiated follow up, could result in moving from the current paternalist system to one that empowers cancer survivors to have more control (Lorenc *et al.*, 2022a). However, it is recognised that there are important facets and considerations within this, such as cancer survivor confidence in seeking help and the patient-clinician relationship. Cancer survivors need to feel they are being taken seriously and have appropriate and timely responses from clinicians (Lorenc *et al.*, 2022b).

Self-management support can reduce symptom severity in fatigue, pain, anxiety and give rise to improvements in self efficacy (Howell *et al.*, 2021; Boland, Bennett and Connolly, 2018; Kim, Kim and Mayer, 2017; Foster *et al.*, 2016; Hammer *et al.*, 2015), and interventions for supported self-management of pain in cancer survivors can be effective (Hernandez Silva, Lawler and Langbecker, 2019). However, support for self-management is not consistent (Foster, 2022; Howell *et al.*, 2021). Barriers to self-management can include a paternalistic model of care, whereby the 'expert' holds the power and responsibility for care, and/or the healthcare professional is reluctant to relinquish control and they do not believe individuals are capable of supported self-management (Howell *et al.*, 2021). However, evidence from the patient representatives in the expert review panels of this thesis, explained what 'good' support services would look like: *'good would be well informed patients and healthcare professionals that are making good decisions together'.* This is the hallmark of supported self-management and thus there needs to be a cultural shift to embrace these partnerships (Foster, 2022; Howell *et al.*, 2021).

There have also been attempts to improve the long-standing challenge of communication between primary and secondary care. Cancer survivorship plans and end of treatment summaries have been introduced in the UK to improve communication across the cancer care pathway (Maher *et al.*, 2018) . Whilst provision of treatment summaries is not universal (Walter *et al.*, 2015), and incomplete follow up letters can be a barrier to primary care providing cancer care reviews (Gopal *et al.*, 2022), they are considered a useful communication tool (Jefford *et al.*, 2022) and have been found to enhance patient understanding and perception of the quality of care provided (Corsini *et al.*, 2020).

In addition to the cultural changes to the care pathways for cancer survivors, various actions could increase access to rehabilitation and support services for cancer survivors living with chronic pain after cancer treatment. Firstly, greater awareness from healthcare professionals of chronic pain after cancer treatment to enable them to inform people living with and beyond cancer about it and signpost to support services when required. Secondly, to enable signposting, directories of pain management programmes have been published by the British Pain Society (Kelly and Williams, 2020) and the Pelvic Radiation Disease Association have produced a list of cancer late effects services across the UK (Pelvic Radiation Disease Association, 2022b). Greater promotion of these directories will support healthcare professionals to identify appropriate services to signpost cancer survivors living with chronic pain after cancer treatment to. Finally, recent guidance on the provision of pain services for adults across the UK with cancer or life limiting disease, including cancer survivors, has been published. This guidance seeks to inform and stimulate delivery of pain services in secondary care, which is offered by most district level hospitals, and identify referral pathways to highly specialist pain management services (Faculty of Clinical Oncology, The Royal College of Radiologists, 2019). This guidance will ensure each of the 211 Clinical Commissioning Groups (England), 14 NHS Boards (Scotland), 7 Health Boards (Wales), or 5 Heath and Social Care Trusts (Northern Ireland) will enable direct and rapid access to services to support patients with persistent or recurrent pain who are not adequately managed in the primary or generalist setting. Services will hold a weekly multi-disciplinary meeting comprising nursing, physiotherapy, pain and palliative medicine clinicians and other healthcare professionals to undertake clinical assessments that should include pain diagnosis and aetiology, further investigations as required, and an agreed management plan consistent with the patient’s goals and preferences. Whilst this guidance is for the UK as a whole, it is not clear if referral across national boundaries will be possible. However, this guidance will be key to ensuring equitable access to support and rehabilitation services across the UK.

There are some very encouraging facilitators in the support of cancer survivors living with chronic pain after cancer treatment. Within this thesis, a key sign of enthusiasm and commitment to this area was the number of participants willing to take part in the healthcare professional study and expert review panels. Healthcare professionals wanted to increase their knowledge about chronic pain after cancer treatment and asked for more learning resources. This is mirrored in the literature (Fauer, Ganz and Brauer, 2022). Furthermore, momentum is building to increase research in this area. This is evidenced by the James Lind Alliance including the management of persistent pain as a top 10 living with and beyond cancer research priority (Li et al., 2019). Furthermore, the European Expert Consensus Statements on Cancer Survivorship for promoting high quality care and research include physical long-term and late effects of cancer and cancer treatment and chronic medical conditions, including pain, as a priority to address patients’ needs (Vaz-Luis et al., 2022).

There has been a recent plethora of research into patients and chronic pain after cancer treatment (Dugué et al., 2022; Dupoiron et al., 2022; Halpern, de Moor and Yabroff, 2022;

Rosenberg, Butow and Shaw, 2022; Schmidt et al., 2022), healthcare professionals' knowledge and chronic pain after cancer treatment (Fauer, Ganz and Brauer, 2022; Silbermann et al., 2022; Slaghmuylder et al., 2022) and a recognition for greater healthcare professional education about cancer survivorship (ACCEND, 2023; Chan et al., 2022). Furthermore, there have been recent publications to support the management of chronic pain in cancer survivors (De Groef et al., 2022; Emery et al., 2022; Marshall et al., 2022) and discussions on how services are co-ordinated (Foster, 2022; Jefford et al., 2022). This thesis has contributed to this evidence base.

6.2: Implementation strategy

- **Develop and promote educational resources for healthcare professionals**

Bitesize, freely available and accessible educational resources should be developed to highlight and reinforce the importance and value of listening to, believing and acknowledging people who live with and beyond cancer when they talk about their experiences of chronic pain after cancer. Further, the educational resources should inform and educate about prevalence rates, risks and the impact of living with chronic pain after cancer. These, evidence-based, multidisciplinary educational resources should be co-designed and developed with clinical, research and pedological experts, people with lived experience of chronic pain after cancer plus partners such as charities and commissioners. Types of resources could include videos, podcasts, e-learning and booklets. The resources should be freely available on charity websites and learning platforms and evaluated to identify impact on practice.

In addition to the above resources, healthcare professionals should have access to high quality Continued Practice Development (CPD) courses that include innovative and reflective teaching and learning methods such as simulation, virtual reality and action learning sets, to explore and develop own learning and practice and enhance confidence of late effects of cancer, including chronic pain.

- **Co-design patient information resources about chronic pain after cancer**

Co-design, with patients, healthcare professionals and digital literacy teams, patient information resources, including webinars, podcasts and leaflets to raise patient awareness and understanding of chronic pain after cancer treatment. Resources should include information on the causes, risks, management and support of chronic pain after cancer treatment. To increase accessibility, leaflets to be available in multiple formats including online, print and audio. These should be promoted via national charities, clinical practice, cancer organisations and local patient events and networks. Further, increase awareness of support services through promotion of directories of support services, such as those offered by the Pelvic Radiation Disease Association (https://www.prda.org.uk/late-effects-services/) and British Pain Society, to healthcare professionals and people living with and beyond cancer.

- **Increase cancer education in pre-registration healthcare programmes**

Embed the ACCEND Career Pathway, Core Cancer Capabilities and Education Framework into pre-registration healthcare programmes using resources such as the Foundations of Cancer Care e-learning (Armoogum 2023, Armoogum et al 2023). Create a national working group, including representatives from the Council of Deans of Health (CODH), Higher Educational Institutions (HEI), NHS England, Northern Ireland, Wales and Scotland and clinical practice to develop national pre-registration guidelines for clinical practice and Higher Education Institutions (HEIs) to increase cancer education in pre-registration curricular.

- **Co-create self-management interventions with stakeholders to support people with chronic pain after cancer treatment**

Develop self-management interventions for people living with chronic pain after cancer. It is essential that these meet the needs of those who will be using them. Guided by the MRC framework for developing and evaluating complex interventions, core elements of intervention development for supported self-management for people experiencing chronic pain after cancer treatment should be explored. This should include consideration of the context, by reviewing published studies, guidelines and policies investigating self-management interventions for people with chronic pain to inform potential programme theories. There should be extensive stakeholder engagement including patient and public involvement activities to enhance understanding of how self-management interventions for people living with chronic pain after cancer could work, for whom and in what circumstances. It is essential that any intervention is for the whole population, and therefore public and patient activity should be mindful to include engagement with under-served communities. Key uncertainties should be identified and acknowledged and considerations should be given to how these could impact on the interventions and delivery. The interventions should be refined and potential models for interventions should be co-designed with stakeholder input including patient and public involvement, cancer chronic pain clinical experts and charity representatives. The potential models need to be further refined using consensus methodology to identify areas of prioritisation. Full economic considerations should be explored to understand the financial implications of different interventions and to aid decision making.

6.3: Evaluation of the impact of the public contributors on the research

Two public contributors worked alongside JA and the supervisory team on this research for four years. It is recognised that it is important to identify and share the difference that public involvement makes to research (UK Public Involvement Standards Development Partnership, 2019). Documenting the various public involvement activities carried out during the course of research is useful for monitoring and evaluating public involvement (Kok *et al.*, 2018). To support this, a public involvement impact log (Kok *et al.*, 2018) was maintained throughout the research and was used to record discussions with the public contributors and the resultant impacts. Areas where the public contributors impacted on the research included offering to send GP letters to participants, timings of the interviews and the wording of patient facing documentation. Discussion with the public contributors gave reassurance about an aspect of the research JA had felt particularly uncomfortable about: the term 'cancer survivor'. Due to evidence of contention within the literature, and many years of clinical experience within cancer care, JA grappled with using the term 'cancer survivor' within this thesis. JA felt particularly uncomfortable about the war metaphors surrounding 'survivor' (Parikh, Kirch and Brawley, 2015) and felt it did not sufficiently encompass the complexity of life after cancer. However, in the absence of a better alternative, it was decided to use the term within the thesis. Ultimately, it was one of the public contributors that settled JA's anxiety about adopting the term. JA was explaining her apprehensions and the public contributor gently, but firmly, pointed out that this research was indeed focused on those who has finished treatment, were no longer cancer patients and therefore were survivors of cancer – thus the term accurately described the population under study. Further examples of the impact of the public contributors are provided in appendix 26.

The impact log provided an opportunity to record outcomes from the PPI involvement within this study, but it did not evaluate the process or quality of the PPI involvement (Kok *et al.*, 2018). Kok *et al.,* (2018) offer four approaches to PPI evaluation, on a continuum from basic to realist evaluation (figure 13).

Figure 13: Approaches to evaluating PPI in research (Kok et al., 2018)

Impact log	'Cube' Framework	Public Involvement Impact Assessment Framework (PiiF)	Realist evaluation
• A simple method of recording outcomes in PPI research • Useful for basic evaluation of impact	• Used to evaluate process or quality of PPI • Particularly useful when immediate results are need e.g. to identify areas or concern and take remedial action	• A two part planning tool or problem solving mechanism • Part 1: planning PPI in a research project • Part 2: designing a plan to evaluate the impact of PPI • Comprehensive method, requiring time to execute	• Identifies what works for whom (outcome) in what circumstances and in what respects (context) and how (mechanism) • Complex, but useful when it is important to understand the factors shaping the impact of PPI

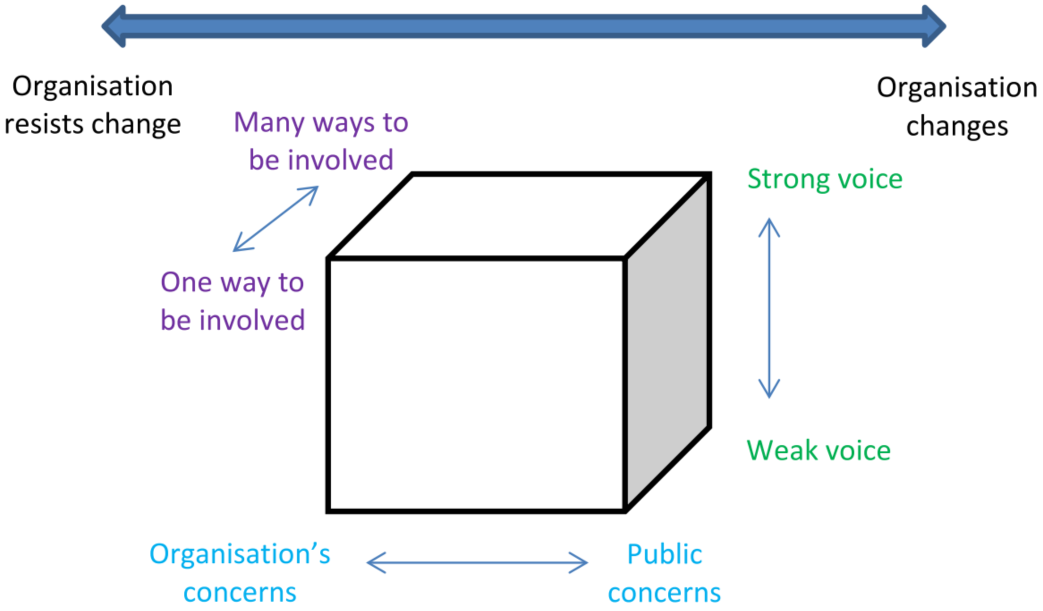
To evaluate the PPI impact on this research, it felt important to go beyond basic evaluation and simply recording the outcomes in an impact log. However, it was recognised that fully assessing the impact of PPI by comprehensive, but complex, approaches such as the Public Involvement Impact Assessment Framework (Collins *et al.*, 2018) or a realist evaluation (Pawson and Tilley, 1997) was not appropriate. This was because there was not the time or resource within the PhD to undertake a full impact assessment, nor was it the methodological focus of the PhD. However, the 'cube' framework (Gibson, Welsman and Britten, 2017) provided a structured approach to evaluation and offered an opportunity to evaluate PPI mid-way through the PhD, so any changes, suggestions or improvements could be implemented for the remainder of the programme of study.

The CUBE framework acknowledges that public and patient involvement (PPI) is dependent on context and involves interactions between different forms of knowledge (public, professional) within a ‘knowledge space’. Gibson and colleagues (2017) suggest there are four dimensions of knowledge space (voices, involvement, concerns, change) and each of these are on a continuum (table 29 and figure 14) (Gibson, Welsman and Britten, 2017)

Table 29: The four key dimensions of a knowledge space (Gibson, Welsman and Britten, 2017)

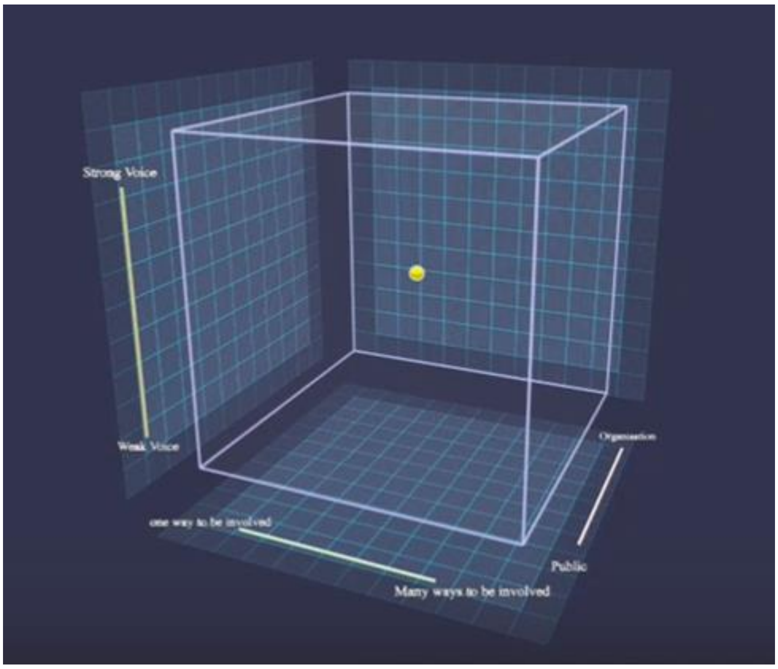
Dimension	Explanation
Weak voice or strong voice	Strong voices discuss issues and influence decision-making. Weak voices may discuss issues, but have little influence on decision-making
One way to be involved or many ways to be involved	Knowledge can take on different forms, which may not be equally valued. A single involvement approach is likely to privilege one social/cultural group over another, thus perpetuating inequality.
Organisation’s concerns or public concerns	Public concerns are in the context of social action, e.g. public opinion, norms and values, as well as individual experiences and behaviours. Organisation’s concerns are, e.g. bureaucracies and markets.
Organisation changes or organisation resists change	Decision-makers’ willingness and ability to respond to issues raised by participants in knowledge spaces depend on contextual factors, e.g. economic resources and national policies

Figure 14: The four dimensional 'cube' depicting a knowledge space (Gibson, Welsman and Britten, 2017)



To evaluate PPI within research, each member of the team is required to attend a workshop to discuss their involvement. Within the workshop, each participant uses a sticky note with an arrow on it to indicate where along the dimension they feel best represents their PPI experience (Gibson, Welsman and Britten, 2017). Dr Andy Gibson, Associate Professor in Patient and Public Involvement at the University of the West of England, kindly agreed to co-facilitate the workshops with JA to evaluate impact of PPI in this research. To enable people to speak freely, three separate workshops were planned, one for the PhD supervisors, one for the public contributors plus one facilitated by Dr Gibson whereby JA could reflect on her experiences. The workshops had been planned between March and June 2020 but needed to be postponed because of the Covid-19 pandemic. In November 2020, Dr Gibson explained that the team had created a virtual option for the CUBE evaluation and offered to run a virtual workshop with JA to evaluate the PPI impact in this project. The scores would be entered into a virtual CUBE (see figure 14).

