



## Healthcare professionals' knowledge, understanding and confidence to manage chronic pain after cancer treatment: A UK survey

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### ABSTRACT

**Introduction:** Healthcare professionals are vital in preparing people living with and beyond cancer about the risks of chronic pain after cancer treatment. To do so, healthcare professionals need to be knowledgeable and confident about chronic pain after cancer treatment, yet little is known about their understanding or confidence of this common long-term and late side effect of cancer treatment.

**Aim:** To identify healthcare professionals' knowledge and understanding of chronic pain after cancer treatment and consider how confident they are to inform, listen and signpost people living with and beyond cancer to appropriate information and support.

**Method:** A cross sectional online survey was distributed to healthcare professionals in the UK via cancer and primary care networks, cancer alliances and social media. The survey consisted of four domains: 1) knowledge and understanding, 2) information and support, 3) confidence and 4) barriers. Quantitative data were analysed with descriptive statistics and free text comments were analysed using qualitative content analysis.

**Results:** Healthcare professionals reported limited knowledge and understanding of chronic pain after cancer treatment. Healthcare professionals lacked confidence to talk to people about chronic pain after cancer treatment and viewed their lack of knowledge as a barrier. Additional barriers included 'Limited service provision', 'Conflict between services', 'Not my role' and 'Challenges in diagnosing chronic pain in cancer survivors'.

**Conclusion:** Chronic pain after cancer can be a significant issue for those living with and beyond cancer, yet healthcare professionals report limited knowledge of it or understanding of the impact. More education is needed to increase healthcare professionals' knowledge and confidence in chronic pain after cancer treatment.

### 1. Introduction

Chronic pain is a common side effect of cancer treatment and prevalence rates of chronic pain in cancer survivors are reported as approximately 40% (Jiang et al., 2019; Van Den Beuken-Van Everdingen et al., 2016). Chronic pain is frequently cited as a top concern and unmet need for cancer survivors (Schmidt et al., 2022; Sodergren et al., 2019) and living with chronic pain after cancer treatment has detrimental effects on cancer survivors' physical, psychological and social wellbeing and quality of life (Dugué et al., 2022; Filippini et al., 2022). However, many cancer survivors feel uninformed and ill prepared for the risk or reality of chronic pain after cancer treatment (Armoogum et al., 2023a;

Armoogum et al., 2020; Smith et al., 2023) and find identifying and accessing support challenging (Armoogum et al., 2023a; Fitzgerald Jones et al., 2023). Some cancer survivors report feeling dismissed when talking to healthcare professionals about their chronic pain and feel healthcare professionals do not have sufficient knowledge and understanding of chronic pain (Armoogum et al., 2023a; Smith et al., 2023). In response to this, it is important to determine if there are gaps in healthcare professionals' knowledge and understanding of chronic pain after cancer treatment. Understanding gaps in healthcare professional knowledge could be of value when developing future recommendations to improve the experiences of people living with chronic pain after cancer treatment.

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The structure and content of specialist cancer education for nurses and allied health professionals is guided by cancer educational frameworks, such as the European Oncology Nursing Society Cancer Nursing Education Framework (EONS, 2022) and the ACCEND Career Pathway, Core Cancer Capabilities and Education Framework (Health Education England, 2023) in the UK. Standards and guidelines for clinical care recognise that cancer survivors with chronic pain require a multifaceted approach, focused on rehabilitation, which addresses all aspects of the biopsychosocial model of pain and is delivered by a comprehensive multidisciplinary team which engages, educates and empowers the person with pain throughout the process. (Faculty of Pain Medicine, 2021). However, despite these guidelines, it has been reported across America and Europe that clinicians can find managing chronic pain after cancer challenging. Clinicians report a lack of clarity over which healthcare professionals are best positioned to manage this group of people (Check et al., 2023) and consider they do not have sufficient knowledge about the causes and management of chronic pain after cancer treatment (Slaghmuylder et al., 2022). However, it is not known if this is reflected among UK healthcare professionals.

This paper describes a quantitative study aiming to investigate healthcare professionals' knowledge, understanding, experience and confidence to support people living with chronic pain after cancer treatment in England, UK.

