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## Exploration of pain assessment and management processes in oncology outpatient services with healthcare professionals: a qualitative study

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6 2 **Title:**  
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9 3 Exploration of pain assessment and management processes in oncology outpatient services  
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11 4 with healthcare professionals: a qualitative study  
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14  
15  
16 27 **Key words**

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19 28 Pain Assessment, Oncology, Outpatient, Cancer Pain, Pain Management, Qualitative,  
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22 29 Semi-structured interviews.

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25 30 **Abstract**

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28 31 **Objectives:** This study explored cancer pain management practices and clinical care  
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30 32 pathways used by healthcare professionals (HCPs) to understand the barriers and  
31  
32 33 facilitators for standardised pain management in oncology outpatient settings (OS).

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35 35 **Design:** Data were collected using semi-structured interviews that were audio-  
36  
37 36 recorded and transcribed. The data was analysed using Thematic Analysis.

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40 38 **Setting:** Three NHS trusts with oncology OS in Northern England.

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42  
43 40 **Participants:** Twenty HCPs with varied roles (e.g. oncologist, nurse) and experiences  
44  
45 41 (e.g. registrar, consultant) from different cancer site clinics (e.g. breast, lung). Data  
46  
47 42 were analysed using Thematic Analysis.

48  
49  
50 44 **Results:** HCPs discussed cancer pain management practices during consultation and  
51  
52 45 supporting continuity of care beyond consultation. Key findings included: (1) HCPs'  
53  
54 46 level of clinical experience influenced pain assessments; (2) remote consulting  
55  
56 47 impeded experienced HCPs to do detailed pain assessments; (3) diffusion of HCP  
57  
58 48 responsibility to manage cancer pain; (4) nurses facilitated pain management support

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4 49 with patients; and, (5) continuity of care for pain management was constrained by the  
5 50 integration of multi-disciplinary teams.  
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9 52 **Conclusions:** These data demonstrate HCP cancer pain management practices varied  
10 53 and were unstructured. Recommendations are made for a standardised cancer pain  
11 54 management intervention: (1) detailed evaluation of pain with a tailored self-  
12 55 management strategy; (2) implementation of a structured pain assessment that  
13 56 supports remote consultations, (3) pain assessment tool that can support both  
14 57 experienced and less experienced clinicians. These findings will inform the  
15 58 development of a cancer pain management tool to integrate within routine oncology  
16 59 OS.  
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### 24 25 26 61 **Strengths and Limitations of this study**

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28  
29 62 - To our knowledge, this is one of the first qualitative studies that has provided a  
30 63 descriptive account of cancer pain management processes and experiences in  
31 64 oncology outpatient settings from the perspective of healthcare professionals.  
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35 65

36 66 - A structured sampling framework was used to ensure a heterogeneous sample  
37 67 of roles, seniority and clinical speciality were recruited to the study. This  
38 68 enabled a detailed understanding to different types of pain prevalence patients  
39 69 experienced.  
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46 71 - Our recruitment strategy (i.e. self-referral sampling after receiving an  
47 72 information pack) may have led to bias, as individuals with strong negative or  
48 73 positive views may have been more likely to self-refer and agree to participate  
49 74 to the study.  
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## 76 Introduction

77 In the UK, approximately 167,000 people die of cancer each year (1) of whom half will  
78 experience moderate to severe pain, and a third are undertreated for their pain (2, 3).

79 Under-treatment of cancer pain reduces patients' quality of life and increases  
80 healthcare service use and costs (3). For patients, the burden of chronic cancer-pain  
81 is associated with anxiety, depression (4) and significantly reduces physical and  
82 emotional wellbeing (5).

83 The underlying pathophysiology of cancer pain is complex; nociceptive, inflammatory,  
84 and neuropathic mechanisms exist in concert with psychological and emotional  
85 components of chronic pain, making cancer pain challenging to manage clinically (6)  
86 (7). Historically, the management of cancer pain has been based on evaluating the  
87 subjective intensity of pain (via 0-10 Likert scales) (8) which do not evaluate aetiology,  
88 mechanisms or psychological components of pain (9). In addition, the challenging  
89 clinical environment within an oncology outpatient department means that cancer pain  
90 management is one of many competing priorities that healthcare professionals (HCPs)  
91 must manage during a time-limited consultation. In the UK and Europe, cancer  
92 patients are mainly treated at oncology outpatient services (OS), within secondary or  
93 tertiary healthcare systems. Care in OS differs from inpatient hospital settings;  
94 outpatient clinics are dedicated services patients visit for specific appointments, so  
95 their care can be monitored, reviewed and treated by HCPs (i.e. oncologists, nurses).  
96 Despite support given to cancer patients at outpatient clinics, uncontrolled cancer pain  
97 is the most common reason for contacting GP out-of-hours services (10).