Figure 15: Example of the virtual cube



Each participant was provided with an individual link to the 'virtual cube' ahead of the workshop and participants entered a rank score for each theoretical component alongside any comments. Their score was reflected as the coloured dot within the virtual CUBE. JA and Dr Gibson met to discuss the findings.

Findings from the Cube evaluation

There was agreement and consensus among the public contributors, supervisors and JA regarding where on the continuum the role of the PPI had occurred for each of the dimensions of the cube. All comments and rankings are in appendix 27.

<u>One way to be involved or many ways to be involved</u>

The public contributors marked this as 100 or 71 towards the 'many ways to be involved' end of the continuum for this dimension. The supervisors ranged from 74-87 and JA ranked it as 90. The average rank was 82. Comments about involvement focused on practical activities such as *'We have been involved in many ways at every stage, reviewing documents, how to engage the public, who to involve, where to advertise, qualitative analysis of data, poster development.'(Public contributor)* but also methods of involvement such as *'many opportunities between formal meetings to contribute via email' (Public contributor)* and *'1-2-1 and 1-2-2 phones calls between JA & PPI, face to face meeting, emails, tele and video conferences with supervisors. Included as authors on conference poster'(JA).*

Weak voice or strong voice

There was agreement among all participants that the public contributors had had a strong voice during the research process. Scores were ranked between 84-100 with a mean of 90. The public contributor explained that *'The way I am treated by professionals and other PPI is very important. If listened to and encouraged, as has been the case here, my voice continues to be strong. If the opposite happens, my voice can definitely be weakened' (Public contributor)* and *'I feel my voice as a PPI representative has been valued and respected from the outset' (Public contributor).*

Organisation's concerns or public concerns

The mean score for this dimension was 56 (41-84). In this scenario, the 'organisation' was taken to be the PhD. There was consensus that *'it's been pretty balanced' (Supervisor)* between the concerns of the public contributors and the organisation and it was recognised that *'the agenda of the project has been necessarily geared to academic rigour and to the standards required to fulfil the criteria of a doctoral qualification…..PPI contributors have been used effectively in shaping the research design and in managing* *the conduct of studies' (Supervisor).* A public contributor reflected that *'Julie sets the agenda for us but we have had the opportunity to modify the agenda, and our suggestions have always been listened to and taken on board when appropriate. I think I view us as an equal team, but with Julie leading and steering, if that makes sense, hence my 50.50 view'.*

Organisation changes or organisation resists change

The mean scores for this dimension were 91 (range 80-100) towards the 'organisation is willing to change' end of the spectrum. A public contributor commented that *'Julie has changed things as a result of our input, but more importantly has always been open to change'* and a supervisor explained *'Julie has been very open to change, ideas and feedback at all stages'.*

In summary, the evaluation demonstrated that all members of the research team felt the public contributors had a strong voice within the project, they were involved in many ways and the organisation was willing to change. There was recognition that within this particular project the 'concerns of the organisation' (i.e., a PhD) meant that JA needed to lead the project as the PhD candidate, and the PhD needed to meet the university doctoral descriptors, thus, the organisation's concerns were of equal value and importance as the public contributor contribution. The findings of the evaluation reassured the team that PPI was working effectively, everyone felt involved and respected and could continue for the remainder of the PhD.

Limitations of the evaluation

Public contributors were involved with the development and conduct of the study, and it was helpful that their impact was formally evaluated (UK Public Involvement Standards Development Partnership, 2019; Kok *et al.*, 2018; Gibson, Welsman and Britten, 2017), however, as the research team consisted of only seven people, the evaluation was very small scale. Despite this, evaluation and reflection on the impact of public contributors to doctoral research should be encouraged and disseminated (Jones and Hunt, 2022; Dawson *et al.*, 2020). Further, whilst the recruitment of the public contributors followed guidance to encourage maximum participation (National Institute for Health Research, 2014), the recruited public contributors were white, educated, retired professionals. Lack of diversity and representation is a common issue in patient and public involvement (Ocloo *et al.*, 2021). However, it is recognised that the public contributors had a demanding role within this thesis. Without the appropriate literacy skills, they would have found it very challenging, and may possibly not have been able to maintain the momentum required to work on a project for many years. To encourage as much opportunity for public involvement as possible within the PhD, patients were also represented in the expert review panels in chapter 5. This was a single event, whereby no literary skills were needed, and maximum flexibility could be offered in terms of meeting times and method. Consequently, patient representatives could be involved that may not have had the stamina, will or desire to contribute to the whole thesis.

6.4: Thesis summary

Thesis aims and objectives

This thesis aimed to identify the experiences of cancer survivors living with chronic pain after cancer treatment and consider how their experiences can be improved. The objectives were:

- To identify, review and synthesise the qualitative literature surrounding the experience of chronic pain after cancer in adult cancer survivors.
- To qualitatively explore the experiences, needs and service provision for cancer survivors living with chronic pain after cancer treatment.
- To establish healthcare professional understanding, experience, and confidence regarding chronic pain after cancer treatment.
- To describe future research and clinical recommendations to improve patient experiences relating to chronic pain after cancer treatment in people living with and beyond cancer.

Data gathered from published literature combined with new insights from cancer survivors and healthcare professionals were used to meet the aims and objectives. The combined findings were used to develop clinical recommendations to improve the experience of chronic pain after cancer treatment for people living with and beyond cancer. Fundamental to realizing the recommendations is increasing knowledge and understanding about chronic pain in cancer survivors among healthcare professionals. Every opportunity has been taken to disseminate the findings from this thesis as the PhD has progressed, to raise awareness of chronic pain after cancer treatment to different clinical, academic and public audiences. Further research is needed into the most effective ways to increase healthcare professionals knowledge and understanding so that improvements in clinical practice can be seen and experienced by people living with and beyond cancer.

A personal reflection of the PhD experience by the researcher is included in appendix 28.

6.5: Conclusions

The thesis sought to answer the overarching research question: What are the experiences of cancer survivors living with chronic pain after cancer treatment in England, UK and how can their experiences be improved?

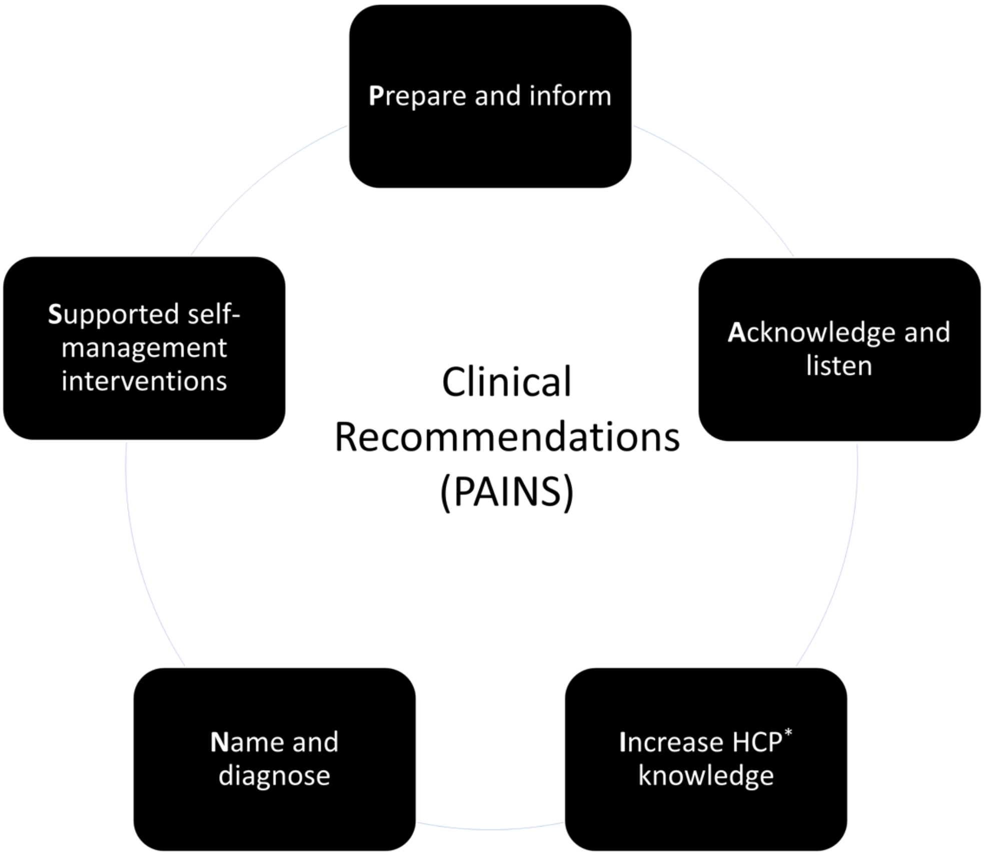
The new knowledge generated by this thesis demonstrates, prior to this thesis, there was a paucity of qualitative research into cancer survivors experience of chronic pain after cancer treatment, and none of these studies were conducted in the UK. All published work focused exclusively on breast cancer, with women and within 30 months of treatment.

The thesis is the first to convey the experiences of mixed gender English cancer survivors who experience chronic pain after cancer treatment. It has demonstrated survivors did not feel informed or prepared for the risk or reality of chronic pain after cancer treatment and this compounded the difficulties of coping with and managing their pain. Survivors reported they had not been listened to when they tried to talk about their chronic pain after cancer treatment, nor at times, believed. They felt healthcare professionals lacked knowledge and understanding regarding chronic pain after cancer treatment. Survivors encountered unclear and limited pathways for support and often bounced from one support team to another. Identifying and accessing services was a challenge, and the responsibility of this was often left to the survivor. However, palpable relief and benefit was felt when healthcare professionals diagnosed and acknowledged chronic pain after cancer treatment.

The research found limited knowledge and understanding of chronic pain after cancer treatment by healthcare professionals. Whilst many thought it was, or might be, their role to talk to people living with and beyond cancer about chronic pain after cancer treatment, almost a quarter reported they rarely or never did. Healthcare professionals lacked confidence to talk to people about chronic pain after cancer treatment and viewed their lack of knowledge as a barrier.

The new knowledge generated within this PhD was used to draft key findings and recommendations and these were discussed and refined within expert review panels. The final recommendations (PAINS) are summarised in figure 16.

Figure 16: Clinical recommendations arising from the overall PhD key findings (PAINS)



* HCP_ Healthcare professional

Two public contributors were recruited to be involved with the PhD and a small scale evaluation of the impact they had on the research was included with the thesis. To conclude, this PhD has contributed new knowledge to the field of chronic pain in cancer survivorship.

6.6: Limitations of the thesis

This thesis has included four studies. The limitations of each study have been addressed within the corresponding chapter. However, there are some limitations to the thesis overall. Firstly, the focus of the PhD was cancer survivors who were diagnosed and treated with cancer as adults. The justification for this was valid because this aligned with the aims of the PhD. However, by excluding cancer survivors of childhood cancer, there was a large population of cancer survivors who may experience chronic pain after cancer treatment whose needs and experiences were not captured within the thesis (Tonorezos et al., 2022). Furthermore, the PhD focused on one long-term and late effect, namely chronic pain after cancer treatment. The research findings have provided important insight into this phenomenon and having such a narrow focus enabled the research to have clear and defined boundaries. However, when considering recommendations for services and support for people living with and beyond cancer, it may be helpful to consider the impact of chronic pain in conjunction with symptoms such as fatigue. If symptoms are 'clustered' together, it may mean there would be greater chance for support services to be commissioned.

6.7: Future research

Recommendations for future research include:

- Development of educational resources to support healthcare professionals improve their knowledge of chronic pain after cancer treatment. These should be informed by pedological underpinnings and the impact on healthcare professionals' knowledge, practice and confidence should be evaluated.
- Review of effectiveness of existing interventions, and considerations of novel interventions, to support cancer survivors living with chronic pain after cancer treatment such as a self-management programme to support people living with and beyond cancer to manage their chronic pain after cancer treatment.

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Appendices

Appendix 1: Public contributor role description

Role description for steering group member for doctoral research project: What are the experiences and healthcare needs of cancer survivors with chronic pain and does current service provision meet their needs? (working title)

Background:

This steering group will support the development of research to explore the experiences and healthcare needs of cancer survivors with chronic pain and map current service provision in England to determine if current provision meets their needs.

This programme of study will use information gathered from literature and cancer survivors to identify experiences and healthcare needs of cancer survivors living with chronic pain. Cancer survivors from different cancer sites and stages of cancer survivorship will be included to gain insight into their needs and experiences over a varied time trajectory. Current service provision for cancer survivors with chronic pain in England will be mapped to create a picture of service provision in 2019/20. Findings from the literature review, qualitative study and mapping exercise will be used collectively to establish healthcare needs of cancer survivors with chronic pain and review how well current services meet their needs. From these findings, areas for future research and clinical initiatives will be proposed.

The steering group will include the student and her PhD Supervisors and up to three Public Research Partners

Public involvement in research is a rapidly developing and important field. In becoming Public Research Partner, who is, or wishes to become, actively involved in research, your experience and your input will be invaluable in giving a patient's perspective on the running of the research study. Your experience will be crucial in influencing how we communicate with potential participants and how the research data we collect will be analysed and interpreted.

Public Research Partners will have opportunity to review protocols and participant information sheets and contribute to study design, data analysis and interpretation of findings if they wish. Attendance at meetings would be welcomed but is not required. The student and her PhD supervisory team will be meeting monthly throughout 2019. Primarily these meetings are in Bristol, with one or more supervisors dialling in from Bath and/or Southampton. You are not expected or required to attend all of these meetings but you are most welcome if you can. We will also be communicating via email and telephone at regular intervals.

Your responsibilities:

Having an induction/briefing session with Julie Armoogum to learn more about the overall PhD proposal, either over the telephone, face to face or email, depending on your preference and practicalities of travel. This would be approximately 30 minutes.

Reviewing and commenting on the research protocols (project plans) and participant information sheets. This can be done either over email or on paper. Electronic copies or paper copies can be provided dependent on your preference. This is likely to take one to two hours.

Completing the reviewing and feedback by a mutually agreed date.

You can be feedback to the group either electronically over email, over the telephone or via the post if paper copies provided.

Attendance at steering groups meetings if you so wish. Attendance can be face to face or over the telephone.

It would be expected that you keep the protocols and our discussions confidential

Our responsibilities:

Providing you with support and training in the induction/briefing session

Ensuring any documents are provided to you either electronically or on paper, dependent on your preference

You can contact Julie Armoogum at any stage for support or advice. You will be provided with her email and telephone number.

Duration of role:

It is hoped that you would continue on the steering group for the duration of the PhD (expected submission date is October 2022) but this can be reviewed at any timepoint

Payment and expenses:

You will be paid for your time at a University agreed rate of £15/hr.

Expenses can be paid for attendance at face to face meetings

Person specification:

People who have had a cancer diagnosis, have completed primary treatment and experience chronic pain. People who are able to read and write in English

Contact details:

Julie Armoogum, Macmillan Senior Lecturer, UWE Bristol

Email: Julie.armoogum@uwe.ac.uk, Telephone: 0117 32 88658 Twitter: @JulieArmoogum

Closing date for applications: December 2018

Appendix 2: NHS Research Ethics Approval

This appendix has been redacted because it contains personal data.

Appendix 3: Health Regulatory Authority (HRA) approval

This appendix has been redacted because it contains personal data.

Appendix 4: UWE Ethics approval

This appendix has been redacted because it contains personal data.

Appendix 5: Access letter from Penny Brohn UK

This appendix has been redacted because it contains personal data.

Appendix 6: Access letter Royal United Hospitals

This appendix has been redacted because it contains personal data.

Appendix 7: Timeline through ethics

25.03.19 – submitted to IRAS for proportionate review

26.04.19 – Email sent from Bristol rec to request additional info (radio transcripts and clarify some points). Went into my junk folder so I didn't know about it so was unable to respond.

15.05.19 – Contacted IRAS as no feedback. Advised to check junk folder. Saw email, responded to queries

28.05.19 – Resubmitted.

29.05.19 – Made valid by HRA.

06.06.19 – Initial assessment letter received from HRA

17.06.19 – Reviewed for proportionate review by Manchester Central REC

31.07.19 – Access letter for Penny Brohn received

02.08.19 – REC Favourable opinion given

03.08.19 – HRA request substantial amendment (request for reply slip to be submitted as separate document rather than appendix in protocol plus clarify some points)

08.08.19 – Amendment submitted

17.09.19 – Validation letter from HRA received

11.10.19 – REC favourable opinion given

16.10.19 - HRA approval received

18.10.19 – UWE ratification received

22.10.19 – Amendment submitted to UWE (Penny Brohn personnel change)

23.10.19 – UWE approval for amendment

31.10.19 – Access letter for RNHRD received

Appendix 8: Study introduction letters

Appendix 8a: Centre 1. Complex Cancer Late Effects Rehabilitation Service (CLERS) at the Royal National Hospital for Rheumatic Diseases (RNHRD)

Appendix 8b: Centre 2. Penny Brohn UK

Appendix 8c: Centre 3. HORIZONS study, University of Southampton

Appendix 8d: Centre 4. R.A.G.E

These appendices have been redacted because they contain personal data.