### 1.1. Research questions

Primary research questions.

- What understanding and experience do healthcare professionals have about chronic pain after cancer treatment?
- How confident do healthcare professionals feel to inform, listen and signpost people living with and beyond cancer (LWBC) to appropriate information and support?

The secondary research questions were.

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

## 2. Methods

### 2.1. Design and survey development

The study adopted a cross sectional survey design. No standardised, validated surveys exist to measure healthcare professionals' knowledge and understanding of chronic pain after cancer treatment and therefore a data collection approach needed to be developed. An online survey was developed using Qualtrics. In line with best practices for developing scales, phase one included 'item development' to 1) identify domains and generate initial appropriate questions and 2) test for content validity to assess if the items adequately measured the domains of interest (Boateng et al., 2018). Based on published literature and prior research, JA proposed initial domains and questions. These were reviewed, discussed and amended by four clinical experts and two public contributors, the latter being cancer survivors living with chronic pain. Moving to phase two, 'scale development', the survey was piloted with 48 participants (40 nurses, five Allied Health Professionals, two public contributors and a GP). The purpose of the pilot was to confirm relevance of content and check for acceptability including wording and survey length. Feedback was gathered from pilot participants via two focus

groups and individual discussions. In addition to demographic questions (professional group, workplace setting, proportion of main professional role involving people who are living with and beyond cancer, and length of time working with people who may be living with and beyond cancer), the final survey consisted of 19 questions across four domains (1. knowledge and understanding, 2. information and support, 3. confidence and 4. barriers). In the knowledge domain, participants were asked six questions, with either a multiple choice or dichotomous response, about prevalence rates of chronic pain after cancer treatment, timing of onset of that pain and its causes and risks.

In the understanding domain, twenty verbatim statements from cancer survivors living with chronic pain after cancer treatment were provided, and participants were invited to select if they thought the statements were from a) cancer survivors living with chronic pain after cancer treatment, b) people living with non-cancer chronic pain, or c) both. Using a similar approach to Kennedy and colleagues (2009), the quotes were extracted from qualitative interviews in a prior study with cancer survivors living with chronic pain after cancer treatment (Armoogum et al., 2023a). These questions were designed to determine if participants understood the breadth of impact that living with chronic pain after cancer treatment can have on cancer survivors. In the information and support domain, participants were asked three questions about when, how and by whom people LWBC should be informed and supported about chronic pain after cancer treatment. In addition, participants were asked how often they listened, talked and signposted about chronic pain after cancer treatment in their clinical practice. Responses were captured on a four-point Likert Scale ranging from never to always.

In the confidence and barriers domains, questions elicited participants' clinical experiences and they were asked to rate their confidence on a scale of 0–100 (zero = not confident, 100 = very confident) regarding talking, signposting and listening to cancer survivors living with chronic pain after cancer treatment, and to list any barriers experienced. Two questions included multiple choice responses with a free text option. These questions focused on whose role it is to give information about chronic pain after cancer treatment and what barriers there are to giving information and support. The final question offered participants an opportunity to comment on anything else they felt was relevant or important to this area of research.

### 2.2. Recruitment and participants

The online survey was advertised via cancer clinical networks, UK cancer alliances and included UK healthcare professionals undertaking a post registration university module in long term conditions. The survey was also promoted via social media from UK based cancer organisations, charities and researcher social media platforms. It was open for six weeks with active advertising and recruitment continuing throughout this time. Ethical approval was granted (REC REF No: HAS 21.02.109). A participant information sheet was provided when the survey link was opened and consent to participate was assumed by virtue of survey completion.

### 2.3. Data analysis

Item by item 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. Free text comments were analysed using inductive content analysis to provide a descriptive analysis (Elo and Kyngäs, 2008). Inductive qualitative content analysis involves three phases: preparing, organising and reporting data (Elo et al., 2014; Elo and Kyngäs, 2008; Graneheim and Lundman, 2004). During the preparation phase, units of analysis were selected, and first author 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. Final categories were then reported (Elo et al., 2014;

Elo and Kyngäs, 2008; Graneheim and Lundman, 2004). To increase trustworthiness in the organisation phase and to check the credibility of the analysis, it is recommended that the analysis is shared with people who are familiar with the research topic to ensure it is representative of the data as a whole and ‘matches reality’ (Elo et al., 2014, pp. 6). In this study, a summary of development of codes, sub categories and categories were shared with remaining authors and the public contributors to confirm relevance and representation. 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).