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4 98 When cancer pain is routinely assessed on hospital wards or in outpatient clinics, this  
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6 99 improves pain control for patients (11). The UK Faculty of Pain Medicine has published  
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9 100 Core Standards for cancer pain management (12) which state that cancer patients  
10  
11 101 should receive a pain assessment at each encounter with an oncology clinician that  
12  
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14 102 covers intensity, mechanisms, aetiology and impact. Yet, oncology literature shows  
15  
16 103 there is currently no standardised procedure for managing pain in an outpatient setting  
17  
18  
19 104 (13). Despite decades of national and international guidelines on cancer pain  
20  
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22 105 management (6, 8) inadequate pain assessment continues to be a barrier to good pain  
23  
24 106 control for patients with cancer. Wider oncology literature has suggested HCPs  
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26  
27 107 required more educational opportunities for prescribing complex pain relief  
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29  
30 108 medications to cancer patients (14).  
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32  
33 109 External factors can also influence effective pain management processes. In the UK,  
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36 110 referral to oncology begins in primary care, this is community-based care provided by  
37  
38 111 general practitioners (GPs). Reduced referrals from primary care during the COVID-  
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41 112 19 pandemic has led to an increase in the numbers of patients diagnosed with  
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44 113 advanced cancer post-pandemic. This has been compounded by staff shortages in  
45  
46 114 oncology OS and increasing levels of sickness absence and burnout in the workforce  
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48  
49 115 (15). In the UK, minimal qualitative studies have explored current pain management  
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52 116 practices for people with cancer in oncology OS. The aim of this qualitative  
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54 117 investigation was to describe cancer pain management practices and clinical care  
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56 118 pathways for cancer pain management used by HCPs to understand the barriers and  
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59 119 facilitators for standardised pain management in oncology OS.  
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6 121 **Methods**7  
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9 12210  
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12 123 **Design**13  
14 124 Qualitative interview study exploring pain management practices for people with  
15 125 cancer in oncology OS from the perspective of HCPs.  
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23 127 **Research participants**24  
25 128 HCPs were recruited from oncology OS in three National Health Service (NHS) trusts  
26  
27 129 in Northern England. Eligible HCPs were required to have at least 6-months  
28  
29 130 experience of managing cancer pain in an oncology outpatient setting. Purposive  
30  
31 131 sampling was used to recruit participants that had varied job roles (oncologist, clinical  
32  
33 132 nurse specialist (CNS)), with a staff sample to reflect different staff grades (consultant,  
34  
35 133 registrar), working from a range of outpatient sub-specialities (lung, breast, bowel).  
36  
37  
38 134 This ensured a broad range of experiences of cancer pain assessment, support and  
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40 135 management for patients with differing disease trajectories were included in the  
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42 136 sample.  
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52 138 **Recruitment**53  
54 139 Eligible HCPs were identified and recruited via co-applicant HCPs embedded within  
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56 140 the clinical teams, who emailed study information packs (i.e. information sheet,  
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4 141 consent form) to their entire clinical teams. Contact information of the research team  
5  
6 142 (OR/MM) was included in study information packs and potentially eligible participants  
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8  
9 143 were asked to contact the research team (OR/MM). When potentially eligible  
10  
11 144 participants contacted the research team (OR/MM) the study was discussed in detail,  
12  
13  
14 145 any questions answered, and a date/time arranged for an interview. Interviews were  
15  
16 146 conducted through telephone and video calling software to suit the participants. Verbal  
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18  
19 147 consent was obtained by OR at the beginning of the interview. The consent audio was  
20  
21  
22 148 recorded and stored separately to the main interview recording.  
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## 25 26 150 **Patient and Public Involvement**

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29 151  
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31 152 A patient and public involvement (PPI) group was established at the beginning of the  
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33 153 project. Our PPI group included people with personal experiences of managing cancer  
34  
35  
36 154 pain and one former carer. One PPI member was also a grant co-applicant. The PPI  
37  
38  
39 155 group met during the study development phase to contribute to the design and delivery  
40  
41 156 methods. This included providing feedback on the development of study documents  
42  
43  
44 157 and processes. Once data had been collected, transcribed and summarised the PPI  
45  
46  
47 158 group met to provide feedback on the initial themes and sub-themes identified from  
48  
49 159 the data.  
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## 52 53 161 **Data collection**

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56 162 Interviews were conducted by OR between March 2022 and May 2022. Sample size  
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58  
59 163 was determined based on previous qualitative studies conducted in oncology OS (16,  
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4 164 17). Recruitment and analysis continued in tandem until data saturation was reached.  
5  
6 165 An interview topic guide was informed by existing literature and expert input from the  
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9 166 research and Patient and Public Involvement group (see additional file 1). Participants  
10  
11 167 were asked about their experiences of cancer pain management in oncology OS. This  
12  
13  
14 168 included exploring current practice, challenges and identifying what could be done to  
15  
16  
17 169 improve how pain is managed. OR and MM held weekly meetings to discuss the  
18  
19 170 interviews and influence of researcher bias on the dataset was documented.  
20

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## 23 172 **Data analysis**

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25  
26 173 Data analysis was done using Braun and Clark's Thematic Analysis (18). With consent  
27  
28 174 from participants, interviews were audio-recorded and transcribed verbatim by OR and  
29  
30  
31 175 LA. Analysis was an inductive-deductive process derived from participant interviews;  
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34 176 preliminary analyses was undertaken throughout the data collection process and the  
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37 177 topic guide was adjusted accordingly to explore existing and new patterns identified  
38  
39 178 within the data. After familiarising themselves with the transcripts, initial coding and  
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41  
42 179 development of themes was done by OR, MM and SP. Through a series of data  
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44  
45 180 analysis meetings, the initial themes and sub-themes were presented to the wider  
46  
47  
48 181 research team and our PPI group to explore their meaning and significance. During  
49  
50  
51 182 these meetings each theme and sub-theme was described in detail and supporting  
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54 183 evidence (codes and quotes) was presented and discussed. Following each data  
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57 184 analysis meeting the themes and sub-themes were refined in an iterative process until  
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4 185 the themes were agreed. Anonymised verbatim quotes from the data were used to  
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6 186 illustrate and give credibility to findings.  
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188 **Results**

189 Interviews were conducted with 20 HCPs from three NHS trusts, lasting between 30-  
 190 minutes to 45-minutes (Table 1. Participant characteristics).

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192 *Table 1. Participant characteristics (N=20)*

Participant characteristics	
<i>Healthcare professionals (n=20)</i>	
Male	8
Female	12
Role	
Consultant	12
Clinical Nurse Specialist (CNS)	3
Registrar	4
Pharmacist	1
<i>Cancer sub-speciality area</i>	
Urology	2
Prostate	2
Skin	2
Upper Gastrointestinal tract (GI)	2
Haematology	5

Lung	6
Breast	1

193

194

### 195 **Thematic analysis**

196 Thorough analysis of the transcripts produced two primary themes: (1) *Pain*  
 197 *management practices during oncology outpatient consultations* and (2) *delivering*  
 198 *continuity of care beyond oncology outpatient consultations* (table 2). Each theme  
 199 contained four sub-themes to further describe the specific elements of each.

200

201

202 *Table 2. Thematic analysis themes and sub-themes*

<b>Theme 1: Pain management practices during oncology outpatient consultations</b>
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<b>Sub-themes:</b>
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<b>1.1 Staff experience influenced pain assessment practice</b>
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Assessment of pain was influenced by HCPs seniority and experience, often using clinically based judgements to manage pain.
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<b>1.2 Variation in pain management practice</b>
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There was variation in when and how HCPs approached cancer pain management during consultations, related to time and rapport.
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<b>1.3 Remote consulting impacted pain assessment</b>
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HCPs felt remote consultations impeded even experienced HCPs ability to perform a detailed pain assessment.