Appendix 9: Participant Information Sheet

This appendix has been redacted because it contains personal data.

Appendix 10: Follow up letters

Appendix 10a: Centre 1. Complex Cancer Late Effects Rehabilitation Service (CLERS) at the Royal National Hospital for Rheumatic Diseases (RNHRD)

Appendix 10b: Centre 2. Penny Brohn UK

Appendix 10c: Centre 3. HORIZONS, University of Southampton

Appendix 10d: Centre 4. R.A.G.E

These appendices have been redacted because they contain personal data.

Appendix 11: Eligibility screening tool

Study number		
Person confirming eligibility		
	Yes	**No**
Over 16 at diagnosis and treatment		
Completed anti-cancer therapy		
Pain lasting for 3 months of more		
Previously seen by chronic pain team for non-malignant chronic pain		
No known active disease		
Eligible for study		

Appendix 12: Consent form

IRAS ID: 255086

CONSENT FORM

Participant Information Sheet: An exploration of the experiences and needs of cancer survivors with persistent pain.

I confirm that I have read the information sheet dated XXX (version X) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers.

I understand I may be contacted in the future to consider participating in further research that forms part of this doctoral study.

I agree to my General Practitioner being informed of my participation in the study.

I would like to be informed of the findings of the study

I agree to take part in the above study

____________________	____________________	____________________
Name of Participant	Date	
____________________	____________________	____________________
Name of Person taking consent	Date	Signature

One copy of this form will be sent to participants, one copy will be scanned on a UWE owned and managed scanner and stored in a password protected folder on a UWE password protected OneDrive cloud storage facility. Paper copies will then be securely destroyed.

Appendix 13: GP letter

UWE Bristol headed paper

Dear……

We would like to inform you that your patient……………. has agreed to participate in a research study called: A qualitative exploration of the experiences and needs of cancer survivors with persistent pain.

The research study fits into a programme of work that aims to establish healthcare needs of cancer survivors with persistent pain and review how well current services meet their needs. The work will be submitted as a doctoral thesis and the PhD supervisory team includes Professor Candy McCabe (University of the West of England, Bristol), Professor Diana Harcourt (University of the West of England, Bristol), Professor Claire Foster (University of Southampton) and Dr Alison Llewellyn (University of the West of England, Bristol).

If you would like more information about the research, please do not hesitate to contact me:

Julie Armoogum, Macmillan Senior Lecturer, University of the West of England, 2B28, Glenside Campus, Blackberry Hill, Bristol, BS16 1DD

Telephone: 0117 32 88658 Email: Julie.armoogum@uwe.ac.uk

With very best wishes,

Julie Armoogum

Macmillan Senior Lecturer

University of the West of England

Appendix 14: Interview schedule

Welcome, introductions, brief questions to build rapport and put participant at ease (travel, comfort, check seating and temperature etc).

Explain purpose of interview - part of a programme of looking at experiences, needs and service provision for cancer survivors with persistent pain. We'll start with some brief demographic questions and then we'll talk about your experiences of cancer and your persistent pain. After that, we'll move on to the support you have received to help with your pain and any support you think would be or would have been helpful.

Confirm consent.

Experiences

Can you tell me about your cancer diagnosis and treatment? (if needed, probe for type of cancer, time since treatment has finished and if had chemotherapy, radiotherapy, surgery, hormone therapy or other types of treatment. Ask about age at diagnosis and age now)

And how have things been since?

When did your pain related to the cancer treatment first start?

Can you tell me more about what it's been like living with the pain?

What were you told about the risks of persistent pain?

Probing questions as participant talks: Can you tell me more? Can you describe? What do you think? What do you feel? Can you reflect? What else is of importance?

In general have you felt supported in coping with your treatment related pain?

Services

Moving onto look at service provision…

What services have supported you with your pain?

How did you access those services?

Did you have problems in accessing the services?

What do you think worked well? Less well? What hindered or helped?

Can you tell me a bit more about that? How did you feel about that?

What would have been helpful to you at the beginning?

What would be helpful for you now?

Draw interview to close. Thank for time. Offer support leaflet.

Appendix 15: Support leaflet for participants

Thank you for participating in this research. We really value your views and are very grateful for your time.

If you would like to talk through any issues that may have arisen by taking part in this research, please contact your G.P, care team or one of the charities listed below.

Macmillan Cancer Support – Telephone: 0808 808 00 00. Lines are open seven days a week, 8am –to 8pm and it is free to call.

The Website offers lots of information and practical advice and support:

https://www.macmillan.org.uk/information-and-support

Maggie's Centres – Telephone: 0300 123 1801. There are Maggie's Centres nationwide that offer free practical, emotional and social support to people with cancer and their families and friends.

The website gives details of the centres and also offers an Online Centre for practical, emotional and social support:

https://www.maggiescentres.org/how-maggies-can-help/help-available/

Penny Brohn UK – Telephone: 0303 3000 118. Penny Brohn UK has a national centre in Bristol and works in partnership with other healthcare organisations to provide support across the UK.

Penny Brohn supports a Whole Life Approach and focuses on building resilience in every aspect of life and supporting the body's natural ability to heal and repair itself. The website has lots of information and support and details of course they run:

https://www.pennybrohn.org.uk/

Appendix 16: Example of thematic map

This appendix has been redacted because it contains personal data.

Appendix 17: Dissemination activities

Published papers:

Armoogum, J., Foster, C., Llewellyn, A., Harcourt, D., McCabe, C. S. (2023) 'I think it affects every aspect of my life, really': Cancer survivors' experience of living with chronic pain after curative cancer treatment in England, UK. PLOSOne (under review)

Armoogum, J., Harcourt, D., Foster, C., Llewellyn, A., & McCabe, C. S. (2020). The experience of persistent pain in adult cancer survivors: A qualitative evidence synthesis. European Journal of Cancer Care, 29(1), https://doi.org/10.1111/ecc.13192. Available from https://uwe-repository.worktribe.com/output/5035663

Conference oral presentations and posters

Armoogum, J (2023) Chronic pain after cancer treatment: Insights from cancer survivors and healthcare professionals in England, UK to consider how cancer survivors' experiences can be improved. CHCR Doctoral Showcase, UWE Bristol

Armoogum. J (2022) 'We don't understand…. They don't understand' Chronic pain in cancer survivorship. CHCR Conference, UWE Bristol

Armoogum, J., Foster, C., Llewellyn, A., Harcourt, D and McCabe, C. (2021) Healthcare professionals' views regarding chronic post cancer treatment pain in cancer survivors: understanding, experience and confidence. UK Oncology Nursing Society (UKONS) Conference, Virtual

Armoogum, J., McCabe, C., Harcourt, D., Foster, C. and Llewellyn, A. (2021) What are the experiences and healthcare needs of cancer survivors with chronic post cancer treatment pain (CPCTP) and does current service provision meet their needs? CHCR Doctoral Showcase, UWE Bristol

Armoogum, J., McCabe, C., Harcourt, D., Foster, C., & Llewellyn, A. (2020). An exploration into the experience, needs and service provision for cancer survivors living with persistent pain. International Conference on Cancer Nursing (ICCN), London, UK, Virtual (accepted, but cancelled due to Covid-19 pandemic)

Armoogum, J., McCabe, C., Harcourt, D., Foster, C. and Llewellyn, A. (2020) Persistent pain in cancer survivors. CHCR Doctoral Showcase, UWE Bristol

Armoogum, J., McCabe, C., Harcourt, D., Foster, C. and Llewellyn, A. (2019) Cancer survivors and chronic pain. CHCR Doctoral Showcase, UWE Bristol

Conference Posters

Armoogum, J., McCabe, C., Harcourt, D., Foster, C. and Llewellyn, A. (2022) Healthcare professionals' understanding, experience and confidence surrounding chronic post cancer treatment pain in cancer survivors: results of an e-survey. CHCR Conference, UWE Bristol

Armoogum, J., McCabe, C., Harcourt, D., Foster, C. and Llewellyn, A. (2019) What is the experience of chronic pain in adult cancer survivors?. British Pain Society (BPS) Annual Scientific Meeting, London, UK

Armoogum, J., McCabe, C., Harcourt, D., Foster, C., & Llewellyn, A. (2019). Cancer survivors with persistent pain: Filling in the gaps. UK Oncology Nursing Society (UKONS), Telford, UK.

Armoogum, J., McCabe, C., Harcourt, D., Foster, C. and Llewellyn, A. (2019) The experience of persistent pain in adult cancer survivors: A qualitative evidence synthesis. British Psychosocial Oncology Society (BPOS) Conference, Chester, UK

Armoogum, J., McCabe, C., Harcourt, D., Foster, C. and Llewellyn, A. (2019) A qualitative exploration of the experiences and needs of cancer survivors with chronic pain: a research proposal. CHCR Conference, UWE Bristol

Armoogum, J., McCabe, C., Harcourt, D., Foster, C. and Llewellyn, A. (2019) A qualitative exploration of the experiences and needs of cancer survivors with chronic pain: a research proposal. HAS PGR Conference, UWE Bristol

Armoogum, J., McCabe, C., Harcourt, D., Foster, C. and Llewellyn, A. (2018) The experience of chronic pain in adult cancer survivors: A qualitative evidence synthesis. UK Oncology Nursing Society (UKONS) Conference 2018, Glasgow, UK

Armoogum, J., McCabe, C., Harcourt, D., Foster, C. and Llewellyn, A. (2018) What is the experience of chronic pain in adult cancer survivors? A qualitative evidence synthesis. HAS PGR Conference, UWE Bristol

Informing policy

Inclusion of chronic pain as late effect in ACCEND framework (ACCEND, 2023)

E-Learning

Armoogum, J *et al.,* (2023) Personalised treatment and care for cancer, Foundations of Cancer Care, E-learning for Health. Health Education England

Armoogum, J *et al.,* (2023) Living with and beyond cancer, Foundations of Cancer Care, E-Learning for Health. Health Education England

Armoogum. J., Cook. J (2021) Chronic pain in cancer survivors . PRosPer (Cancer Prehabilitation and Rehabilitation): Rehabilitation for management of specific symptom or consequence of cancer and its treatment. E-Learning for Health. Health Education England

Talks

Armoogum, J, Galligan, M, Cook, J (2023) The nature and impact of long term and late effect cancer-related pain in people affected by cancer. UKONS webinar.

Armoogum (2022) What are the experiences of cancer survivors living with chronic post-cancer treatment pain and how can they be supported? South West Cancer Alliance Group (SWAG) AHP meeting

Armoogum (2022) What matters to me. Macmillan Patient and Public Involvement Conference, UWE Bristol

Armoogum (2022) What are the experiences of cancer survivors living with chronic post-cancer treatment pain (CPCTP) and how can they be supported? Palliative & EOL South West Journal Club

Armoogum, J (2019) Chronic pain in cancer survivors. Macmillan Cancer Survivorship Research Group, University of Southampton

Teaching

Armoogum. J (2018, 2019, 2020, 2021, 2022) Chronic pain in cancer survivors. Cancer care choice undergraduate module, UWE Bristol

Armoogum. J (2021, 2022, 2023) Principles of Cancer Care Level 3/Level M module

Armoogum. J (2020, 2021, 2022, 2023) Long Term Conditions Level 3/level M module

Armoogum. J (2019) Nature and Treatment of Cancer level 3/level M module

Patient groups

Armoogum (2022) What matters to me. Macmillan Patient and Public Involvement Conference, UWE Bristol

Appendix 18: Summary of amendments from pilot study

Section of questionnaire	**Amendments made during piloting phase**
Introduction page	More information given about the study including a brief introduction, purpose of the survey and time to complete. Define cancer survivors and chronic pain after cancer treatment
Consent	Include a forced response to make sure participants consent
Q1 - role	Change from ‘how would you describe your professional role’ to ‘how would you describe your *main* professional role’ Add in a question asking how much of their main professional role involves people who are living with and beyond cancer (Q2)
Q4 – location	Initially just healthcare professionals from England (to reflect patient study) but changed to UK as using social media. Have included standardised list to make analysis more straightforward – England, Scotland, Wales, Northern Ireland.
Q5 - % of cancer survivors with chronic pain after cancer treatment	Approximate percentages changed to ranges based on literature findings. Added an ‘over 60%’ option Change ‘pain’ to ‘chronic pain after cancer treatment’ Add an ‘I don’t know’ option to factual questions to avoid guessing
Q6 – severity of pain	Add ‘over 60%’ option Change ‘pain’ to ‘chronic pain after cancer treatment’
Q8 – Types of treatment	Change from free text question to multiple choice
QQ9 – Types of cancer	Change from free text question to multiple choice
Q11 – Patient quotes	Split into two questions 1) awareness and 2) their clinical experience. Quotes updated to most appropriately reflect question. Awareness - Participants are informed that the statements are from people living with chronic pain after cancer treatment and they are asked to select which ones are from cancer survivors living with chronic pain after cancer treatment. Clinical experience of chronic pain after cancer treatment - the quotes are used as statements and participants are asked to move a slider to indicate the extent they have come across the patient experience in their clinical practice. Add ‘I don’t know’ option to avoid guessing. Add a ‘Both’ option
Q12	Give more context to know survey about people LWBC so changed to: ‘This time, please consider to what extent

	you have come across people living with and beyond cancer experiencing these statements in your clinical practice (move the slider across to indicate your views).
Q13 – when to give information	Change question from 'When do you think people living with and beyond cancer should be informed about chronic pain after cancer treatment?' to 'When do you think people living with and beyond cancer should be informed about *the potential of* chronic pain cancer treatment?' Add 'during treatment' option
Q12-13 Support	Remove 'support'
Q18 - Barriers	Participants offered suggestions for the barriers they felt prevented or inhibited them from talking to people about chronic pain after cancer treatment. These included: - People I care for, work with, and support do not mention it - I don't want to bring it up as I know there is limited support available to offer - It's hard to know what is helpful for people - It can lead to uncomfortable questions about health promotion (i.e. need to lose weight) - It's hard to work out if the pain is related to the cancer treatment or something else - If it is years after cancer treatment, the pain must be related to something else rather than their cancer treatment These comments were added as potential responses and options to the multiple choice question about barriers.
General	Include request responses so participants can go back to questions they have not completed Add in a back button Switch off capturing IP addresses for extra anonymity Add in question numbers so participants can see them as well as progress bar Increase sizes of texts boxes Increase size of font on matrix question options Correct typo – 'do' to 'to' Include some education about chronic pain cancer treatment on the thank you page

Appendix 19: Copy of survey

Healthcare professionals' views on chronic post cancer treatment pain

Welcome to our survey about health care professionals' understanding, experience and confidence surrounding chronic pain after cancer treatment. Please participate if you are a UK based healthcare professional who works with people living with and beyond cancer who may experience, or be at risk of, chronic pain after cancer treatment. The survey will take approximately 15 minutes to complete and there are 19 questions.

This survey is part of a PhD exploring the experiences of people living with chronic pain after cancer treatment. The term 'cancer survivor' is used to describe people who have finished their primary cancer treatment (with the exception of maintenance therapy) and have no active disease (Moser et al.,, 2011). 'Chronic pain' refers to chronic post-cancer treatment pain that lasts for three months or more (Bennett et al.,, 2019).   Please read the Participant Information Sheet for more information before proceeding.

I do consent

I do not consent

Q1. How would you describe your main professional role?

Hospital based Allied Health Professional, please add specialty

Community based Allied Health Professional, please add specialty

Hospital based doctor, please add specialty

GP

Hospital based nurse, please add specialty

Practice nurse

Community nurse

Hospice nurse

Cancer support worker

Educator

Other, please specify

Q2. How much of your main professional role involves people who are living with and beyond cancer?

More than 75%

Between 50 and 75%

About 50%

Between 25 and 50%

Less than 25%

Q3. How long have you been working with people who may be living with or beyond cancer?

Up to a year

Between one and five years

Between six and ten years

Between 11 and 20 years

Over 20 years

Q4. Which area of the UK do you work in?

Northern Ireland

Scotland

Wales

England

Q5 In your opinion, what percentage of cancer survivors experience chronic pain after their treatment has ended? (please select one answer)

Up to 10%

Between 10 and 20%

Between 20 and 30%

Between 30 and 40%

Between 40 and 50%

Between 50 and 60% ’Over 60%

I don't know

Q6 Of those cancer survivors living with chronic pain, how many, do you think, would describe their pain as moderate to severe? (please select one answer)

Up to 10%

Between 10 and 20%

Between 20 and 30%

Between 30 and 40%

Between 40 and 50%

Between 50 and 60% ’Over 60%

I don't know

Q7 When do you think chronic pain arising from cancer treatment can occur? (you can select more than one answer)

During treatment

Up to a year after treatment has finished

Between a year and five years after treatment has finished

Between five years and 10 years after treatment has finished

Over 10 years after treatment has finished

I don't know

Q8 What cancer treatments do you think may cause chronic pain? (you can select more than one answer)

Chemotherapy

Radiotherapy

Surgery

Hormone treatment

Other, pleas’ specify

I don't know

Q9 Which cancers can lead to chronic pain after treatment? (you can select more than one answer)

Head and neck

Lung

Breast

Gastrointestinal

Prostate

Gynaecological

Haematological

Other, please specify

All of the above

I don't know

Q10 Do you think these statements are true or false?