2.4. Inclusion criteria

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

If participants met these inclusion criteria, and consented to complete the survey, no additional exclusion criteria were applied.

2.5. Public involvement

Two public contributors, who are cancer survivors living with chronic pain after cancer treatment, were involved with the development of this study. Public contributors commented on research aims, research questions, inclusion criteria, survey questions and analysis.

3. Results

3.1. Study participants

A total of 135 healthcare professionals submitted responses to the online survey. Over half (51.9%, n = 70) were nurses and over three quarters (77.0%, n = 104) were involved with people LWBC for more than 50% of their main professional role. Most had worked with people LWBC for over 6 years (75.6%, n = 102) (Table 1). Of the 36 AHPs, 14 provided details of their specific profession (nine radiographers, two

Table 1  
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

occupational therapists, two physiotherapists and a clinical psychologist).

Fifty-two participants (38.5%) provided a total of 70 free text comments within the online survey. Most comments were from nurses (53.8%, n = 23), working in a hospital setting (78.8%, n = 41).

1) Understanding and experience of chronic pain after cancer treatment

3.2. What awareness do healthcare professionals have about the prevalence and risk, of cancer survivors living with chronic pain after cancer treatment?

Prevalence rates of chronic pain after cancer treatment are approximately 40% (Jiang et al., 2019; Van Den Beuken-Van Everdingen et al., 2016). Participants were asked, in their opinion, what percentage of cancer survivors experience chronic pain after their cancer treatment has ended. In total, 135 participants responded to the questions about prevalence rates and risks and fifth (20%, n = 27) identified a prevalence rate of 30–40%. Most underestimated prevalence rates (38.5%, n = 52), a quarter overestimated (26.7%, n = 36) and 14.8% (n = 20) did not know. Participants were presented with statements relating to risks associated with chronic pain after cancer treatment and asked to identify if the statements were true or false (Fig. 1).

Over 80% (n = 110) correctly identified that pre-existing anxiety can increase risk of chronic pain after cancer treatment. Over three quarters of participants (77%, n = 104) correctly identified that chronic pain that starts years after cancer treatment can be related to previous cancer treatment, 18% (n = 24) did not know and 5% (n = 7) said it could not. Over 40% (n = 56) incorrectly stated that older people are at greater risk compared to younger people.

3.3. What understanding do healthcare professionals have about the impact and experience of living with chronic pain after cancer treatment?

One hundred and six participants (79%) responded to the survey questions exploring their understanding of the experience of living with chronic pain after cancer treatment. The demographics of the 29 (21%) participants who did not respond to these questions were broadly similar to those who did respond. Participants were asked to select which statements they thought were from cancer survivors, which were from people with non-cancer chronic pain and which were from both cancer survivors and people living with non-cancer chronic pain. Participant responses to individual statements are reported in Table 2. All statements were from cancer survivors with chronic pain after cancer treatment. The statements that were most commonly attributed incorrectly were: 1) ‘You feel as if you’re a liar. It’s as if they (healthcare professionals) don’t believe you’ (n = 32, 30.2%) 2) ‘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 silly ... but erm, you do feel a little bit inferior’ (n = 27, 25.5%) 3) ‘Nobody is there to tell you at all about where to go for help’ (n = 20, 18.9%).

3.4. What setting, when and by whom, do healthcare professionals think people diagnosed with cancer should be informed about the potential for chronic pain after cancer treatment?

Participants were offered multiple choice responses to questions about what setting, when and by whom they thought people should be informed about the risk of chronic pain after cancer treatment. Participants could select as many options as they agreed with and there was also an additional free text response option. In total, 106 participants answered these questions and almost all participants (93.4%, n = 99) thought people LWBC should be informed about the potential for chronic pain before cancer treatment starts, and over half (54.7%, n = 58) thought this should be at a ‘Living with and beyond cancer’ event.