#### 1.4 HCP's roles and responsibilities

There was variation in the extent to which HCPs felt responsible to manage cancer pain.

### Theme 2: Continuity of care following oncology outpatient consultations

#### Sub-themes:

#### 2.1 Utilisation of outpatient oncology clinical nurse specialists

HCPs felt oncology speciality nurses had more time to build rapport with patients and enable patients to openly disclose their experience of cancer pain.

#### 2.2 Integration of supportive services

Optimal pain management involved utilising supportive services (i.e. pain management teams) for advice and guidance to develop appropriate treatment pathways.

#### 2.3 Reassessment and monitoring of cancer pain between primary and secondary care

Outpatient clinicians' opportunity to re-assess and monitor cancer pain is constrained by the frequency of appointments.

#### 2.4 Providing patients with supported self-management plans to manage cancer pain at home

HCPs created self-management plans for patient to ensure their cancer pain was adequately reviewed.

203

### 204 Pain management practices during oncology outpatient consultations

205 Participants reported factors such as time, rapport, mode of assessment (i.e.  
206 telephone) and diffusion of responsibility influenced the extent pain management was  
207 explored with patients.

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4 208 Staff experience influenced pain assessment practice

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6 209 Assessment of pain in outpatient clinics was influenced by individual HCP's seniority  
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9 210 and experience. Experienced consultants expressed confidence assessing and  
10  
11 211 treating cancer pain because it was an area of care they *"do a lot of"*-[P012].  
12  
13  
14 212 Experienced HCPs stated *"I don't use any pain guidelines"*-[P011] or *"I just pull on my*  
15  
16 213 *own experience"*-[P013] to describe how pain was assessed in practice. Senior staff  
17  
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19 214 appeared more likely to use tacit knowledge in addition to drawing on clinically based  
20  
21  
22 215 observations (i.e. non-verbal behaviours) and conversations with the patient before  
23  
24  
25 216 determining an appropriate treatment plan:

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27  
28 217 *"They [the HCP] might be looking at how far can you lift the leg, the pressure*  
29  
30 218 *that they can put on the leg and how much feeling there is on the leg"* P004  
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32  
33 219 *[CNS, haematology clinic]*

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35  
36 220 HCPs used open-ended questions that *"triggered"*-[P011] patients to discuss pain or  
37  
38  
39 221 discomfort followed by an assessment for severity of pain. Using a verbal description  
40  
41  
42 222 of a numerical pain intensity scale encouraged patients to *"score it, 0-10"*-[P009]. Yet,  
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45 223 several HCPs felt pain scales did not provide a valid representation of a patient's pain  
46  
47 224 because the subjective nature of pain made it *"difficult to apply to numbers"*- [P006].  
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50 225 Asking questions associated with the type of cancer, initiated patients to think in-depth  
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52 226 about the context, triggers, occurrences and nature of the pain:  
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4 227 *“Thoracic cancers I’d always ask about chest pain specifically and risk of pain*  
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6 228 *or swelling outside of the chest and with gynaecological cancers I’d say “have*  
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8 229 *you had any abdominal pain or bloating” P008 [Registrar, lung clinic]*

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15 231 Variation in pain management practice

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17  
18 232 There was variation in when and how HCPs approached cancer pain management  
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20 233 during consultations, related to time, rapport and location. Participants stated pain  
21  
22 234 management conversations required *“empathy and sensitivity”* – [P001], yet  
23  
24 235 developing the necessary rapport took time. Participants suggested patients received  
25  
26 236 pain assessments at different points in a care journey, i.e. initial or follow-up  
27  
28 237 consultations. HCPs acknowledged the extent to which pain management was  
29  
30 238 approached and communicated to patients depended on specific diagnosis groups  
31  
32 239 with differing levels of associated pain. If HCPs were seeing a *“new cancer patient*  
33  
34 240 *with less pain”- [P008]* consultants prioritised other areas of the patient’s care (i.e.  
35  
36 241 arranging treatment, discussing patient concerns):

37  
38  
39 242 *“If I’m consenting them for radiotherapy a lot of them won’t really be having any*  
40  
41 243 *pain, so you know I’ll ask, and if they’re saying no, then that’s fine” P008*  
42  
43 244 *[Registrar, Lung clinic]*

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46  
47 245 HCPs suggested discussing other areas of cancer-related care meant opportunities  
48  
49 246 for an in-depth, detailed pain assessment were potentially lost. For patients with  
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51 247 specific cancer types, where pain was highly prevalent, HCPs tacit pain assessment



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4 248 identified pain management as a priority. HCPs made clinical judgements on the  
5  
6 249 extent and timing of pain management discussions. This included recognising when  
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9 250 external factors could potentially exacerbate pain, for example, “*frailty in older patients,*  
10  
11 251 *comorbidities or smoking*”- [P003].

12  
13  
14 252 “*Some patients are straightforward. Whereas a lot of lung patients have been*  
15  
16  
17 253 *heavy smokers. They've got COPD and ischemic heart disease...where you*  
18  
19  
20 254 *really have got to get into conversations about pain in a big way*” P003  
21  
22 255 *[Consultant, haematology clinic]*

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24  
25 256 HCPs suggested follow-up consultations were variable and depended on the care  
26  
27  
28 257 needs and severity of the patient’s cancer. For patients with advanced cancer that  
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31 258 were seen weekly it could be easier to monitor and explore pain. HCPs described  
32  
33 259 difficulties with building rapport to explore pain when appointments were infrequent  
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36 260 and patients did not see the same HCP at follow-up appointments.