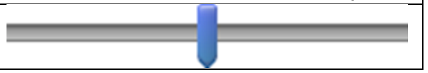
	True	False	I don't know
Women have greater risk of chronic pain after cancer surgery compared to men			
Older adults are more at risk of chronic pain after cancer surgery compared to younger adults			
A lower BMI can increase the risk of chronic pain after cancer treatment			
Pre-existing anxiety prior to cancer treatment increases the risk of chronic pain after cancer treatment			
Pain that starts years after cancer treatment has ended can't be related to previous cancer treatment			

Q11 Here are 20 statements from people living with chronic pain. Select which statements are from cancer survivors, which are from people with non-malignant chronic pain and which are from both cancer survivors and people living with non-malignant chronic pain. You can move between quotes by selecting the arrow keys. Please complete all 20 statements before moving on to the next question

Statement	Cancer survivor with chronic pain	Person with non-malignant chronic pain	Both
1. Living in chronic pain affects every aspect of my life			
2. You just feel really alone			
3. My life has got smaller and smaller			
4. Everything ' have enjoyed, I've lost			
5. It's like basically my confidence is shot – and by 'confidence' I mean physically, socially, professionally, sexually, and spiritually			
6. That fear is horrendous. It's still there. Five years down the line or six years down the line, I'm still... Every time I get a particular bad pain I thin' "the cancer" it's back again"			
7. It is rough. It's rough every single day. When I wake up in the middle of the night, I think, "Oh, my God, this is going to go on forever. It's always going to be the same. I'm never going to not be in any pain			
8. I've actually lost four inches in height... it's psychologically so difficult to look at somebody in the chest when you used to look at them in the eye. ..you know, it's very very silly... but erm, you do feel a little bit inferior			
9. I mean I now feel that to me, the cancer was much less bad than the after effects because .... I can no way lead a fairly normal life because I'm in pain constantly. So it's worse			
10. The alternative was not very good, so I would have had all of the treatment anyway. I would rather be alive and in pain than not			

11. The pain has taken away the joy and the pleasures of life that I had			
12. I don’t think I’d ever had one single conversation with anyone about pain at all…nothing was ever said about pain at all. I didn’t have one single conversation with anyone about pain			
13. You feel as if you’re a liar. It’s as if they (healthcare professionals) don’t believe you			
14. Nobody (healthcare professionals) really, when it happened to me, wanted to know about it			
15. They say to you, basically, “We treat your cancer. Anything else, you have to go your GP.” Then you go to your GP and they say, “ask them in oncology.” Basically, you’re stuffed because nobody really wants to know			
16. An awful lot of it is you have to figure it out yourself			
17. It is the feeling of being discarded and not having that, having somebody to discuss things with, I found difficult			
18. Nobody seems to listen			
19. Nobody is there to tell you at all about where to go for help			
20. Then they (healthcare professionals) give me the name for it.. I just cried. It was like it was so amazing to have it understood that these particular kinds of pain associated with going through cancer were known and treatable in some ways, that they were not necessarily curable but that there were things that could help. It was amazing			

Q12 This time, please consider to what extent you have come across people living with and beyond cancer experiencing these statements in your clinical practice (move the slider across to indicate your views)

Statement	Never Always
1. Living in chronic pain affects every aspect of my life	

2. You just feel really alone	
3. My life has got smaller and smaller	
4. Everything ’ have enjoyed, I've lost	
5. It’s like basically my confidence is shot – and by ‘confidence’ I mean physically, socially, professionally, sexually, and spiritually	
6. That fear is horrendous. It’s still there. Five years down the line or six years down the line, I’m still... Every time I get a particular bad pain I thin’ “the cancer” it's back again"	
7. It is rough. It’s rough every single day. When I wake up in the middle of the night, I think, “Oh, my God, this is going to go on forever. It’s always going to be the same. I’m never going to not be in any pain	
8. I’ve actually lost four inches in height... it’s psychologically so difficult to look at somebody in the chest when you used to look at them in the eye. ..you know, it’s very very silly... but erm, you do feel a little bit inferior	
9. I mean I now feel that to me, the cancer was much less bad than the after effects because .... I can no way lead a fairly normal life because I’m in pain constantly. So it’s worse	
10. The alternative was not very good, so I would have had all of the treatment anyway. I would rather be alive and in pain than not	
11. The pain has taken away the joy and the pleasures of life that I had	
12. I don’t think I’d ever had one single conversation with anyone about pain at all...nothing was ever said about pain at all. I didn’t have one single conversation with anyone about pain	
13. You feel as if you’re a liar. It’s as if they (healthcare professionals) don’t believe you	
14. Nobody (healthcare professionals) really, when it happened to me, wanted to know about it	
15. They say to you, basically, “We treat your cancer. Anything else, you have to go your GP.” Then you go to your GP and they say, “ask them in oncology.” Basically, you’re stuffed because nobody really wants to know	
16. An awful lot of it is you have to figure it out yourself	

17. It is the feeling of being discarded and not having that, having somebody to discuss things with, I found difficult	
18. Nobody seems to listen	
19. Nobody is there to tell you at all about where to go for help	
20. Then they (healthcare professionals) give me the name for it.. I just cried. It was like it was so amazing to have it understood that these particular kinds of pain associated with going through cancer were known and treatable in some ways, that they were not necessarily curable but that there were things that could help. It was amazing	

Q13 When do you think people living with and beyond cancer should be informed about the potential of chronic pain after cancer treatment (you can select one or more options)

Before treatment

During treatment

Immediately after treatment

At a living with and beyond cancer event

When symptoms start

When symptoms continue

Q14 Whose role do you think it is to give people living with and beyond cancer information about the potential of chronic pain after cancer treatment? (you can select one or more options)

Acute cancer services

Specialist pain services

Cancer late effects services

Primary care

Support centres (Maggie’s, Macmillan Centres etc.)

Other, please specify

Q15 Do you think it is your role to talk to people living with and beyond cancer about the potential of chronic pain after treatment?

Yes

Maybe

No

Q16Iw often do you....

	Never (1)	Rarely (2)	Sometimes (3)	Always (4)
Talk to people living with and beyond cancer about chronic pain after treatment				
Signpost people living with and beyond cancer to support about chronic pain after treatment				

Listen to people talk about their
experiences of living with chronic
pain after treatment

Q17 How confident do you feel about…. (move the slider across to indicate your views)

Statement	Not at all confident Very confident
Talking to people living with and beyond cancer about the risks of chronic pain after cancer treatment	
Where to signpost people living with and beyond cancer about information and support for chronic pain after cancer treatment	
How to support cancer survivors who are living with chronic pain after treatment	
How to help cancer survivors manage their pain	
Listening to cancer survivors talk about their experience of living with chronic pain after treatment	

Q18 What prevents you from talking about chronic pain after cancer treatment with people living with and beyond cancer? (you can select as many options as you would like)

☐ I don't think it is part of my role

☐ I don't feel I have the appropriate knowledge about the risks of chronic pain

☐ I don't feel I have the appropriate knowledge about how to signpost people for support

☐ I don't feel I have the appropriate knowledge to support people

☐ I don't think I see people at the appropriate time in their treatment journey

☐ I don't think it is a priority

☐ I find it hard to have the time

☐ It doesn't seem relevant

☐ People I care for, work with, and support do not mention it

☐ I don't want to bring it up as I know there is limited support available to offer

☐ It's hard to know what is helpful for people

☐ It can lead to uncomfortable questions about health promotion (i.e. need to lose weight)

☐ It’s hard to work out if the pain is related to the cancer treatment or something else

☐ If it is years after cancer treatment, the pain must be related to something else rather than their cancer treatment

☐ None of the above, I feel I do talk and listen to people living with and beyond cancer about chronic pain

☐ Other reasons, please specify

Q19 Is there anything else you feel is relevant or important about this area of research? Please comment below

Appendix 20: Participant Information Sheet

Healthcare professionals' views regarding chronic pain in cancer survivors: understanding, experience and confidence.

You are invited to take part in research taking place at the University of the West of England, Bristol. Before you decide whether to take part, it is important for you to understand why the study is being done and what it will involve. Please read the following information carefully and if you have any queries or would like more information please contact Julie Armoogum, School of Health and Social Wellbeing, University of the West of England, Bristol on julie.armoogum@uwe.ac.uk

Who is organising and funding the research?

The Chief Investigator for this study is Julie Armoogum, a Macmillan Senior Lecturer and PhD student at the University of the West of England in Bristol. The PhD Supervisory team include Professor Candy McCabe (University of the West of England, Bristol, UK), Professor Diana Harcourt (University of the West of England, Bristol, UK), Professor Claire Foster (University of Southampton, UK) and Associate Professor Alison Llewellyn (University of the West of England, Bristol, UK). It is funded by Macmillan Cancer Research and the University of the West of England, Bristol, UK.

What is the aim of the research?

To determine healthcare professionals' understanding and experience of chronic post-cancer treatment pain and establish how confident they feel to inform, listen and signpost people living with and beyond cancer about it.

Why have I been invited to take part?

As a healthcare professional working with people living with and beyond cancer who may experience, or be at risk of, chronic post-cancer treatment pain, we are interested in gaining information about your views and experiences.

Do I have to take part?

You do not have to take part in this research. It is up to you to decide whether or not you want to be involved. If you do decide to take part, you can download this information sheet and you will be asked to tick the relevant box on the survey tool website to consent. If you do decide to take part, you are able to withdraw from the research at any time, without giving a reason, by leaving the online survey. Deciding not to take part or to withdraw from the study does not have any penalty.

What will happen to me if I take part and what do I have to do?

If you agree to take part you will be asked to complete an online survey. This will be conducted with Qualtrics software. The survey will take approximately 15 minutes to complete and can be completed on a mobile device, laptop or PC. Your answers will be fully anonymised.

What are the benefits of taking part?

If you take part, you will be helping us to gain a better understanding of healthcare professionals' views and understanding of chronic pain after cancer treatment. This will help inform future clinical recommendations and the development of educational initiatives around the subject area.

What are the possible risks of taking part?

We do not foresee or anticipate any significant risk to you in taking part in this study. If, however, you feel uncomfortable at any time, then please feel free to stop completing the survey. If you need any support during or after completing the survey, please contact the researcher and she will be able to put you in touch with suitable support agencies. The research team are experienced in conducting surveys and are sensitive to the subject area. The survey has been designed with these considerations in mind.

What will happen to your information?

All the information we receive from you will be treated in the strictest confidence. No personal or identifying information will be collected. We will not ask for your name or place of work.

Where will the results of the research study be published?

The results of this study will be analysed and used as part of a programme of work that will be submitted as a doctoral thesis. This thesis will be available on the University of the West of England's open-access Research Repository. The anonymised results may also be used in conference papers and peer-reviewed academic papers and disseminated via professional networks.

Who has ethically approved this research?

The project has been reviewed and approved by the Faculty of Health and Applied Science, University of the West of England University Research Ethics Committee(UWE REC REF No: HAS 21.02.109). Any comments, questions or complaints about the ethical conduct of this study can be addressed to the Research Ethics Committee at the University of the West of England at:

Researchethics@uwe.ac.uk

What if something goes wrong?

If you are concerned or worried about any aspect of this research please contact Julie Armoogum in the first instance. You can also contact the Director of Studies, Professor Candy McCabe (contact details are at the end of this information sheet).

What if I have more questions or do not understand something?

If you would like any further information about the research please contact:

Chief Investigator: Julie Armoogum, Macmillan Senior Lecturer, University of the West of England. Telephone: 0117 32 88658 Email: Julie.armoogum@uwe.ac.uk

Director of Studies: Professor Candy McCabe, Florence Nightingale Foundation Clinical Professor in Nursing, University of the West of England and Head of Research, Dorothy House Hospice Care, Winsley, Bradford on Avon, Wiltshire, BA15 2LE. Email: Candy.mccabe@uwe.ac.uk

Purpose of the Privacy Notice

This privacy notice explains how the University of the West of England, Bristol (UWE) collects, manages and uses your personal data before, during and after you participate in Healthcare professionals' views regarding CHRONIC PAIN AFTER CANCER TREATMENT in cancer survivors: understanding, experience and confidence. 'Personal data' means any information relating to an identified or identifiable natural person (the data subject). An 'identifiable natural person' is one who can be identified, directly or indirectly, including by reference to an identifier such as a name, an identification number, location data, an online identifier, or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person.

This privacy notice adheres to the General Data Protection Regulation (GDPR) principle of transparency. This means it gives information about:

How and why your data will be used for the research;

What your rights are under GDPR; and

How to contact UWE Bristol and the project lead in relation to questions, concerns or exercising your rights regarding the use of your personal data.

This Privacy Notice should be read in conjunction with the Participant Information Sheet and Consent Form provided to you before you agree to take part in the research.

Why are we processing your personal data?

UWE Bristol undertakes research under its public function to provide research for the benefit of society. As a data controller we are committed to protecting the privacy and security of your personal data in accordance with the (EU) 2016/679 the General Data Protection Regulation (GDPR), the Data Protection Act 2018 (or any successor legislation) and any other legislation directly relating to privacy laws that apply (together "the Data Protection Legislation"). General information on Data Protection law is available from the Information Commissioner's Office (https://ico.org.uk/).

How do we use your personal data?

We use your personal data for research with appropriate safeguards in place on the lawful bases of fulfilling tasks in the public interest, and for archiving purposes in the public interest, for scientific or historical research purposes.

We will always tell you about the information we wish to collect from you and how we will use it.

We will not use your personal data for automated decision making about you or for profiling purposes.

Our research is governed by robust policies and procedures and, where human participants are involved, is subject to ethical approval from either UWE Bristol's Faculty or University Research Ethics Committees. This research has been approved by The University of the West of England FREC (UWE REC REF No: HAS 21.02.109). The research team adhere to the **Ethical guidelines of the British Educational Research Association (and/or the principles of the Declaration of Helsinki, 2013) and the principles of the General Data Protection Regulation (GDPR).**

For more information about UWE Bristol's research ethics approval process please see our Research Ethics webpages at:

www1.uwe.ac.uk/research/researchethics

What data do we collect?

The data we collect will vary from project to project. Researchers will only collect data that is essential for their project. The specific categories of personal data processed are described in the Participant Information Sheet provided to you with this Privacy Notice

Who do we share your data with?

We will only share your personal data in accordance with the attached Participant Information Sheet and your Consent.

How do we keep your data secure?

We take a robust approach to protecting your information with secure electronic and physical storage areas for research data with controlled access. If you are participating in a particularly sensitive project UWE Bristol puts into place additional layers of security. UWE Bristol has Cyber Essentials information security certification.

Alongside these technical measures there are comprehensive and effective policies and processes in place to ensure that users and administrators of information are aware of their obligations and responsibilities for the data they have access to. By default, people are only granted access to the information they require to perform their duties. Mandatory data protection and information security training is provided to staff and expert advice available if needed.

How long do we keep your data for?

Your personal data will only be retained for as long as is necessary to fulfil the cited purpose of the research. The length of time we keep your personal data will depend on several factors including the significance of the data, funder requirements, and the nature of the study. Specific details are provided in the attached Participant Information Sheet Anonymised data that falls outside the scope of data protection legislation as it contains no identifying or identifiable information may be stored in UWE Bristol's research data archive or another carefully selected appropriate data archive.

Your Rights and how to exercise them

Under the Data Protection legislation you have the following **qualified** rights:

The right to access your personal data held by or on behalf of the University;

The right to rectification if the information is inaccurate or incomplete;

The right to restrict processing and/or erasure of your personal data;

The right to data portability;

The right to object to processing;

The right to object to automated decision making and profiling;

The right to complain to the Information Commissioner's Office (ICO).

Please note, however, that some of these rights do not apply when the data is being used for research purposes if appropriate safeguards have been put in place.

We will always respond to concerns or queries you may have. If you wish to exercise your rights or have any other general data protection queries, please contact UWE Bristol's Data Protection Officer (dataprotection@uwe.ac.uk).

If you have any complaints or queries relating to the research in which you are taking part please contact either the research project lead, whose details are in the attached Participant Information Sheet, UWE Bristol's Research Ethics Committees (research.ethics@uwe.ac.uk) or UWE Bristol's research governance manager (Ros.Rouse@uwe.ac.uk)

v.1: This Privacy Notice was issued in April 2019 and will be subject to regular review/update.

Appendix 21: Ethical approval letter

This appendix has been redacted because it contains personal data.

Appendix 22: Draft findings and recommendations

Concerns and recommendations (summary tables)

Abbreviations: QES = qualitative evidence synthesis, Qual study = Qualitative cancer survivor study, HCP = Healthcare professional study, LWBC = Living with and beyond cancer.