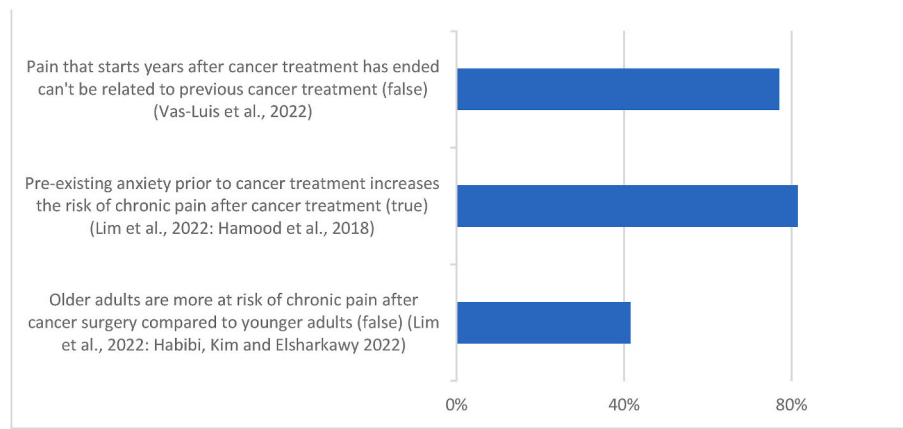


Fig. 1. % Of participants who correctly identified statements to be true or false.

Table 2

Participants' perceptions on the source of patient statements. All statements came from cancer survivors living with chronic pain after cancer treatment.

Patient statement	Perceived 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 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-cancer chronic pain, NR\* No response.

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. Almost half (46.2%, n = 49) thought it should be specialist pain services.

In total, 104 responded to the survey questions reflecting on their own roles and clinical practice. Of these, most were nurses (51.0%, n = 53), almost a quarter were allied health professionals (28.4%, n = 30) and 13.5% (n = 14) were doctors. Nearly half of respondents worked with people LWBC for more than 75% of their main professional role (49.0%, n = 51).

When asked if they thought it was their role to talk to people LWBC about the potential of chronic pain after cancer treatment, over half of participants (55.8%, n = 58) said it was their role and 40.4% (n = 42) thought it may be. This was reflective across professional groups, workplace settings and those whose role involves working with people LWBC for more than 75% of the time.

Participants were asked how often they talk, signpost or listen to people LWBC about chronic pain after cancer treatment. Approximately a quarter reported never or rarely talking (27.9%, n = 29), signposting (26.0%, n = 17) or listening (20.2%, n = 21) to people LWBC about

chronic pain after cancer treatment (Table 3).

### 3.5. What factors may prevent healthcare professionals from discussing chronic pain after cancer treatment with those LWBC?

Participants were asked what prevented them from talking to people LWBC about chronic pain after cancer treatment. Ninety six participants 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. A quarter (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. Thirty-nine (40.6%) felt there were no barriers, and they did talk, listen, and signpost.

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 to for further support and advice’ (AHP, community)*

And a recognition that there is *‘Much misunderstanding and misconceptions about chronic pain, it’s cause and treatment’ (nurse, hospital setting)*.

Content 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 LWBC 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)*

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 service

The frustration and conflict participants felt between different services was evident, with primary care staff particularly feeling secondary

**Table 3**  
Frequency of talking, signposting and listening to people LWBC about chronic pain after cancer treatment.

How often do you ....	Never or rarely		Sometimes		Always		Total	
	n	%	n	%	n	%	n	%
Talk to people LWBC about chronic pain after cancer treatment	29	27.9	63	60.6	12	11.5	104	100
Signpost people LWBC to support about chronic pain after cancer treatment	27	26.0	57	54.8	20	19.2	104	100
Listen to people talk about their experiences of living with chronic pain after cancer treatment	21	20.2	48	46.2	35	33.7	104	100

care was not doing enough:

*‘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)*

#### Not my role

Some participants felt that they did not see people LWBC who experienced chronic pain:

*‘It is not a common effect of treatment with most of my patients’ (nurse, hospital setting)*

*‘Patients usually discharged from oncology clinic (therefore I do not see them)’ (Hospital based doctor)*

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:

*‘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)*.