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42 262 Remote consulting impacted pain assessment

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45 263 Management of oncology outpatient care has changed since COVID-19 pandemic and  
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48 264 more consultations are conducted remotely. HCPs described advantages to remote  
49  
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51 265 consulting as it enabled easier, more frequent contact with patients and supported  
52  
53 266 continuity of care:

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56 267 “*We would, you know put that as part of our diary for the following day to call*  
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58  
59 268 *back and see. Make sure that it was working*” P005 [CNS, upper GI clinic]

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4 269 However, some HCPs found remote consulting prevented non-verbal observations of  
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6 270 pain and experienced clinicians recognised that this impeded their ability to do a  
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9 271 detailed pain assessment:

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12 272 *“And saying to a patient, is it the lumbar region? Why would they know that”*

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15 273 *P004 [CNS, haematology clinic]*

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18 274 HCPs described a risk of patients misattributing cancer-related pain for side effects  
19  
20 275 and symptoms during remote consultations, making it challenging to provide  
21  
22  
23 276 appropriate treatment. HCPs had to *“take [it] on the patient’s own word”-[P002]* feeling  
24  
25  
26 277 there was *“no other option”- [P002]*. Some HCPs felt pain assessments began from  
27  
28 278 observations of non-verbal cues when *“they call the patient from the waiting room”-*  
29  
30  
31 279 *P011*, which was not possible in telephone consultations. This contributed to the  
32  
33  
34 280 overall judgement of the patient’s pain:

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37 281 *“You notice whether they’re in a wheelchair, how they’re able to get out of their*

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39 282 *chair, whether they can walk down the corridor as fast or slower than you can”*

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42 283 *P018 [Consultant, breast clinic].*

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49 285 Healthcare professional’s roles and responsibilities

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51 286 There was a diffusion of responsibility when HCPs discussed pain management. Due  
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54 287 to other community-based HCPs (i.e. GPs, palliative care teams) also being able to  
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57 288 monitor and manage a patient’s pain, some oncologists in secondary care felt it was  
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59 289 not their responsibility therefore did not engage in detailed pain conversations, e.g. it  
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4 290 was a “community palliative nurse’s job to manage pain”- [P003]. However, HCPs did  
5  
6 291 not want to put a patient at risk of uncontrolled pain whilst they were waiting to discuss  
7  
8  
9 292 this pain with the patient’s community teams and thus developed a self-management  
10  
11 293 plan for the patient to follow:

12  
13  
14 294 *“You’re thinking about, well, the patient could be suffering tonight. You know, I*  
15  
16  
17 295 *can maybe address some of these issues now” P003 [Consultant, haematology*  
18  
19  
20 296 *clinic].*

21  
22  
23 297 Some HCPs described how patients needed to take “ownership”-[P014] and  
24  
25 298 “responsibility”-[P003] to disclose if they were experiencing pain because patients  
26  
27  
28 299 often withheld the extent of their pain due to “fears of bothering the clinician”- [P008]  
29  
30  
31 300 making it more challenging to accurately assess and manage. In some instances,  
32  
33  
34 301 HCPs felt patients needed to provide honest opinions to support a thorough  
35  
36 302 assessment and avoid uncontrolled pain:

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38  
39 303 *“You know autonomy to the patient and responsibility to the patient to tell you if*  
40  
41  
42 304 *there’s a problem you know” P014 [Registrar, upper GI clinic]*

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### 307 **Continuity of care following oncology outpatient consultations**

308 Participants indicated continuity of care for pain management was facilitated by CNS,  
309 relationships between oncology HCPs and supportive services (i.e. palliative care

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4 310 teams, pain management services), re-assessment and monitoring of cancer pain  
5  
6 311 between primary and secondary care and self-management plans to manage cancer  
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8  
9 312 pain at home.

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11  
12 313 Utilisation of outpatient oncology CNS

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14 314 Most registrars and consultants entrusted CNS with following up patients and  
15  
16  
17 315 providing pain management support beyond their initial consultation with an  
18  
19  
20 316 oncologist. This was a component of the CNS role to undertake follow-up remote  
21  
22  
23 317 consultations (i.e. telephone or video call) including the re-assessment of pain and  
24  
25 318 other symptoms:

26  
27  
28 319 *"I have the support of CNSs, it will be within days [referring to follow-up calls],*  
29  
30 320 *you know hopefully within a week then I have somebody else checking in on*  
31  
32  
33 321 *them as to whether medication levels need increasing" P007 [Consultant,*  
34  
35 322 *prostate clinic].*

36  
37  
38  
39 323 Consultants reflected on a CNS ability to build rapport with patients and provide a  
40  
41  
42 324 personalised continuity of care making patients more willing to openly disclose their  
43  
44  
45 325 pain. One example showed CNS identifying problematic pain with a patient and  
46  
47  
48 326 escalating this to the consultant to be explored further at follow-up consultations so  
49  
50 327 changes can be made to medication:

51  
52  
53 328 *"If there's a note or a, verbal reminder [referring to a nurse providing notes to a*  
54  
55 329 *consultant about a patient's pain]. Actually, they have had some problems with*

1  
2  
3  
4 330 *pain or this particular issue then that definitely works well” P011 [Consultant,*  
5  
6 331 *haematology clinic].*  
7  
8

9 332 If there were little or no CNS staff available to support the management of pain  
10  
11 333 following consultations with an oncologist, participants suggested it placed strain on  
12  
13 334 other HCPs to fulfil this role. Consultants and registrars expressed concerns for having  
14  
15 335 *“triple booked clinics”- [P003] and calling patients “three hours after their appointment*  
16  
17 336 *time”-[P003] when there were no CNS staff to support clinics.*  
18  
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26 338 Integration of supportive services

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28  
29 339 Relationships between supportive services (i.e. palliative care, community nursing  
30  
31 340 teams and pain team) and oncology HCPs were essential to cancer pain management.  
32  
33 341 While HCPs expressed confidence in their ability to identify and treat cancer pain,  
34  
35 342 there were circumstances where HCPs described *“reaching their limits”- [P012] on*  
36  
37 343 *providing recommendations on complex opioid medication and required specialist*  
38  
39 344 *support:*  
40  
41  
42  
43  
44

45 345 *“we’re used to drugs like Gabapentin, Amitriptyline but when patients are still*  
46  
47 346 *having pain, that’s when you need help and we’re lucky, we can ring the palliative*  
48  
49 347 *care team and there is somebody that can review the patient...usually you can get*  
50  
51 348 *access to that specialist advice if you need”.P012 [Consultant, lung clinic]*  
52  
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55