Table 1: Concerns and recommendations

Concern	**Recommendation**
Living with chronic pain after cancer treatment affects physical, psychological, social, emotional, financial, and social wellbeing	People LWBC should have access to rehabilitation and support services
2. People LWBC are not prepared for chronic pain after cancer treatment: 1. Not informed of risks of chronic pain after cancer treatment at diagnosis and pre-cancer treatment 2. Not aware of signs and symptoms of chronic pain when they arise	People LWBC should be given accessible information about risks of late effects of cancer, including chronic pain, before treatment and throughout pathway
Healthcare professionals lack knowledge, understanding and confidence about chronic pain after cancer treatment	Raise awareness of chronic pain after cancer treatment amongst healthcare staff (pre reg and registered)
Chronic pain after cancer treatment is not discussed with people LWBC *(incorporating 'not listened to', 'not believed', 'resistance to talk')*	Raise HCP awareness, knowledge and understanding of chronic pain after cancer treatment and confidence to address it
Unclear and limited pathway for support for people living with chronic pain after cancer treatment	Identify pathways for support and communicate pathways with HCPs and people LWBC

Table 2: Evidence for concerns and recommendations plus discussion points for how recommendations may be addressed

Concern 1	**Living with chronic pain after cancer treatment affects physical, psychological, social, emotional, financial, and social wellbeing**
Evidence for concern	*Literature* – impact of pain, impact of late effects *QES* – Theme: 'The physical impact of chronic pain' and 'The emotional experience of chronic pain' *Qual study* – Theme: 'Living with chronic pain after cancer treatment impacts and shapes daily life'
Recommendation	**People LWBC should have access to rehabilitation and support services**
Evidence for recommendation	*Literature* – Lancet series, policy docs etc *Qual study* – Theme: 'Importance of a chronic pain diagnosis after cancer treatment *HCP study* – Theme: Limited service provision
How	Increase awareness among HCP to enable signposting Increase awareness amongst people LWBC to enable supported self-management, self-referral to rehabilitation services Access to a Directory of Services More services (!) specialist/late effects clinics
Issues/Discussion points	HCP signposting impossible/challenging when 1) limited knowledge re prevalence and risks (*qual study and HCP study*) 2) minimal awareness of current services *(qual study and HCP study)* 3) limited services available (*Qual study and HCP study)* Supported self-management challenging when people LWBC not aware of risks and symptoms *(Literature and Qual study)* Directory of Services (who complies? Who updates? Hosted where? Advertised where and how?) More services – funding, communication
What have done so far/plans	Dissemination activities Pain Network Survey

Concern 2	**People LWBC are not prepared for chronic pain after cancer treatment:** **1. Not informed of risks of chronic pain after cancer treatment at diagnosis and pre-cancer treatment** **2. Not aware of signs and symptoms of chronic pain when they arise**
Evidence for concern	*Literature* – pt views on explanations of side effects: overall, late effects, chronic pain *QES* – Theme: 'Lack of preparedness and support for persistent pain' *Qual study* – Theme: 'Scarcity of knowledge and understanding about chronic pain after cancer treatment' Subtheme: 'Unexpected experience' *HCP study:* 27.9% (n-29) never or rarely talking to people LWBC about chronic pain after cancer treatment. No statistical difference between acute/community
Recommendation	**Patients should be given accessible information about risks of late effects of cancer, including chronic pain, before treatment and throughout pathway**
Evidence for recommendation	*Literature:* Lancet series, guidelines, Scottish NCPE survey 'Not feeling that individual needs were met'- Most expressed a wish that they had been given more detailed and honest information about treatment options, side effects and self-management, as well as about other services they could access for specific support and information (Cunningham and Wells, 2017) *Qual study:* Theme: 'Scarcity of knowledge and understanding about chronic pain after cancer treatment' Subtheme: 'Unexpected experience' *HCP study:* Section: 'Views on information and support' category: Throughout the pathway but definitely before treatment'.
How	Access to information – written, verbal, online Increased awareness amongst HCP to inform people LWBC (acute and community)
Issues/Discussion points	Timing – when? *Qual study;* Before treatment, before symptoms. Theme: 'Scarcity of knowledge and understanding about chronic pain after cancer treatment' Subtheme: 'Unexpected experience' *HCP study:* 93.4% (n-99) thought risks should be explained before treatment but in 'Views on information and support' category: 'Throughout the pathway but definitely before treatment' Timing, overwhelm and recall *Literature:* 'there was so much information that it was very hard to absorb everything that was said, especially so close to being diagnosed with cancer (Tanay et al.,, 2019). Some patients were clearly overwhelmed by the amount of information they received (Cunningham and Wells, 2017)

	Qual study: So much info to take in, hard to recall. Theme: ‘Scarcity of knowledge and understanding about chronic pain after cancer treatment’ Subtheme: ‘Unexpected experience’ *HCP study*: some thought it was not appropriate to discuss pain prior to treatment, acknowledged that patients have a lot of information to take in before treatment, and they may not remember it all so the importance of repeated information throughout the pathway was paramount: Timing, ? not a priority compared to info recall/understanding about immediate, life threatening side effects, i.e. neutropenic sepsis HCP can not inform if they themselves have a lack of knowledge and understanding (see concern 3)
What have done so far/plans	Increased awareness - People LWBC and HCP – dissemination activities

Concern 3	**Healthcare professionals lack knowledge, understanding and confidence about chronic pain after cancer treatment**
Evidence for concern	*Literature:* Poor levels of cancer pain knowledge (Bouya et l 2019) cancer pain management (Breuer et al., 2015), pain knowledge and empathy (Dag et al., 2022). Cancer nurses see survivorship care part of their role but least performed survivorship care items were discussing fertility issues, communicating survivorship care with primary healthcare team (i.e. general practitioners) and discussing sexuality issues (Chan et al.,, 2018). Most H&N HCPs agreed or strongly agreed that they had the knowledge, skills and confidence to manage common symptoms and problems such pain (and others). Most confident discussing the long-term effects of treatment and least confident about (1) providing complex symptom management; (2) reviewing and managing medications and their effects (Wells et al.,, 2015) *Qual study:* Many felt they had encountered healthcare professionals who *"didn't know anything about it" (Olivia)* and this culminated in the feeling that *"They (healthcare professionals) don't understand" (Fiona)* *HCP study.* Low levels of knowledge, understanding and confidence.
Recommendation	**Raise awareness of chronic pain after cancer treatment amongst all staff (pre reg and registered)**
Evidence for recommendation	*Evidence for concern plus:* *Literature:* Almost 70% (n – 246) of nurses, both in the hospital and community setting, and allied health professionals, considered knowledge of long term health effects of cancer treatment to be a training priority (Faithfull et al.,., 2016). Medical graduates feel their pain current pain education is inadequate (Ellison et al.,., 2022) and most GPs would like for further education to improve their knowledge and expertise about the management of cancer treatment-related side effects (Walter et al.,., 2015) as would general practice nurses (Dyer and Dewhurst, 2020). Specialist training in cancer care associated with higher levels of perceptions of responsibilities in providing intervention for physical and psychosocial consequences of cancer and its treatment as well as coordination of care to ensure that all health needs of the survivors are met (Wong et al.,, 2021) *HCP study:* Participants wanted more education to increase knowledge about chronic pain after cancer treatment. No stat difference in knowledge in sample more experienced or greater % of role LWBC.
How	Education that addresses principles of chronic pain after cancer treatment and fundamentals of care and support (? Post Doc work) – focus on PLANS, for all/fundamental principles
Issues/Discussion points	How? E-learning in cancer (Campbell, Taylor et al., 2019) ? increased education = increased confidence

	? most effective education strategy: Lit review, cancer survivorship education programs for primary care providers (PCPs) and assess their outcomes. 21 studies. All 21 programs were generally beneficial to PCP learners (e.g., increased confidence, knowledge, behaviour change); however, methodological bias suggests caution in accepting claims. Evidence for clinical effectiveness was rarely reported (Chan, Agbejule et al.,, 2022) No stat difference in confidence levels in HCP study between groups but in literature –Older age, more years of experience, having a post-graduate qualification and working in non-metropolitan area were associated with higher levels of perception of responsibilities and confidence in survivorship care (Chan, Button et al.,, 2019).
What have done so far/plans	Dissemination activities ACCEnD impact study

Concern 4	**Chronic pain after cancer treatment is not discussed with people LWBC *(incorporating 'not listened to', 'not believed', 'resistance to talk')***
Evidence for concern	*Literature:* knowledge of side effects, abandoned at end of treatment *QES:* When pain persisted, women felt it was not recognised or acknowledged by some healthcare professionals and when women did tell physicians about their pain, they felt either dismissed or were sent to a psychiatrist *Qual study:* Themes: not listened to, not believed, HCP resistant to discuss *HCP study:* ~ ¼ rarely or never listen, signpost or talk. Some do not know chronic pain after cancer can occur years after treatment has finished
Recommendation	**Raise HCP awareness, knowledge and understanding of chronic pain after cancer treatment and confidence to address it**
Evidence for recommendation	*Qual study:* positive impact when encounter understanding services that inform and discuss about chronic pain after cancer treatment. Harm caused by not being listened to or believed. ? resistance will diminish when more informed, being more informed will increase confidence to discuss
How	Education that addresses principles of chronic pain after cancer treatment and fundamentals of care and support Increased awareness among HCP to enable diagnosis, information giving and signposting Directory of services (Pain network survey) Increase awareness amongst those LWBC – dissemination activities
Issues/Discussion points	Need to address barriers raised in HCP survey (knowledge but also ? aetiology for pain – (but ? more test = avoiding diagnosis? Some say so in HCP study – challenges in diagnosing)
What have done so far/plans	Dissemination activities

Concern 5	**Unclear and limited pathway for support for people living with chronic pain after cancer treatment *(incorporating 'abandoned at end of treatment', 'boomeranging', 'conflict re primary/secondary care', 'identifying and accessing services')***
Evidence for concern	*Literature:* Tanay et al., study and more. (Jefford *et al.*, 2022; Lynch *et al.*, 2021; IJsbrandy *et al.*, 2020). *QES:* When chronic pain manifested, they felt healthcare professionals avoided addressing it or dismissed their concerns and thus they felt abandoned and alone in the responsibility to manage their pain. *Qual study:* abandoned at end of treatment, boomeranging, identifying and accessing services difficult – theme:' Unclear and limited pathway for support' *HCP study:* Do not know what services are available, services overstretched so avoid referral. Theme: 'Unclear and limited pathway for support', 'conflict between services'
Recommendation	**Identify pathways for support and communicate pathways with HCPs and people LWBC** **Information giving and signposting to available services** **Advertisement of services (local and national, HCP and people LWBC)** **Improved communication between primary and secondary care** **Late effects/specialist services**
Evidence for recommendation	Importance of signposting (Qual study) Value of support person after cancer treatment finished (Qual study: difficulty in accessing services). Literature - Value of named person – cite value of CNS work ? impact of late effect clinics
How	HCP education and awareness (acute and community) Directory of services
Issues/Discussion points	Improved communication challenging, many past initiatives (recovery package, personalised care) -evidence it can be unsuccessful – realist evaluation into how and why
What have done so far/plans	Dissemination plans

Appendix 23: PhD summary for Expert Review Panel Members

‘We don’t understand….. they don’t understand’ Chronic pain in cancer survivorship.

Julie Armoogum, Macmillan Senior Lecturer, University of the West of England, Bristol.

PhD Supervisors: Professor Candida McCabe, Professor Diana Harcourt, Professor Claire Foster, Dr. Alison Llewellyn.

Introduction

This executive summary provides a brief overview of doctoral research findings exploring chronic pain in cancer survivors. It outlines the aims and objectives of the PhD, the studies undertaken to meet those aims and objectives and a table of keys findings and recommendations. It concludes with some information about the upcoming expert review panel discussions.

Background

The landscape of cancer care is changing. Improvements in the detection and treatment of cancer have resulted in greater numbers of people surviving. Yet not everyone is living well, and people can experience ongoing side effects of cancer treatment[1–4]. Chronic pain is a common late and long-term side effect[5,6] and can be caused by cancer treatments such as chemotherapy, radiotherapy or surgery[7]. This PhD seeks to explore the experiences of cancer survivors living with chronic pain as a late and long-term effect of cancer treatment and consider how they can be supported.

Operational terms

Cancer survivor: Any person diagnosed with cancer, who has completed his or her primary treatment (with the exception of maintenance therapy) who has no active disease [8]. It is recognised that the term ‘cancer survivor’ can be contentious[9–11] but it describes the population under study within this doctoral work.

Chronic pain after cancer treatment: Chronic post-cancer treatment pain is pain that lasts for 3 months or more, caused by cancer treatments, such as chemotherapy, radiotherapy or surgery [12]. Herein this will be referred to as chronic pain after cancer treatment.

Services: Interactions between cancer survivors and healthcare professionals within the NHS or a third sector organisation e.g. late effects clinics, follow up clinics, telephone support, specialist services, primary care, health and wellbeing events.

PhD aim and objectives

Aim: To explore the experiences of cancer survivors living with chronic pain after cancer treatment and consider how they can be supported

Objectives:

- To identify, review and synthesise the qualitative literature about the experience of chronic pain after cancer treatment in adult cancer survivors
- To qualitatively explore the experiences, needs and service provision for cancer survivors living with chronic pain after cancer treatment
- To establish healthcare professional understanding, experience, and confidence regarding chronic pain after cancer treatment
- To describe future research, educational and clinical initiatives to support people living with and beyond cancer regarding chronic pain after cancer treatment

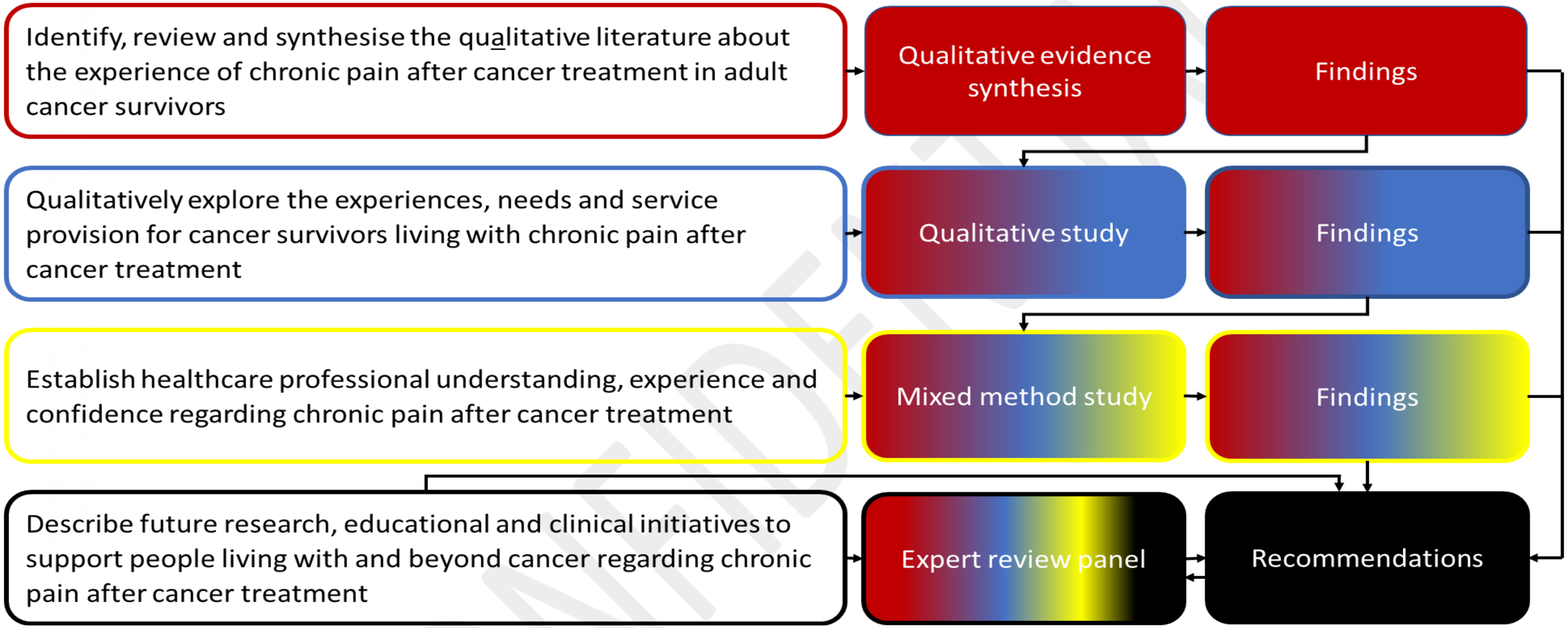
Summary of PhD Studies

A series of studies have been designed and conducted to meet the aim and objectives:

1. A qualitative evidence synthesis whereby the qualitative literature about the experience of living with chronic pain as a cancer survivor was reviewed
2. A qualitative study in which 19 cancer survivors were interviewed about their experiences of living with chronic pain
3. A mixed method study whereby 135 healthcare professionals completed a survey about their knowledge, understanding and practice about chronic pain after cancer treatment

The findings from each study informed the development of the subsequent study. Figure 1 demonstrates the progress of the PhD to date.

Figure 1: What are the experiences of cancer survivors living with chronic pain after cancer treatment and how they can be supported?



Key findings from the studies, alongside clinical recommendations are outlined in table 1.