### 2) Healthcare professional confidence to inform, listen and signpost people living with and beyond cancer (LWBC) to appropriate information and support

Participants were asked how confident they felt about supporting cancer survivors living with chronic pain after cancer treatment using a visual analogue scale where 0 = not confident and 100 = very confident. Mean scores: 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).

## 4. Discussion

This is the first study to investigate UK healthcare professionals’ knowledge, understanding, experience and confidence in supporting people living with chronic pain after cancer treatment. It found a lack of knowledge about prevalence and risks of chronic pain after cancer treatment and mixed levels of understanding of the impact of chronic pain on cancer survivors’ lives.

The study achieved a varied sample of healthcare professionals with a good range of nurses, allied health professionals and doctors. The sample consisted of experienced cancer healthcare professionals with over three quarters having worked with people LWBC for more than 50% of their main professional role and having done so for more than six years. Yet despite being experienced cancer healthcare professionals, the study found most healthcare professionals underestimated the prevalence of chronic pain in cancer survivors. This finding needs, however, to be taken in the context of the challenges of reporting prevalence data in this population: it is difficult to establish the extent co-morbidities and other (non-cancer) pain conditions influence prevalence data,

definitions of chronicity can vary between studies, and there can be variations in pain assessment. The language surrounding pain can be emotive and can influence reporting. People may be hesitant to disclose they are experiencing pain and cancer patients can use metaphors, such as 'like an electric shock' to describe their discomfort (Björkman et al., 2008) 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 and consequently reported prevalence rates should be viewed with caution. Further, in this study, the survey question on prevalence needed a binary answer, however, in practice, prevalence rates are more nuanced and vary between tumour types and cancer treatments received (Dugué et al., 2022; Karri et al., 2021; Hamood et al., 2018) thus participants' experiences may vary depending on the groups of people living with and beyond cancer they work with. However, the underestimation of prevalence rates by healthcare professionals in this study mirrors reports of a lack of recognition among clinicians that chronic pain in cancer survivors is a frequent issue (Check et al., 2023; Slaghmuylder et al., 2022) and this conflicts with the high levels of self-reported pain in cancer survivors (Dugué et al., 2022; Haenen et al., 2022; Jiang et al., 2019).

Healthcare professionals in this study wanted more education and training about chronic pain after cancer. There is currently little or no evidence of pain, cancer, or cancer-related pain education within UK pre-registration healthcare programmes. A review of 71 undergraduate nursing programmes in the UK found the topic of pain was only present in six (8.5%) (Mackintosh-Franklin, 2017). Similarly, pain education can account for less than 1% of programme hours for some medical and health programmes (Briggs et al., 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). When education surrounding pain and cancer pain is scant within undergraduate programmes, it is unsurprising that healthcare professionals graduate with little knowledge of it. This is borne out within this study and others: a systematic review of 12 studies, with 3574 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). There have been calls for greater cancer education in pre-registration healthcare programmes in the UK (Health Education England, 2023; Armoogum, 2023) and cancer education resources are being developed to facilitate this (Armoogum et al., 2023b). However, to ensure that all pre-registration students have a foundational level of cancer knowledge, this needs to be included in Professional Regulation Bodies requirements for healthcare programmes.

Healthcare professionals do not seem to fully understand the impact of living with chronic pain after cancer treatment. In this study, a third of healthcare professionals did not think that a cancer survivor living with chronic pain would be made to feel like 'a liar' and that healthcare professionals would not 'believe' them. However, it has been reported many times that people living in chronic pain, including cancer survivors, can struggle to feel believed by healthcare professionals (Armoogum et al., 2023a; Fitzgerald Jones et al., 2023; Smith et al., 2023) yet validation by healthcare professionals is essential to help people manage their pain (Armoogum et al., 2023a; Toye et al., 2021).

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 LWBC to support and provide information about chronic pain after cancer treatment. This is mirrored in the literature whereby, in a study of 310 haematology nurses in Australia, Chan and colleagues (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).