56 349 In some cases, the level of responsibility and expertise the clinician felt they had over  
57  
58 350 managing a patient’s pain (i.e. pain was important part of consultation discussions)  
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4 351 influenced whether a patient would be referred to another team or managed by  
5  
6 352 themselves. Data suggested optimal pain management often involved HCPs  
7  
8  
9 353 identifying and monitoring pain whilst utilising supportive services for advice and  
10  
11 354 guidance to develop appropriate treatment pathways.  
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14 355

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18 356 Reassessment and monitoring of cancer pain between primary and secondary  
19  
20 357 care

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22  
23 358 Inpatient ward settings enabled HCPs to regularly re-assess cancer pain and make  
24  
25 359 amendments to medication more frequently. In OS a clinicians' opportunity to re-  
26  
27 360 assess and monitor cancer pain was constrained by the frequency of appointments on  
28  
29 361 weekly, monthly or greater basis. Some oncology OS support patients from "*large*  
30  
31 362 *geographical areas*"-[P005] therefore patients might not return for consistent follow-up  
32  
33 363 appointments. Participants reported this made it difficult for HCPs to provide continuity  
34  
35 364 of care and put more dependency on managing cancer pain between primary and  
36  
37 365 secondary care:  
38  
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41  
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43

44 366 *"What we don't have a mechanism like we do on the ward... We simply don't*  
45  
46 367 *have that contact, so we are next seeing the patients usually in three or six*  
47  
48 368 *weeks' time. So the pattern of medical interaction it simply doesn't map on to*  
49  
50 369 *pain relief"* P018 [Consultant, breast clinic]  
51  
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55  
56 370 HCPs emphasised pain management decisions needed to be made in line with the  
57  
58 371 patient's needs and their ability to conveniently access primary care. As a result of  
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3  
4 372 this, patients and HCPs often had to *“rely on the GPs to issue drugs and escalate pain*  
5  
6 373 *control”- [P014].*  
7  
8

9 374 *“We would also encourage patients to seek support from the GP and there will*  
10  
11  
12 375 *come a time when it's beyond our scope” P005 [CNS, upper GI clinic]*  
13  
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15 376

17  
18 377 Providing patients with supported self-management plans to manage cancer  
19  
20  
21 378 pain at home  
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23  
24 379 Due to the challenges with assessment and re-assessment in OS, some HCPs  
25  
26 380 suggested providing a *“safety net”-[P016]*for the patient was a crucial aspect to ensure  
27  
28  
29 381 cancer pain was adequately reviewed. This involved developing a strategy so a patient  
30  
31 382 knew what to do if the pain relief was not effective or if they were still experiencing  
32  
33  
34 383 severe pain:  
35

36  
37 384 *“I want you to see how those go and then perhaps give them a time period, so this*  
38  
39  
40 385 *is gonna take a few days for this to start to work better. If things are not any better,*  
41  
42  
43 386 *then to call us back” P016 [Consultant, haematology clinic]*  
44

45 387 Some HCPs provided patients with documentation that included information on how,  
46  
47  
48 388 when and what medication to take, as well as contact information for the OS and out-  
49  
50  
51 389 of-hours services. This was one-way HCPs ensured patients were supported to self-  
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53 390 manage cancer pain at home:  
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391 *“If there is anything of concern there is a number that you can call 24 hours a*  
392 *day, 7 days a week, 365 days a year and then we can see them on the acute*  
393 *unit and take it from there” P006 [Registrar, urology clinic]*

For peer review only



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4 394 **Discussion**

5  
6 395 We found an unstructured and variable approach to pain management affected  
7  
8 396 multiple components of a patient's outpatient cancer care. Firstly, HCPs used clinical  
9  
10 397 judgement in place of a structured assessment to manage a patient's pain. This  
11  
12 398 explains why HCPs might not use pre-existing guidelines and tools that have been  
13  
14 399 published (6, 8). Research has highlighted disadvantages to using pain assessment  
15  
16 400 tools, such as oversimplification of the multi-dimensional pain experience and not an  
17  
18 401 appropriate reflection of a patient's pain (19). Pain management tools can be efficient  
19  
20 402 especially when HCPs have limited time or when pain assessments are combined with  
21  
22 403 an individualised assessment to fully understand how pain is affecting the patient  
23  
24 404 physically, psychologically, socially and culturally.

25  
26  
27 405 Our data show that pain management in oncology outpatient services was influenced  
28  
29 406 by variation in HCPs' expectation of responsibility for pain management; i.e. it was  
30  
31 407 often considered to be someone else or another services' responsibility. This diffusion  
32  
33 408 of responsibility is well reported in healthcare settings and is known to lead to  
34  
35 409 underperformance of clinical activities and fragmented care in circumstances of  
36  
37 410 shared accountability (20) Fallon et al. (2018) showed that when structured pain  
38  
39 411 assessment processes are implemented within routine clinical care, this leads to a  
40  
41 412 more consistent approach to pain management, a reduction in the diffusion of  
42  
43 413 responsibility and improved pain outcomes for cancer patients (11).  
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4 414 Our data showed variation across the roles and responsibilities of HCPs supporting  
5  
6 415 the continuity of pain management. Oncology outpatient literature suggests some  
7  
8  
9 416 HCPs perceived their primary duty was to provide patients with their disease status  
10  
11 417 and have conversations around treatment (21). However, our data shows that HCPs  
12  
13  
14 418 who expressed clinical responsibility around pain management were inclined to  
15  
16 419 develop self-management plans to support patients to manage cancer pain at home.

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18  
19  
20 420 This study aimed to describe current pain management and thus the interview topic  
21  
22 421 guide was not developed to explored nuances of self-management practices.  
23  
24  
25 422 However, we know from previous studies there is variation in self-management  
26  
27 423 approaches (22). In OS, development of self-management support for patients is  
28  
29 424 crucial to a continuity of care. This includes providing elements of educational  
30  
31 425 interventions to facilitate problem solving and adequate decision-making skills and  
32  
33 426 tailoring recommendations to the individual's situation and defining goals with action  
34  
35 427 plans (22). By developing supportive plans, it ensures patients understand what to do  
36  
37 428 if pain escalates or becomes unmanageable. Subsequently, it could encourage  
38  
39 429 patients to initiate re-assessment of their pain at primary and secondary care services.