Table 1: Key findings and clinical recommendations

Key findings	Clinical recommendation	Evidence
1. Living with chronic pain after cancer treatment effects physical, psychological, social, emotional, financial, and social wellbeing	People living with and beyond cancer should have access to rehabilitation and support services	1*, 2*, 3*
People living with and beyond cancer are not prepared for chronic pain after cancer treatment: . They are not informed of risks of chronic pain after cancer treatment at diagnosis and pre-cancer treatment 2. They are not aware of signs and symptoms of chronic pain when they arise	People living with and beyond cancer should be given accessible information about risks of late effects of cancer, including chronic pain, before treatment and throughout pathway	1*, 2*, 3*
3. Health care professionals lack knowledge, understanding and confidence about chronic pain after cancer treatment	Raise awareness of chronic pain after cancer treatment amongst healthcare staff	1*, 2*, 3*
4. Chronic pain after cancer treatment is not discussed with people living with and beyond cancer	Raise healthcare professional awareness, knowledge and understanding of chronic pain after cancer treatment and increase confidence to acknowledge and address it	1*, 2*, 3*
5. There is an unclear and limited pathway for support for people living with chronic pain after cancer treatment	Identify pathways for support and communicate pathways with healthcare professionals and people living with and beyond cancer	1*, 2*, 3*

1* Qualitative evidence synthesis, 2* Qualitative cancer survivor study, 3*Mixed method healthcare professional study

Expert review panel discussion

Expert review panels will consist of a combination of cancer survivors living with chronic pain, clinicians, educators, and researchers with expertise in cancer, cancer late effects and pain. During the expert review panel discussions, the following questions will be posed:

a. To meet these recommendations, what would ‘good’ look like?
b. How would it be measured?
c. What could enable this?
d. What are the challenges and barriers?

******* Thank you for taking the time to read this executive summary *******

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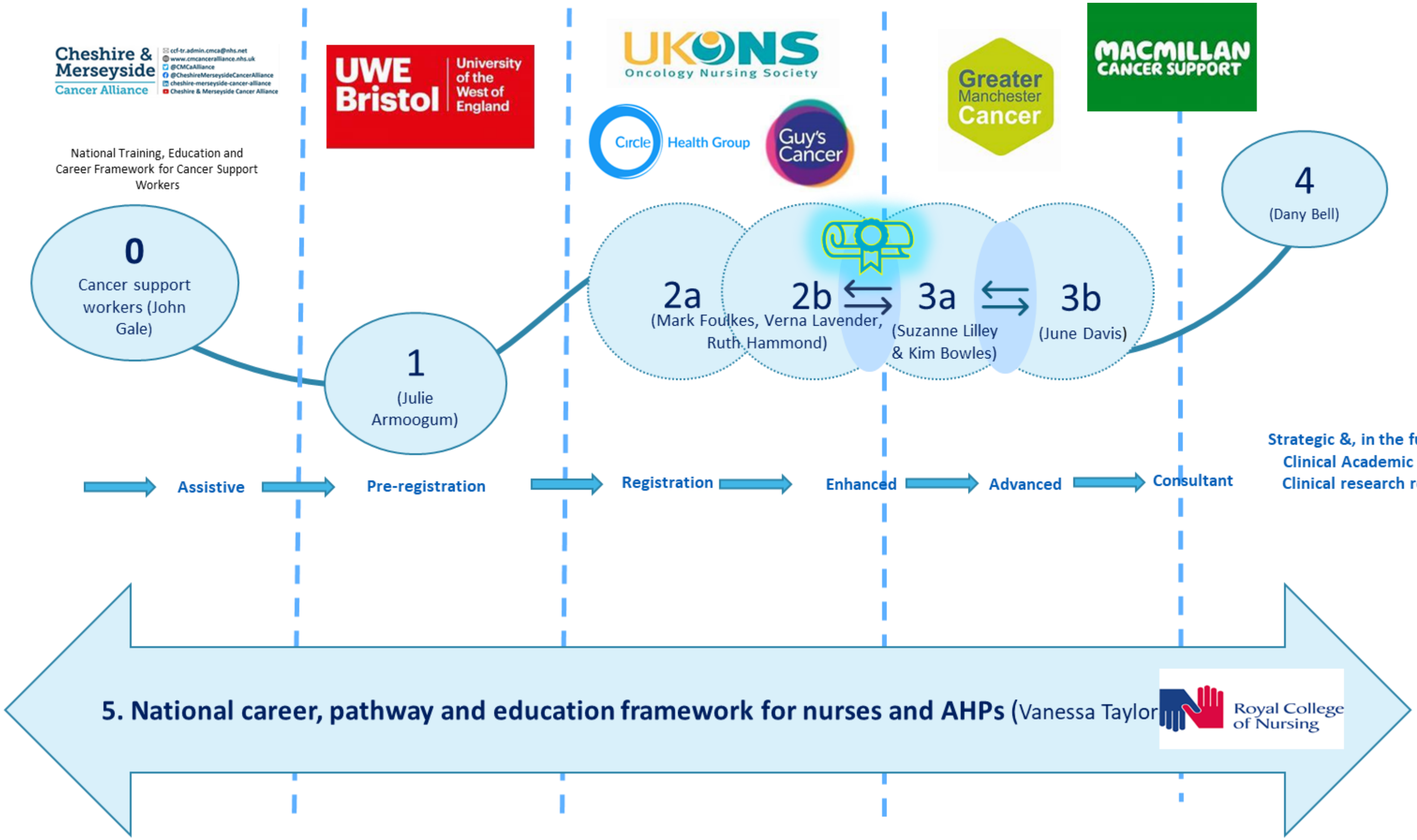
Appendix 24: Expert review panel members

This appendix has been redacted because it contains personal data.

Appendix 25: Aspirant Cancer Career Education and Development Programme (ACCEND) Workstreams



Appendix 26: Impact of public contributors

This appendix has been redacted because it contains personal data.

Appendix 27: Results of CUBE PPI evaluation workshop

This appendix has been redacted because it contains personal data.

Appendix 28: Personal reflection

Looking back at the girl at school who wanted to nurse because she ‘liked people’, I would never have imagined I would be submitting a PhD thesis, and that the world of research and academia would be somewhere I would inhabit. I didn’t really know that nurses were involved with research, or even what research really was, when I started my four-year undergraduate Nursing Studies degree at Kings College London (KCL) in 1997. My time at KCL showed me how nursing is pivotal to improving care – and that nurses need to understand research, embed research in their practice but also be actively involved with and *lead* research. I joined a large London NHS Trust and had a variety of clinical roles in cancer care. I returned to KCL in 2006 to study for a part time MSc whilst working in clinical trials and then a clinical nurse specialist in bone marrow transplantation. I completed my MSc dissertation whilst on maternity leave and loved it. I received excellent academic and pastoral support from my supervisors. I was awarded a distinction, won the Wilson Barnet prize for the best dissertation and published my work (Armoogum, Ames and Richardson, 2013) (the paper was accepted with no corrections, I naively did not realise how rare that was at the time – now I know!). My MSc was objectively a piece of high-quality academic work. I was really proud of it. However, at the time, I felt it had little impact on clinical practice. I felt disheartened and dejected. On reflection, there were a variety of reasons that research did not have the impact I had hoped, or naively, believed would just ‘happen’. Firstly, I worked very conscientiously, but privately. I was ambitious to conduct research, and be a mum, and keep all the life balls in the air – but I was so busy doing, and coping, that I didn’t take a moment to create a plan for dissemination, give thought to implementation or the need to bring the clinical team with me. I didn't really share with the clinical team the work I was doing until it was a fait accompli. Had I communicated plans along the way, the clinical team may have felt more involved and invested in the work, however, as my confidence had taken a dip, alongside the challenges of returning to work after maternity leave, I did not feel I could reach out. Then my personal life, with baby number two on the way, meant we moved to Bristol to be closer to family. Moving to the university setting felt like a natural move. I also hoped that this would enable me to continue to increase my research skills and be involved with research. I moved to the University of the West of England (UWE), passionate to bring cancer nursing and research to undergraduates. I was able to combine teaching with evaluation projects, and was involved in a successful bid to Prostate Cancer UK to create and evaluate virtual patients to increase education for nurses about prostate cancer care (Moule *et al.*, 2015) and whilst I was keen to conduct more research – I had no capacity to undertake anything further beyond studying for a Post Graduate Certificate in Teaching and Learning. I continued to share work with the cancer community at conferences (Armoogum and Hepplewhite, 2015), co-authored papers on service evaluation in nursing (Moule *et al.*, 2016, 2017) and my role was adopted by Macmillan in 2016 in recognition of my expertise in cancer care. However, I missed London and the (possibly self-perceived) credibility of associations with big London based organisations. I felt that cancer nursing research was happening 'elsewhere' and I had somehow missed the boat. I felt encouraged that I had carved out a specialist cancer role within UWE and was developing cancer education through the undergraduate and postgraduate programmes, however, I really wanted to conduct research and knew a PhD was the best way to both learn and develop, but also have credibility as a researcher. UWE developed a pre-doctoral training programme and I was accepted onto the first cohort. During my pre-doctoral fellowship, I assembled my supervisory team. Professor Candy McCabe is a world leading nurse researcher in pain and is based at UWE. From our first meeting Candy was inspirational, supportive and encouraging and I knew I would love to have her as my Director of Studies. My research interest was cancer survivors' experiences and focusing on chronic pain enabled me to work with Candy and align my research ideas with university research themes. This enabled me to garner university support to fund my PhD fees. Alongside Candy, it felt essential to have cancer researchers on the team and I was delighted when Professor Diana Harcourt and Professor Claire Foster agreed to be part of the team. Finally, Associate Professor Alison Llewellyn completed the team, bringing qualitative research expertise. I approached Macmillan and secured additional funding, which combined with UWE support, resulted in just over one day a week of time to study for a part time PhD. Fifteen years after leaving KCL, I had finally secured funding and had a (brilliant) supervisory team in place. I was raring to go.

I started this PhD with expertise in cancer care and experience with research and evaluation. I had felt frustrated it had taken so long to start the PhD programme and I was very focused and determined in the first year to 'make progress'. In many ways that was successful, as the qualitative evidence synthesis was completed within the first year and I tightly managed the supervision meetings – organising them in advance, maintaining meticulous record keeping of meetings and ensuring momentum was established. However, my team advised me to relax into the project, learn to enjoy the process and remember that PhDs are marathons not sprints. This was really helpful advice, as it reminded me that studying for a PhD was a long-held dream – and I was doing it! It is a once in a lifetime experience and I wanted to enjoy it. I feel I was able to take on that advice and I can genuinely say that I have loved it – I have enjoyed managing a long-term project and working consistently and steadily on it for a number of years, I have loved watching the thesis take shape and work through each study. I have been inspired by my team and grateful for their fantastic communication and encouragement. Their written and verbal feedback has been supportive, encouraging and criticisms have been constructive. This has influenced me in my professional role outside of the PhD – when conversing with other professionals and when feeding back to students in my lecturing role. I have tried to avoid the mistakes of my MSc dissertation and have made sure I have been sharing my work with clinical, public and academic communities throughout the PhD and feel proud of my dissemination record. Disseminating the work in this way has helped me hone my ideas and ensure it is connected to practice. I feel I achieved this and the enthusiasm for participation on the expert review panels could be evidence that healthcare professionals feel engaged with the work.

There have been, however, challenges. At times I have felt that I lacked credibility to discuss pain with clinical experts as prior to the PhD I had limited specialist pain expertise or experience. I recognised this limitation and have made efforts to join the pain community. During the PhD I have ensured that I shared my work with the specialists– including presenting a poster at the British Pain Society conference. I have built relationships with pain specialists and this collaboration has led to the formation of the 'cancer pain nurses group', a subgroup of the Pain Nurses Network and we have successfully conducted a survey to locate cancer pain services across the UK and have shared this work at UKONS (Galligan *et al.*, 2022). Another challenge has been the pressure I have put on myself for the work to be 'ground-breaking'. I am confident in my role of educator and appreciate the high regard I enjoy amongst my colleagues and peers.

However, I am still learning to be a researcher. I feel vulnerable and at risk of exposing myself as 'not good enough'. I have found it difficult to bring the PhD to a close and felt responsibility to propose changes that would rectify all the problems I identified in the research findings (I see the irony of that – it mirrors healthcare professionals wanting to *'sort their (patients) problems out'* in the expert review panels). I have needed to remind myself (as my supervisors have tried to reassure me and so did the participants in the expert review panels) that my role of researcher is to design and conduct high quality research and disseminate the findings. It is outside of the scope for this PhD to change the world (however much this disappoints me!). Despite these challenges, completing this PhD, whilst juggling work, life, family and children is a huge personal sense of achievement. When reflecting with my mum and 14 year old daughter on the last few years of balancing motherhood, work and studying – my daughter said to me 'Mum, you've smashed it!' – never will a review mean so much!

Publications arising from the thesis

Publication 1: The experience of persistent pain in adult cancer survivors: A qualitative evidence synthesis

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ORIGINAL ARTICLE

European Journal of Cancer Care WILEY

The experience of persistent pain in adult cancer survivors: A qualitative evidence synthesis

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Abstract

Objective: This qualitative evidence synthesis aimed to identify, review and synthesise qualitative research describing the experience of persistent pain in adult cancer survivors.

Methods: A systematic literature search was conducted between December 2007 and June 2019. Data synthesis followed Thomas and Harden's (2008) method of thematic synthesis.

Results: Four studies were identified, together incorporating findings from 52 female breast cancer survivors. Six themes were generated as follows: (a) interwoven relationship between experience of cancer and persistent pain, (b) lack of preparedness and support for persistent pain, (c) physical impact of persistent pain, (d) employing coping strategies, (e) emotional experience of persistent pain and (f) conceptualisation of persistent pain.

Conclusions: Persistent pain is intrinsically interwoven with women's experiences of cancer. Persistent pain was unexpected, and women did not feel supported. Women need more information about persistent pain after cancer treatment and support with self-management of pain. Ways to best support cancer survivors with persistent pain need exploration and a review of currently available services is required. More research is needed to understand the experiences of men and other cancer groups.

KEYWORDS
cancer, cancer survivor, chronic pain, living with and beyond cancer, persistent pain

1 | INTRODUCTION

Survival rates for cancer are improving and more people are living for longer following their cancer treatment (Maddams, Utley, & Møller, 2012; Siegel & Miller, 2019). However, people can experience many problems and symptoms in the months and years following treatment (Armes et al., 2009; Bennion & Molassiotis, 2013; Maher, Petchey, Greenfield, Levitt, & Fraser, 2018). A common problem and concern for cancer survivors is pain (Capelan et al., 2017; Schmidt, Wiskemann, & Steindorf, 2018). A recent systematic review of 117 studies ($n = 63{,}533$) found 39% of people treated for cancer, experience pain after curative treatment (Van Den Beuken-Van Everdingen, Hochstenbach, Joosten, Tjan-Heijnen, & Janssen, 2016). Similarly, Schmidt et al. (2018) found 34% of breast cancer survivors experienced pain. A study into the prevalence of unmet needs in 625 women living beyond a diagnosis of early breast cancer found 19% had unmet needs relating to pain (Capelan et al., 2017). These findings demonstrate that pain

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is a significant problem for cancer survivors, yet they do not describe cancer survivors' experiences of pain. Understanding the experiences and needs of cancer survivors is key to improving how well people live after cancer (Maher et al., 2018). The current study therefore aimed to identify, review and synthesise qualitative research describing the experience of persistent pain in adult cancer survivors.

A particular challenge in this field is the lack of consensus in the literature or national clinical guidelines regarding definition of the term "cancer survivor" (Rees, 2018). The European Organisation for Research and Treatment of Cancer (EORTC) Survivorship Task Force define it as any person diagnosed with cancer, who has completed his or her primary treatment (with exception of maintenance therapy) and who has no active disease (Moser & Meunier, 2014). This study adopts this definition. Persistent pain is defined as pain that persists for 3 months or more (IDC11).

2 | METHODS

2.1 | Protocol registration

A protocol for this study was registered with the international prospective register of systematic reviews (PROSPERO) in December 2017 (PROSPERO 2017 CRD42017082562).

2.2 | Review question

What is the experience of persistent pain in adult cancer survivors?

2.3 | Search strategy

A comprehensive search strategy was developed to locate all available studies. Key search terms were used to search relevant databases: CINAHL Plus, Medline, PsycINFO, Embase and Cochrane (Table 1). The search terms were informed by a cancer survivor, the published pain literature and discussion with the study team. Reference lists of identified papers were reviewed. Figure 1 outlines the search strategy. A search limit of 2007–2019 was set.