Findings from this study highlight that healthcare professionals' confidence about chronic pain after cancer treatment is low. This is reflected in the wider literature surrounding nurses and allied health professionals (Faithfull et al., 2016) and doctors (Ellison et al., 2021, 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, pp7). In the current study, the perceived lack of knowledge about the risks of chronic pain after cancer treatment, or how to support and signpost, was cited as the largest barrier to talking to people LWBC about chronic pain after cancer treatment. This is reflected in a global survey of 1639 physicians and nurses, from 56 countries, which found the barriers to improve cancer pain management included a lack of appropriate training and education at all levels (Silbermann et al., 2022). This demonstrates the need for more education and continued practice development to increase confidence.

This study found organisational barriers to supporting people with chronic pain after cancer. Two thirds of participants thought support should be through cancer late effects clinics, however, the provision of late effects clinics across the UK is inconsistent (Galligan et al., 2023). Further, the composition of support and rehabilitation services needs consideration as interdisciplinary team working is regarded as essential for chronic pain rehabilitation in cancer (De Groef et al., 2019) yet Galligan et al. (2023) 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. This issue is not unique to the UK and represents a global problem (IJsbrandy et al., 2020; Jefford et al., 2022; Lynch et al., 2021; Slaghmuylder et al., 2022).

This study identified conflict between primary and secondary care services regarding who should support people who are experiencing chronic pain after cancer treatment. 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 or inappropriate 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., 2024). Supported self-management interventions are possible solutions to increase access to support, improve the experiences for people living with chronic pain after cancer treatment and reduce the burden on community services.

#### 4.1. Limitations

Study respondents were from England, Scotland Wales and Northern Ireland, however the majority were from England and therefore the findings may not be wholly representative across the UK.

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). Promotion via social media may have limited the participants to those who engage with social media platforms.

This study achieved an overall sample size of 135, which is in keeping with similar studies looking at training needs analysis (Dyer and Dewhurst, 2020), and generated some relevant and interesting findings. However, the numbers of respondents representing individual groups, such as profession, workplace setting and time working in cancer were small. This meant advanced statistical analysis to identify potential between-group differences was not appropriate. If possible, it would be helpful to include additional statistical analysis in future work to gain further insights to help plan educational programmes and who to target.

The survey was developed specifically for this study, and whilst

extensive piloting took place to test the face validity of the survey, resources were not available for psychometric testing for internal and external validity and reliability. There were some inconsistencies in the data collected, for example, in the questions that included patient statements (Table 2), some participants said the statement did not come from a cancer survivor, yet the statement contained the word ‘cancer’. These inconsistencies may have been because the survey was long and contained too many statements, so participants may not have read the statements accurately. Further testing for reliability and validity of the survey, such as a Cronbach’s alpha coefficient calculation and principal components analysis, may have resolved this issue.

## 5. Conclusion

Chronic pain after cancer can be a significant issue for those living with and beyond cancer, yet this research found that healthcare professionals have limited knowledge of it or understanding of the impact. Healthcare professionals lacked confidence to talk to people about this issue and viewed their lack of knowledge as a barrier. More education is needed to increase healthcare professionals’ knowledge and confidence in chronic pain after cancer treatment and it is important to include the topic of pain within educational recommendations. Evidence-based, interdisciplinary educational resources are needed that are co-designed with clinical, research and pedagogical experts and people with lived experience of chronic pain after cancer treatment and evaluated to identify impact on practice. Further, healthcare professionals should have access to high quality Continued Practice Development (CPD) courses to explore and develop own learning and practice and enhance confidence of late effects of cancer, including chronic pain.

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## CRedit authorship contribution statement

**J. Armoogum:** Writing – review & editing, Writing – original draft, Project administration, Methodology, Funding acquisition, Formal analysis, Data curation, Conceptualization. **D. Harcourt:** Writing – review & editing, Supervision, Methodology, Conceptualization. **C. Foster:** Writing – review & editing, Supervision, Methodology, Conceptualization. **A. Llewellyn:** Writing – review & editing, Supervision, Methodology, Conceptualization. **J. Hepburn:** Writing – review & editing, Methodology. **M. Prior:** Writing – review & editing, Methodology. **C. McCabe:** Writing – review & editing, Supervision, Methodology, Conceptualization.

## Declaration of competing interest

No competing interests are declared.

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