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46 430 We found system-level challenges impacted the extent to which pain was explored  
47  
48 431 with patients and monitored by outpatient HCPs. Exacerbated by the impact of the  
49  
50 432 COVID-19 pandemic, clinics are often over-booked, short staffed, and have long  
51  
52 433 waiting lists (15). In addition, our data show that the complexity surrounding the  
53  
54 434 interface between primary and secondary care and challenges with integration of  
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4 435 multi-disciplinary teams meant continuity of care, in particular re-assessment and  
5  
6 436 monitoring of pain, was difficult as patients were referred back to primary or community  
7  
8  
9 437 care teams.

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11  
12 438 Oncologists found it difficult to build rapport with patients that might not return to  
13  
14 439 outpatient appointments and felt they had to prioritise topics of care with the limited  
15  
16  
17 440 time they had. Consultations take a patient-centred approach that prioritises care  
18  
19  
20 441 practices that are responsive to a patient's preferences and values and thus not  
21  
22 442 focusing on pain management may be appropriate for some patients. However, this  
23  
24  
25 443 study and previous research has highlighted patients can often be reluctant to express  
26  
27  
28 444 their concerns and preferences without prompting (13). This suggests the  
29  
30 445 development of rapport with patients is essential to gain full understanding of a  
31  
32  
33 446 patient's care needs. We found CNS had more opportunities to build rapport and have  
34  
35  
36 447 discussions about pain with patients. However, in line with previous studies (14)  
37  
38 448 opportunities for pain management discussions are often missed if there are nurses  
39  
40  
41 449 with less experience and confidence to conduct pain assessments. Recommendations  
42  
43  
44 450 from this study highlight the benefit of providing training for HCPs to support pain  
45  
46 451 management conversations and embedding this within routine clinical practice.

47  
48  
49 452 Oncology literature has highlighted the benefits for the use of remote consultations in  
50  
51  
52 453 cancer pain management, where it is used appropriately. For example, reduction in  
53  
54  
55 454 pain severity scores, cost-effective, improved accessibility for patients to receive HCP  
56  
57 455 advice and treatment of symptoms and aided monitoring and re-assessment of  
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4 456 symptoms (23, 24). We found adaptations to pain assessments for remote care  
5  
6 457 impeded experienced HCPs to do a detailed thorough pain assessment, especially if  
7  
8  
9 458 not Audio Visual (AV) facilitated. HCPs become experts in their field through  
10  
11 459 knowledge, skill, training and experiential learning (25). Since COVID-19 the increased  
12  
13  
14 460 use of remote consultations has meant HCPs have to spend more time doing pain  
15  
16 461 assessments remotely. However, due to a lack of experiential learning for conducting  
17  
18  
19 462 pain assessments through remote consultations, this potentially made even  
20  
21  
22 463 experienced HCPs feel like a novice. This coincides with the novice to expert theory  
23  
24  
25 464 (25). Similarly, for those with less experience a change in mode-of-consulting could  
26  
27 465 further impede thorough pain assessments for patients. Without additional support and  
28  
29  
30 466 structured guidance on how to conduct remote consultations there is a risk that  
31  
32  
33 467 patients' pain will not be appropriately managed and key components of a detailed  
34  
35 468 pain assessment potentially missed. Previous research has shown even when pain  
36  
37  
38 469 assessments are standardised and detailed, only modest improvements in pain for  
39  
40  
41 470 patients with cancer are observed, largely because of low delivery fidelity and poor  
42  
43 471 implementation (6). However, Fallon et al. (2018) demonstrated that when  
44  
45  
46 472 standardised pain assessment processes are integrated within routine clinical practice  
47  
48 473 at the level of the service (rather than at an individual clinician level) this leads to  
49  
50  
51 474 greater improvements in pain outcomes for patients and more appropriate analgesic  
52  
53 475 prescribing. This suggests an in-depth implementation plan at service-level would be  
54  
55  
56 476 crucial to the success of a structured pain management intervention.

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4 478 Strengths and limitations  
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6 479 A structured sampling framework was developed by the research team which may  
7  
8 480 have resulted in potential bias. However, this approach provided a heterogeneous  
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10  
11 481 sample of staff roles, seniority and clinical speciality that gave a greater understanding  
12  
13  
14 482 to the management of different types of pain prevalence patients experienced. All  
15  
16 483 participants were from Northern England; therefore, the study's findings may not be  
17  
18  
19 484 generalisable to other regional oncology outpatient settings or international healthcare  
20  
21  
22 485 systems. One limitation is related to our recruitment strategy (i.e. self-referral sampling  
23  
24 486 after HCPs received an information pack); due to the nature of the research aims (i.e.  
25  
26  
27 487 pain management in oncology) participants with strong negative or positive views may  
28  
29  
30 488 have been more likely to agree to participate. However, the themes identified from the  
31  
32 489 data indicated broad perspectives of pain management processes and experience, so  
33  
34  
35 490 it is unlikely that we have sampled an exclusively polarised group of participants.  
36  
37

38 491

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40  
41 492 Implications of clinical research and practice  
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43  
44 493 Faculty of Pain Medicine Core standards for cancer pain management (12) state all  
45  
46 494 patients should receive a pain assessment at each encounter with an oncology  
47  
48  
49 495 clinician that includes exploration of intensity, mechanisms, aetiology and impact.  
50  
51  
52 496 Evidence from clinical trials show that standardising pain assessment in oncology  
53  
54 497 outpatient clinics leads to improvements in patients' pain and quality of life (11). This  
55  
56  
57 498 research recommends the implementation of a structured routine pain assessment  
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4 499 that minimises the risk of diffusion of responsibility and encourages HCPs to  
5  
6 500 incorporate the most crucial components of a pain assessment into patient  
7  
8  
9 501 consultations (i.e. exploration of intensity, mechanisms, aetiology and impact).  
10  
11 502 Secondly, at a service level, uncontrolled cancer pain remains the most common  
12  
13  
14 503 reason for contacting GP out-of-hours service (10). Implementing a structured pain  
15  
16 504 assessment within oncology OS would encourage patients to report pain earlier,  
17  
18  
19 505 enabling HCPs to manage cancer pain earlier, reducing the burden on GP out-of-hours  
20  
21  
22 506 service, and minimising the risk of patients living with undertreated cancer pain.  
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24