2.4 | Inclusion and exclusion criteria

Inclusion:

- Primary research adopting a qualitative methodology (either stand-alone or as a discrete element of mixed-method research)
- Explores cancer survivors' experience of persistent pain
- Includes populations of adults over 18 years old when diagnosed and treated for cancer
- Published in English between 2007 and 2019
- Full peer review articles (not abstracts or conference proceedings only)

Exclusion:

- Quantitative research
- Commentary articles and clinical updates
- Studies including sample populations of those exclusively on active treatment or end-of-life care
- Studies of survivors of childhood cancer

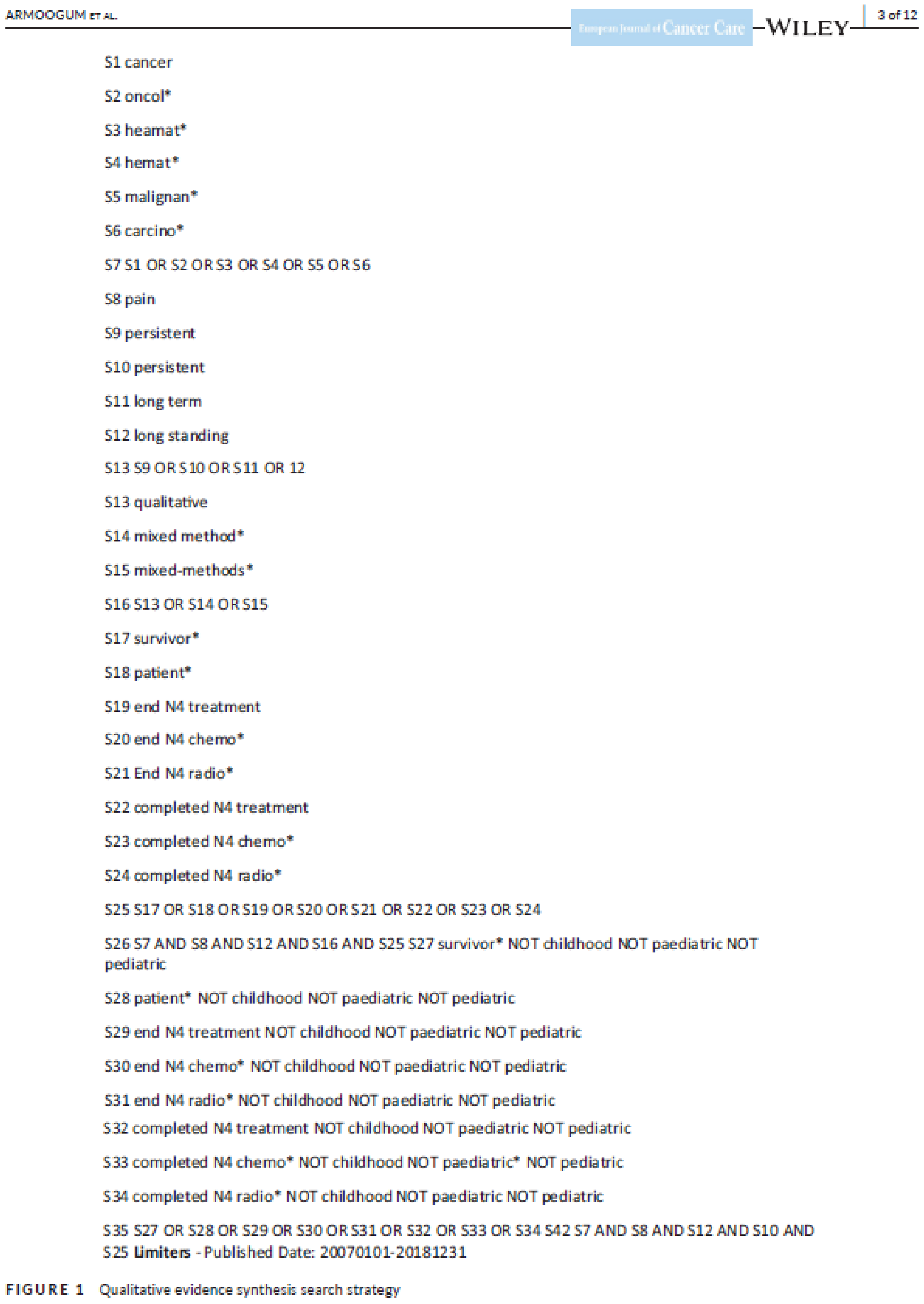
The question is most appropriately addressed by qualitative research as qualitative research seeks to understand lived experience, behaviours and social contexts to explain phenomena of interest (Braun & Clarke, 2013). Survivors of childhood cancer or those at the end of life were excluded. This was because survivors of childhood cancer may have experiences that are unique to that population such as challenges with social integration (Lea et al., 2019) and transitioning from paediatric to adult cancer services (Casillas, Kahn, Doose, Landier, & Bhatia, 2010) or disruption in schooling (Park et al., 2018). Equally, those at the end of life have unique needs (Hackett, Godfrey, Bennett, 2016). A limit of studies published between 2007 and 2019 was applied to ensure the most up to date research was identified. Treatment for cancer has been progressing and changing over time, particularly in breast cancer. Therefore, a start date of 2007 was set as publications beyond that date was likely to be representative of current patient experience.

2.5 | Screening

The search resulted in 683 potential studies. Figure 2 outlines the study selection process. Titles and abstracts were reviewed against

TABLE 1 Key search terms used for study identification

Cancer OR	AND	Pain	AND	Persistent OR	AND	Qualitative OR	AND	Survivor*
Oncol*						Mixed-method*		Patient*
Hemat*				Long-term				End N4 treatment
Haemat*				Long-standing				End N4 chemo*
Malignan*				Long-term				End N4 radio*
Carcino*				Long-standing				Completed N4 treatment
								Completed N4 chemo*
								Completed N4 radio*



S1 cancer

S2 oncol*

S3 heamat*

S4 hemat*

S5 malignan*

S6 carcino*

S7 S1 OR S2 OR S3 OR S4 OR S5 OR S6

S8 pain

S9 persistent

S10 persistent

S11 long term

S12 long standing

S13 S9 OR S10 OR S11 OR 12

S13 qualitative

S14 mixed method*

S15 mixed-methods*

S16 S13 OR S14 OR S15

S17 survivor*

S18 patient*

S19 end N4 treatment

S20 end N4 chemo*

S21 End N4 radio*

S22 completed N4 treatment

S23 completed N4 chemo*

S24 completed N4 radio*

S25 S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24

S26 S7 AND S8 AND S12 AND S16 AND S25 S27 survivor* NOT childhood NOT paediatric NOT pediatric

S28 patient* NOT childhood NOT paediatric NOT pediatric

S29 end N4 treatment NOT childhood NOT paediatric NOT pediatric

S30 end N4 chemo* NOT childhood NOT paediatric NOT pediatric

S31 end N4 radio* NOT childhood NOT paediatric NOT pediatric

S32 completed N4 treatment NOT childhood NOT paediatric NOT pediatric

S33 completed N4 chemo* NOT childhood NOT paediatric* NOT pediatric

S34 completed N4 radio* NOT childhood NOT paediatric NOT pediatric

S35 S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 S42 S7 AND S8 AND S12 AND S10 AND S25 **Limiters** - Published Date: 20070101-20181231

FIGURE 1 Qualitative evidence synthesis search strategy the inclusion and exclusion criteria and were excluded or referred for full-text review. Two authors independently reviewed full texts of remaining studies. Initially, 64 papers were excluded because the study design or patient population did not meet the inclusion criteria for this synthesis, the studies were presented as abstracts only or not published in English. Authors met and discussed decisions and brought the remaining studies (*n* = 16) to the wider team for further discussion. This resulted in clarification of the inclusion and exclusion criteria:

- If the population has completed anti-cancer therapy but were on hormone treatment, they could be included
- If the population had metastatic disease, they would be excluded
- If populations included a mix of those who had completed treatment and those on treatment but results could not be separated between groups, then the study would be excluded
- If studies initially appeared to meet inclusion criteria, but on closer reading did not fully explore experiences of persistent pain as there was only a passing comment about pain, then authors would be contacted to request more data (if available) about the experience of persistent pain.

Twelve authors were contacted for more information about their study. From these, five replied to say they had no further information about the experience of persistent pain or did not have the data readily accessible, and the remaining authors did not reply.

2.6 | Quality assessment (selection and evaluation criteria)

Quality assessment of studies was undertaken using an adapted version of the Critical Appraisal Skill Programme (CASP) Checklist for Qualitative Research (Critical Appraisal Skills Programme, 2017) to ensure methodological rigour and ethical standards were met. Two authors independently assessed and then reached agreement over the quality of the included studies (Table 2).

2.7 | Data extraction

A standardised form, based on Noyes et al (2015) and Tanay, Armes, and Ream (2017), was used to extract data. To ensure accuracy, data were extracted from each study by two authors. Thomas and Harden (2008) suggest that all text labelled as "results" or "findings" should be extracted. The team discussed findings that included direct participant quotes and authors' interpretations of the interview data. The team decided that during

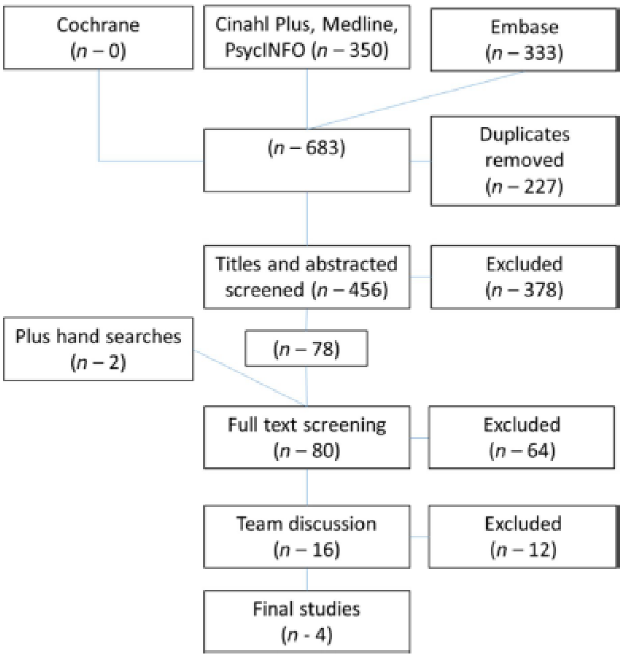


FIGURE 2 Process of study selection

TABLE 2 Quality assessment

Protocol statement	CASP Questions	Paper, author (date)			
		Björkman, Arnér, and Hydén (2008)	Hellerstedt-Börjesson et al. (2016b)	Hovind et al. (2013)	Peretti-Watel et al. (2012)
Adopted an appropriate method and design to meet the aims of the study	Was there a clear statement of the aims of the research?	Yes	Yes	Yes	Yes
	Is a qualitative methodology appropriate?	Yes	Yes	Yes	Yes[a]
	Was the research design appropriate to address the aims of the research?	Yes	Yes	Yes	Yes
Used a suitable data collection strategy	Was the recruitment strategy appropriate to the aims of the research?	Yes	Yes	Yes	Yes
	Was the data collected in a way that addressed the research issue?	Yes	Yes	Yes	Yes
	Has the relationship between researcher and participants been adequately considered?	Not known	Yes	Yes	Not known
Included pertinent methods of data analysis	Was the data analysis sufficiently rigorous?	Yes	Yes	Yes	Yes
Drew conclusions and interpretations that reflected the findings of the study	Is there a clear statement of findings?	Yes	Yes	Yes	Yes
	How valuable is the research?	Valuable	Valuable	Valuable	Valuable
Obtained ethical approval	Have ethical issues been taken into consideration?	Yes	Yes	Yes	Yes

[a] Interview data

the analysis and synthesis phase, when direct participant quotes were provided, then they should be analysed as much as possible. When a quote was not available, author interpretations were to be used. It was agreed that without using both participant quotes and author interpretations, then some of the richness of the papers would be lost.

2.8 | Strategy for data synthesis

Data synthesis followed Thomas and Harden's (2008) method of thematic synthesis of qualitative research. During stage one, two authors independently coded each line of text according to its meaning and context. During stage two, "descriptive themes" were created to summarise meanings of initial groups of codes. The final stage involved "going beyond" the context of original studies to generate "analytical themes." The team discussed the analytical themes and they were further refined until sufficient to reflect all initial descriptive themes.

3 | RESULTS

Four studies were identified. Three studies were from Scandinavia and one from France. These studies generated findings from 52 female breast cancer survivors. Sample sizes ranged from 8 to 21 and women ranged from 26 to 83 years with a median age of 54.5 years. All women were treated with surgery and some with adjuvant radiotherapy, chemotherapy and/or hormone therapy. All were substudies to larger studies, all used interviews for their data collection method and interviews lasted between 30 min and four hours. See Table 3 for characteristics of studies.

From the final stage of Thomas and Harden's (2008) method of thematic synthesis, six analytical themes were generated as follows: (a) an interwoven relationship between experience of cancer and persistent pain, (b) lack of preparedness and support for persistent pain, (c) the physical impact of persistent pain, (d) employing coping strategies, (e) the emotional experience of persistent pain and (f) conceptualisation of persistent pain. Table 4 outlines the presence of themes in each paper.

3.1 | An interwoven relationship between the experience of cancer and persistent pain

Some women found it difficult to distinguish their experience of persistent pain from their experience of a breast cancer diagnosis and the threat to their existence posed by cancer, and these were intricately woven together. The presence of pain was viewed by many as an indicator of their current cancer status and represented their transitional state between health and illness but also served as a reminder of the threat that they had experienced to their mortality.

For some, the pain had negative connotations relating to their cancer diagnosis and when women experienced pain, they immediately started to question what the pain represented and

TABLE 3 Characteristics of included studies

Author, year, origin	Aims of study	Research design/ theoretical framework	Data collection method, data analysis approach	Sampling	*n*	Demographic details	Treatment	Time point
Björkman et al. (2008), Sweden.	To explore women's personal descriptions of if and how phantom breast phenomenon appears within painful sensations	Qualitative, longitudinal and prospective, Explorative	Semi-structured interviews, 4 × 1 hr, discourse and narrative analysis	Consecutive	8	47-72 years, women, breast cancer	Surgery +/− *radiotherapy +/− endocrine or hormonal therapy	1, 6 months, 1, and 2 years after mastectomy
Hellerstedt-Börjesson et al. (2016b), Sweden	To explore memories of CHIP and any experience long-standing treatment related pain	Qualitative, phenomenological lifeworld	Interviews, 30–90 min, guided phenomenological reflection	Consecutive	15	30-79 years, women, breast cancer	Surgery +/− chemotherapy +/− radiotherapy +/− hormone therapy	One year after treatment
Hovind et al. (2013), Norway	Perception of pain and improvement of pain management	Qualitative, descriptive	Semi-structured interviews, 1 hr, Qualitative content analysis	Purposive	8	44–65 years, women, breast cancer	Surgery +/− chemotherapy +/− radiotherapy	Between 12 and 30 months after surgery
Peretti-Watel et al. (2012), France	1. Compare WHOQOL-BREF questionnaire and interview data 2. Explore attitude and meaning to pain	Qualitative, Inductive	In-depth semi-structured interviews, 1–4 hr, Inductive approach based on grounded theory	Purposive	21	26–83 years, women, breast cancer	Surgery +/− chemotherapy +/− hormone treatment	24 months after diagnosis

Note: + = with chemotherapy, radiotherapy or hormone treatment; − = without chemotherapy, radiotherapy or hormone treatment.

wondered what it meant in terms of their cancer—was something wrong? Increased physical symptoms could "automatically reawaken worries about the progress of the cancer" (Bjorkman, Arner, and Hyden (2008) p.1023). Consequently, some exhibited signs of somatisation as they feared for the worse and the pain made them feel vulnerable:

> *You really listen to your body in quite a different way now. Every little thing you feel in your body could be signs of something abnormal.*
> *(10) (Hellerstedt-Börjesson, Nordin, Fjällskog, Holmström, & Arving, 2016b)*

Yet for others, the presence of pain was reassuring and a positive indicator of their cancer status, as they interpreted the pain as a sign that the cancer treatment was working or had worked:

> *(the pain) was proof that everything was reactivated, it was being renewed.*
> *(Sharon) (Peretti-Watel, Bendiane, Spica, & Rey, 2012)*

The presence of pain complicated their feelings and perceptions about finishing their cancer treatment because, whilst they had completed treatment for their cancer, they still experienced pain and the pain sensations "coexisted with a continuum of other altered sensations and sensation disorders" (Bjorkman et al. (2008) p.1022). Thus, they were balanced between a state health and of illness:

> *Now I've finished my treatment but am stuck in a period where I sit and think 'am I healthy or am I not?' It's like something in between.*
> *(10) (Hellerstedt-Börjesson et al., 2016b)*

> *When you think about what you've been through, it's like the pain doesn't only exist in my arm, but in my whole body.*
> *(3) (Hellerstedt-Börjesson et al., 2016b)*

The pain also served as a reminder of the threat that they had experienced to their mortality. This manifested in both an impatience with others and recognition that they had survived their treatment:

> *It felt like everyone was driving too slowly and I didn't have the time to sit there and wait … I felt like 'you have all the time in the world, but my time's running out.*
> *(11) (Hellerstedt-Börjesson et al., 2016b)*

> *There is always someone worse off than yourself. There are those who do not have the chance to live.*
> *(Stella) (Peretti-Watel et al., 2012)*

TABLE 4 Presence of themes in each paper

Theme	Björkman et al. (2008)		Hellerstedt-Börjesson, Nordin, Fjällskog, Holmström, and Arving (2016a)	Hovind et al. (2013)	Peretti-Watel et al. (2012)	
	Author interpretation	Participant quote	Participant quote	Participant quote	Participant quote	Author interpretation
Interwoven relationship between experience of cancer and persistent pain	x		x	x	x	
Lack of preparedness and support for persistent pain			x	x		x
Physical impact of pain			x	x	x	
Employing coping strategies			x	x	x	
Emotional experience of persistent pain	X		x	x	x	
Conceptualisation of persistent pain		x	x	x		

3.2 | Lack of preparedness and support for persistent pain

It was evident that many of the women were unprepared for the experience of persistent pain after their cancer treatment had ended. They expressed an expectation that they would experience acute pain during treatment, and many of the women felt supported during this time, yet did not recall being given information about persistent pain. When persistent pain manifested, they felt healthcare professionals avoided addressing it or dismissed their concerns and thus they felt abandoned and alone in the responsibility to manage their pain.