## 25 507 Conclusion

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27  
28 508 This study demonstrates a variable and unstructured approach to pain management  
29  
30 509 affected multiple components of a patient's outpatient cancer care. We recommend  
31  
32  
33 510 the need for a cancer pain management intervention that standardises pain  
34  
35 511 assessments in oncology OS, which is implemented at the level of the service. This  
36  
37  
38 512 will ensure each patient receives the same detailed evaluation of cancer pain and is  
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40  
41 513 provided with a self-management strategy that facilitates pain management beyond  
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43 514 consultations.  
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46 515

## 49 516 List of abbreviations

50  
51  
52  
53 517 HCP – Healthcare Professionals

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56 518 OS – Outpatient Services  
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4 519 CNS – Clinical Nurse Specialist

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7 520 Upper GI - Upper Gastrointestinal tract

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10 521 NHS – National Health Service

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12  
13 522 AV – Audio Visual

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19 524 **Declarations**

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21  
22 525 **Ethical approval and consent to participate**

23  
24  
25 526 Ethical approval was obtained by University of Leeds, Faculty of Medicine Research

26  
27 527 Ethics Committee and Health Research Authority (21/HRA/5245). Approvals were

28  
29 528 also obtained at each NHS trust.

30  
31  
32 529 **Consent for publication**

33  
34  
35 530 Not applicable

36  
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38 531 **Availability of data and materials**

39  
40  
41 532 Not applicable

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43  
44 533 **Competing interest's statement**

45  
46  
47 534 None declared.

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49  
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51  
52  
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1  
2  
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4  
5  
6  
7 **538** MM is the chief investigator for this study; he conceived the project, led the design and

8  
9 **539** writing of the study protocol, facilitated data analysis and drafting of this manuscript.

10  
11  
12 **540** Methodology (OR, MM). Project administration (OR, MM).

13  
14  
15 **541** OR wrote the study protocol, including drafting the topic guide, completed data

16  
17 **542** curation, data collection and transcribed interviews. OR led the data analysis and

18  
19 **543** interpretation of the data. Review of interpretation of the data and analysis was done

20  
21 **544** by MM, SP, KF, SR, NC. OR wrote the first draft of the manuscript. Writing-review

22  
23 **545** and editing (OR, MM, SR). All authors (OR, SP, KF, NC, MF, SR, CM, EB, DS, AH,

24  
25 **546** SH, MM) contributed to manuscript revision, read and approved the submitted and

26  
27 **547** revised version.

28  
29  
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34 **548**

35  
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38  
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48  
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53 **554**



555 **References**

- 556 1. Cancer Research UK. Cancer Mortality Statistics. (2017-2019).
- 557 2. van den Beuken-van Everdingen MH, de Rijke JM, Kessels AG, Schouten HC, van Kleef M, Patijn  
558 J. Prevalence of pain in patients with cancer: a systematic review of the past 40 years. *Ann Oncol.*  
559 2007;18(9):1437-49.
- 560 3. Shen WC, Chen JS, Shao YY, Lee KD, Chiou TJ, Sung YC, et al. Impact of Undertreatment of  
561 Cancer Pain With Analgesic Drugs on Patient Outcomes: A Nationwide Survey of Outpatient Cancer  
562 Patient Care in Taiwan. *J Pain Symptom Manage.* 2017;54(1):55-65 e1.
- 563 4. Kroenke K, Zhong X, Theobald D, Wu J, Tu W, Carpenter JS. Somatic symptoms in patients with  
564 cancer experiencing pain or depression: prevalence, disability, and health care use. *Arch Intern Med.*  
565 2010;170(18):1686-94.
- 566 5. Wang HL, Kroenke K, Wu J, Tu W, Theobald D, Rawl SM. Cancer-related pain and disability: a  
567 longitudinal study. *J Pain Symptom Manage.* 2011;42(6):813-21.
- 568 6. Fallon M, Giusti R, Aielli F, Hoskin P, Rolke R, Sharma M, et al. Management of cancer pain in  
569 adult patients: ESMO Clinical Practice Guidelines. *Ann Oncol.* 2018.
- 570 7. Bennett MI. Mechanism-based cancer-pain therapy. *Pain.* 2017;158 Suppl 1:S74-s8.
- 571 8. World Health Organisation. WHO guidelines for the pharmacological and radiotherapeutic  
572 management of cancer pain in adults and adolescents. 2019.
- 573 9. Mulvey MR, Rolke R, Klepstad P, Caraceni A, Fallon M, Colvin L, et al. Confirming neuropathic  
574 pain in cancer patients: applying the NeuPSIG grading system in clinical practice and clinical research.  
575 *Pain.* 2014;155(5):859-63.
- 576 10. Adam R, Wassell P, Murchie P. Why do patients with cancer access out-of-hours primary care?  
577 A retrospective study. *Br J Gen Pract.* 2014;64(619):e99-104.
- 578 11. Fallon M, Walker J, Colvin L, Rodriguez A, Murray G, Sharpe M. Pain Management in Cancer  
579 Center Inpatients: A Cluster Randomized Trial to Evaluate a Systematic Integrated Approach-The  
580 Edinburgh Pain Assessment and Management Tool. *J Clin Oncol.* 2018;36(13):1284-90.
- 581 12. Bennett M, Sharma M. Cancer-related Pain. In: Weiss A, Taylor J, Searle R, editors. Core  
582 standards for pain management services in the UK. 2 ed. London: Faculty of pain medicine of the royal  
583 college of anaesthetists; 2021. p. 88-90.
- 584 13. Chapman EJ, Edwards Z, Boland JW, Maddocks M, Fettes L, Malia C, et al. Practice review:  
585 Evidence-based and effective management of pain in patients with advanced cancer. *Palliative*  
586 *medicine.* 2020;34(4):444-53.
- 587 14. Kasasbeh MAM, McCabe C, Payne S. Cancer-related pain management: A review of knowledge  
588 and attitudes of healthcare professionals. 2017;26(6):e12625.
- 589 15. Levell NJ. NHS outpatient secondary care: a time of challenges and opportunities. *Future*  
590 *healthcare journal.* 2022;9(2):106-12.
- 591 16. Graupner C, Breukink SO, Mul S, Claessens D, Slok AHM, Kimman ML. Patient-reported  
592 outcome measures in oncology: a qualitative study of the healthcare professional's perspective.  
593 *Supportive Care in Cancer.* 2021;29(9):5253-61.
- 594 17. Steven B, Lange L, Schulz H, Bleich C. Views of psycho-oncologists, physicians, and nurses on  
595 cancer care—A qualitative study. *PLOS ONE.* 2019;14(1):e0210325.
- 596 18. Braun V, Clarke, V. Thematic analysis: A practical guide. SAGE publications. 2021.
- 597 19. Ruben MA, van Osch M, Blanch-Hartigan D. Healthcare providers' accuracy in assessing  
598 patients' pain: A systematic review. *Patient Education and Counseling.* 2015;98(10):1197-206.
- 599 20. Marcotte LM, Kimmel-Morrison J, Liao JM. How to Keep Diffusion of Responsibility From  
600 Undermining Value-Based Care. *AMA journal of ethics.* 2020;22(9):E802-7.
- 601 21. Thestrup Hansen S, Kjerholt M, Friis Christensen S, Brodersen J, Hølge-Hazelton B. User  
602 experiences on implementation of patient reported outcome measures (PROMs) in a Haematological  
603 outpatient clinic. *Journal of Patient-Reported Outcomes.* 2020;4(1):87.