The absence of preparedness for persistent pain was evident as "some participants clearly lacked information about pain" (Peretti-Watel et al., 2012, pg 6) as "No one told you what kind of pain you could develop" (No 7) (Hovind, Bredal, & Dihle, 2013). Yet it was acknowledged that, at the time of intensive treatment, persistent pain may have been mentioned but women did not view it as important at the time because they were "not concerned about pain. My focus wasn't there" (No 8) (Hovind et al., 2013).

When pain persisted, women felt it was not recognised or acknowledged by some healthcare professionals as when women asked them about it "they were…'Forthcoming, calming… but in terms of pain, I have to talk about it myself" (no 3) (Hovind et al., 2013). However, in some instances, when women did tell physicians about their pain, they felt either dismissed as "they (the doctors) told me it was normal (to feel pain)" (Eva) (Peretti-Watel et al., 2012) or were sent to a psychiatrist. Peretti-Watel et al. (2012) consider that "such 'psychiatrization' of pain made women feel impotent and guilty because it implied that their pain was not 'real'" (pg 6). This emphasised that women felt abandoned by healthcare professionals and alone in managing their pain as they were not given support to self-manage it or its impact:

> *I wished that my pain at home was followed up much more.*
>
> *(No 7) (Hovind et al., 2013)*

> *The problems start after that (the end of treatment): whom do you turn to when you have pain in your hip like I do?*
>
> *(4) (Hellerstedt-Börjesson et al., 2016b)*

The lack of preparedness may have also contributed to a perceived gap in expectation of recovery from women themselves and also their family members:

> *They (the doctors) said in a year you'll be back to your regular everyday life, and I'm not. It's a disappointment.*
>
> *(13) (Hellerstedt-Börjesson et al., 2016b)*

> *I also see that my family demands more of me now, which I'm not always able to live up to.*
>
> *(13) (Hellerstedt-Börjesson et al., 2016b)*

The combination of these elements may have given rise to the feeling of being alone in an existential way—as one women expressed, she "felt disappointed in life, like I was abandoned and totally alone. Not abandoned by my fellowman but abandoned by life…" (Hellerstedt-Börjesson et al., 2016b).

3.3 | The physical impact of persistent pain

The physical impact of the pain on women came across in three studies and was described in terms of both physical limitations and the fact that the pain was ever-present as a bodily sensation. Women felt it "doesn't go away" (Emmy) (Peretti-Watel et al., 2012, p4) and is now a "permanent" (Sharon) (Peretti-Watel et al., 2012, p4) element of their life. One woman said that her pain "doesn't only exist in my arm, but in my whole body" (3) (Hellerstedt-Börjesson et al., 2016b).

Living with persistent pain was hard on the women as it hindered them at work, in physical activities and in their social and personal lives. The physical aspects of the pain caused difficulties in performing day-to-day activities:

> *[what kind of domestic activities did you stop doing because of the pain?] 'cleaning, ironing, washing the windows of course, and I cannot drive on long trips.*
> *(Nancy) (Peretti-Watel et al., 2012)*

> *I can't ride a scooter, I can't raise my arms… I can't lift a pack of milk, it's too painful.*
> *(Emmy) (Peretti-Watel et al., 2012)*

> *When I want to peel something, I drop it.*
> *(8) (Hellerstedt-Börjesson et al., 2016b)*

For one participant, a hairdresser, pain prevented her from drying as many clients' hair as before, therefore, it caused both a physical limitation and negatively affected her ability to work:

> *Before my cancer I used to blow dry 20 clients hair every day, but now after 4 or 5 I must stop because my arm hurts too much.*
> *(Cindy) (Peretti-Watel et al., 2012)*

3.4 | Employing coping strategies

Women adopted a variety of methods of coping with their persistent pain. These included adapting and altering daily activities to work around their pain and the use of social comparison as a coping method. Social comparison was used by the women themselves and also healthcare professionals. For some, there was an acceptance of pain as a normal phenomenon of a cancer journey and recovery, and consequently women "expressed a desire to live as normal a life as possible" (p.1048) despite the pain (Hovind et al., 2013).

Women adapted and altered their daily lives to help them cope with their pain in a physical and social sense. They planned and incorporated regular breaks into their activities and changed how they carried out domestic duties in response to it:

> *I have to make plans, to be careful when moving.*
> *(no6) (Hovind et al., 2013)*

> *If I sit down in the evening, my body starts to twitch, then I have to get up and around again. Just like in the morning, I have to sit for a while.*
> *(8) (Hellerstedt-Börjesson et al., 2016b)*

> *I learned to change some of my movements. I learned movements that relieve. Instead of wringing the kitchen glove like that, now I wring it like this, against the side of the sink.*
> *(Linda) (Peretti-Watel et al., 2012)*

They adapted their activities throughout the day, ensuring they were sufficiently rested, to enable them to have maximum energy for when they felt they needed it most, for example, to care for their children:

> *The space I had when they were in school and at leisure time, when I was able to be at home and rest, gave me energy to take off when they arrived back home again.*
> *(13) (Hellerstedt-Börjesson et al., 2016b)*

In addition to changing how they carried out certain activities, women in the Peretti-Watel et al. (2012) study used downward social comparison as a coping mechanism. Some women were able to take comfort from comparing their pain to others' experiences and if they felt others had more challenging conditions to cope with:

> *I prefer to be like this than in a wheelchair. There are some who are more unfortunate than me. Not thinking only about myself comforts me.*
> *(Mary) (Peretti-Watel et al., 2012)*

> *My boyfriend's situation is worse than mine, he had mouth cancer. They ripped out all his teeth and now he has a special apparatus because he cannot eat, he cannot chew, he must suffer a lot.*
> *(Eva) (Peretti-Watel et al., 2012)*

However, whilst social comparison could be used positively and empower women to feel that they could face the challenge of persistent pain, for some, social comparison could be used as a means to dismiss concerns and worries. This appeared to be used by women but also by healthcare professionals:

> *When I saw myself in this state I thought: there are some people who are worse off. So then I told myself: I have no right to complain… there is always someone worse off than yourself.*
> *(Stella) (Peretti-Watel et al., 2012)*

> *Yes there are difficult moments. But you see, I had two small pupils who had leukemia…. seeing all these little children, with such large perfusions… you know, when I start to complain about my pain, I think about her… and I feel I have no right to complain.*
> *(Linda) (Peretti-Watel et al., 2012)*

> *There is a doctor who told me 'you know, if you feel pain madam, take a short tour of accident and emergency and you'll see, you will immediately get better' He said' go and see a few kids at A&E, you'll stop complaining all the time' I was so shocked that I never returned to that hospital.*
>
> *(Nancy) (Peretti-Watel et al., 2012)*

3.5 | The emotional experience of chronic pain

A wide range of emotions was expressed when describing the experience of living with persistent pain and the emotional aspect of experiencing it during cancer survivorship was evident in all the papers. Women were stoical about how they discussed their pain, talked with seeming acceptance as they tried not to let it have too great an impact and attempted to carry on with what they wanted to do:

> *We must learn to live with it.*
>
> *(Emmy) (Peretti-Watel et al., 2012)*

> *I try to ignore the pain and continue with what I'm doing.*
>
> *(No 7) (Hovind et al., 2013)*

Yet some women also felt frustration with their pain, experienced fatalism that it would carry on and expressed resignation that this was how life was going to be for them now:

> *I can't use the body as I wish to.*
>
> *(8) (Hellerstedt-Börjesson et al., 2016b)*

> *I suppose that this is how I have to live.*
>
> *(No 1) (Hovind et al., 2013)*

> *If it was going to disappear, I think it would already be gone.*
>
> *(Bree) (Peretti-Watel et al., 2012)*

Living with persistent pain also raised fears for the future and the "symptoms constantly reminded them of their own or close relatives'/friends' vulnerability" (Hellerstedt-Börjesson et al., 2016b) (p. 469) and uncertainty of what lay ahead:

> *Sometimes when I wake up I think 'will the pain be like this everyday, always, always… that's hard to manage sometimes.*
>
> *(15) (Hellerstedt-Börjesson et al., 2016b)*

3.6 | Conceptualisation of persistent pain

It was evident in the studies that women struggled to conceptualise and articulate the physical sensation and impact of their pain, and often used metaphors to help to describe it:

> *I felt like I'd been run over by a steamroller.*
>
> *(14) (Hellerstedt-Börjesson et al., 2016b)*

> *I felt like I was in a dryer, and I was thrown back and forth, like I was torn and ripped into pieces.*
>
> *(3) (Hellerstedt-Börjesson et al., 2016b)*

> *It kind of radiates somehow, it's like there are flashes that come into my breast – they come very suddenly, like a wind.*
>
> *(W5) (Bjorkman et al., 2008)*

Over time, it appeared women were more likely to label the sensations they experienced as pain. This was observed most clearly in the longitudinal study by Bjorkman et al. (2008) study which explained that "sensory disturbances were evaluated (by participants) in different ways at different points in time. During later interviews, women retrospectively expressed that sensory disturbances… had been rather painful… in retrospect, the word pain could appear in their descriptions, when it had not … in earlier interview (s)" (p1023) and "it was striking how they initially steered clear of or directly avoided calling their sensations pain, even though the sensations could cause them some discomfort"(p1021). In keeping with this, Hovind et al. (2013) commented that words other than pain were used such as:

> *It is prickly, it hurts and is tender.*
>
> *(no.3) (Hovind et al., 2013)*

To summarise, women's experiences of pain and of cancer were interwoven and persistent pain following treatment was unexpected. When it did occur, they did not feel supported to manage it. Persistent pain had a physical and emotional impact on the women, and they utilised various ways of coping. Women had often used metaphors to help describe and conceptualise their pain.

4 | DISCUSSION

This qualitative evidence synthesis sought to identity and review literature surrounding experiences of persistent pain in adult cancer survivors. A comprehensive search resulted in only four papers. Thus, whilst it is established that almost 40% of cancer survivors

experience pain after cancer treatment (Van Den Beuken-Van Everdingen et al., 2016), very little is known about the experiences and needs of those living with persistent pain.

All participants were female and breast cancer survivors despite the inclusion criteria stipulating that all cancer survivors were included. No research was located that included men or those with non-breast cancer malignancies. It could be that breast cancer survivors have more pain than survivors of other cancers, and thus, research has focused on them. However, in the UK breast cancer receives the most funding for research (National Cancer Research Institute (NCRI), 2018) therefore it could be that pain is reported more in the breast cancer population because there is less research into other cancer sites, rather than survivors from other sites not experiencing persistent pain.

The persistent pain that women experienced had a physical impact on their daily lives. This reflects the literature into the experiences of non-malignant persistent pain. Toye, Seers, and Barker (2017) conducted a *mega*-ethnography study, a synthesis of qualitative evidence syntheses using the methods of meta-ethnography, to explore the experiences of living with persistent non-malignant pain. They cite the "all-pervading nature of pain which invades all aspects of my day and night" (p.5). This suggests it is the symptom of persistent pain and the ever-present bodily sensation of pain, rather than the aetiology, which causes the physical impact on daily life. However, the strongest theme in Toye et al's (2017) study, represented in all qualitative evidence syntheses included in their *mega*-ethnography study, was people's quest for a "holy grail" of a medical diagnosis for their pain (p.5). However, this did not feature in the current study, possibly because women in this study had a known cause for their pain. Paradoxically, the most evident theme in this qualitative evidence synthesis, which featured in all the identified papers, was an interwoven relationship between the experience of cancer and persistent pain. Thus, pain was not considered in isolation but was related to the cancer experience. The experience of pain and cancer were intrinsically linked together, and pain was viewed as an indicator of cancer status. The pain caused the women to question if their cancer was returning. This is reflected in the wider literature in which researchers have suggested that new symptoms can be interpreted by cancer survivors as a sign of cancer recurrence (Raphael, Frey, & Gott, 2019) and the presence of physical symptoms, like pain, can lead to increased risk of fear of recurrence (Simard et al., 2013). Van Den Beuken-Van Everdingen et al (2008) found pain to be a strong predictor of fear of recurrence and Cupit-Link, Syrjala, and Hashmi (2018) discuss this in the context of Damocles' syndrome, whereby the fortune of survivorship is tempered by persisting fears of recurrence and long-term health sequelae after treatment. Bovbjerg et al (2019) found cancer survivors with persistent breast pain had significantly higher levels of emotional distress, pain catastrophising and worry that breast pain indicates cancer compared with survivors without persistent breast pain.

Findings in the current study demonstrate how women compare themselves to others when coping with their persistent pain. This process, known as social comparison, refers to how individuals evaluate their own abilities, opinions, attitudes and feelings in relation to other groups (Guyer & Johnston, 2017). Our data described how women used downward comparisons and self-enhancement, whereby they compared themselves with others who they perceived to be in worse situations than themselves. Thus, for some women in this qualitative evidence synthesis, social comparison appeared to help as they were able to evaluate their own pain experience in the context of other peoples' problems. This mirrors findings of Wood, Taylor, and Lichtman (1985) who found the majority of breast cancer patients in their sample ($n = 78$) instinctively highlighted how their situation, although unfortunate, was preferable to others with more advanced disease. However, it could also be argued that, by comparing themselves to others, women were being overly self-dismissive and discounting their own experiences.

It was evident in the studies that patients felt they had not been given sufficient information regarding the risks of persistent pain. Women expressed they had felt prepared for the risk of acute pain but not persistent pain. Women did acknowledge however, that at diagnosis and treatment, persistent pain may have been mentioned but that it did not seem important at the time. This is similar to suggestions that other late effects, such as chemotherapy-induced peripheral neuropathy, are considered to be of minimal importance in the context of a cancer diagnosis (Tanay et al., 2017) but become more significant once experienced. However, in this synthesis, it appears women's information needs were met at the beginning of treatment, but less so at the end. This is reflected in a recent scoping review that highlights a paucity in the literature relating to information needs following completion of treatment (Fletcher, Flight, Chapman, Fennell, & Wilson, 2017). This may have also contributed to feelings of abandonment that some women expressed. Feeling abandoned by the healthcare system is an experience that has been reported by many cancer survivors at the end of treatment (Bennion & Molassiotis, 2013; Parry, Morningstar, Kendall, & Coleman, 2011). Equally, a lack of empathy by healthcare professionals towards women with persistent pain was shown in the synthesis. Feeney, Tormey, and Harmon (2018) recognise that a lack of empathy towards patients can lead to mistrust and anger which can ultimately damage therapeutic relationships.

These findings highlight that women need more information about the risks of persistent pain after cancer treatment and services to support them with self-management of pain. Healthcare professionals supporting cancer survivors with persistent pain need to be aware of the impact the experience of cancer may have on the intensity and emotional distress surrounding the experience of persistent pain.

4.1 | Limitations

Whilst the literature search and selection process for this qualitative evidence synthesis were thorough and robust, only four studies were identified in which all participants were female and breast cancer survivors. No studies were identified, which reported the experience of men studies with survivors of childhood cancer were excluded and only one longitudinal paper was identified in this search. Within this paper, there were suggestions that how survivors conceptualised pain over time changed and it may have been possible to explore this further if more longitudinal studies had been included. Only studies published within the search dates and in English were included. These factors may have influenced the findings of the synthesis. Future studies may want to address these limitations.

The synthesis adopted a descriptive methodology and, by their very nature, descriptive qualitative evidence syntheses allow for limited interpretation of meaning. However, the approach taken, thematic synthesis, was suitable for studies that explore perspectives and experiences.

4.2 | Conclusions and recommendations for further research

This synthesis has highlighted that persistent pain results in physical difficulties and emotional consequences for cancer survivors. The nature of persistent pain for cancer survivors is intrinsically interwoven with their experiences of cancer and cancer care. Women felt that persistent pain following treatment was unexpected and when it happened, it was not addressed by healthcare professionals. Women felt they were left to manage their persistent pain on their own and used various way to help them do this. This synthesis has highlighted the paucity of research into the experiences and needs of cancer survivors living with persistent pain, especially men and those with non-breast cancer malignancies. Further studies are needed in this area, in particular with respect to male perspectives and those with different cancer types, to explore how healthcare services can help and support cancer survivors with the self-management of their persistent pain.

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CONFLICT OF INTEREST

No conflicts of interest. To ensure methodological rigour and ethical standards of included studies, a quality assessment of studies was undertaken using an adapted version of the Critical Appraisal Skill Programme (CASP) Checklist for Qualitative Research (Critical Appraisal Skills Programme, 2017).

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