- 1  
2  
3 604 22. Bennett MI, Mulvey MR, Campling N, Latter S, Richardson A, Bekker HG, et al. Self-  
4 605 management toolkit and delivery strategy for end-of-life pain: the mixed-methods feasibility study.  
5 606 Health Technology Assessment Programme. 2017;21 (76).  
6 607 23. Buonanno P, Marra A, Iacovazzo C, Franco M, De Simone S. Telemedicine in Cancer Pain  
7 608 Management: A Systematic Review and Meta-Analysis of Randomized Controlled Trials. Pain  
8 609 Medicine. 2023;24(3):226-33.  
9 610 24. Alese OB, Zhang C, Zakka KM, Kim S, Wu C, Shaib W, et al. A cost analysis of managing cancer-  
10 611 related pain among hospitalized US cancer patients. 2020;38(15\_suppl):7079-.  
11 612 25. Guven Ozdemir N. The Development of Nurses' Individualized Care Perceptions and Practices:  
12 613 Benner's Novice to Expert Model Perspective. 2019;12:2-1279.

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For peer review only




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## Interview topic guide

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### ❖ **Professional Background**

*(role, experience, knowledge/training in pain assessment and management, contact with advanced cancer patients)*

### ❖ **Experiences of conducting pain assessments to support to people with advanced cancer**

- Assessment
  - Basic: pain intensity and interference
  - Detailed: underlying aetiology and pain mechanism, linked analgesic prescribing
- Decision-making
- Access to cancer pain management guidelines
- Providing cancer treatments and care
- Communication between oncology and patient
- Follow-up contact between patient and hcp

### ❖ **Identifying triggers for pain assessment**

- *what factors would lead doctor or nurse to undertake a pain assessment*

### ❖ **Specific examples of cancer pain assessments that have been conducted**

- *Talk us through how pain is assessed and managed in practice*

### ❖ **Examples of existing tools used in everyday pain assessment practice**

- *What works with this pain assessment tool or needs improving?*
- *Any challenges with using the tools in everyday practice?*

### ❖ **Anything that is difficult when people have advanced cancer to assess and manage their pain?**

### ❖ **Anything that works well?**

*N.B. Additional questions may be added as the interviews progress and relevant topics begin to be identified from previous interviews conducted.*



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❖ ***Suggestions for how pain assessment could be improved for people with advanced cancer?***

14 *To ask participants that have insight and knowledge into existing clinical pathways:*

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❖ ***Implementing routine pain assessment within existing clinical pathways***

- Describe how a new treatment or procedure is currently integrated into an outpatient service?
- Who is responsible for making sure everyone is trained and using the new treatment or procedure?
- How can routine pain assessments be integrated into existing clinical pathways in your oncology outpatient service?
- Explain what these improvements might make?
- Any potential system level challenges?

❖ ***Anything you would like to add?***

*N.B. Additional questions may be added as the interviews progress and relevant topics begin to be identified from previous interviews conducted.*



**SRQR 21-point checklist**

No.	Topic	Completed	Page no.
1.	Title	<input checked="" type="checkbox"/>	1
2.	Abstract	<input checked="" type="checkbox"/>	2
3	Problem formulation	<input checked="" type="checkbox"/>	3
4.	Purpose or research question	<input checked="" type="checkbox"/>	4
5.	Qualitative approach	<input checked="" type="checkbox"/>	4
6.	Research characteristics and reflexivity	<input checked="" type="checkbox"/>	5
7.	Context	<input checked="" type="checkbox"/>	4
8.	Sampling strategy	<input checked="" type="checkbox"/>	4
9.	Ethical Issues	<input checked="" type="checkbox"/>	5/18
10.	Data collection methods	<input checked="" type="checkbox"/>	5
11.	Data collection instruments and technologies	<input checked="" type="checkbox"/>	5
12.	Units of study	<input checked="" type="checkbox"/>	6
13.	Data processing	<input checked="" type="checkbox"/>	5
14.	Data analysis	<input checked="" type="checkbox"/>	6/7
15.	Techniques to enhance trustworthiness	<input checked="" type="checkbox"/>	5
16.	Synthesis and interpretation	<input checked="" type="checkbox"/>	5
17.	Links to empirical data	<input checked="" type="checkbox"/>	8-13
18.	Integration with prior work, implications, and contribution to field	<input checked="" type="checkbox"/>	14-16
19.	Limitations	<input checked="" type="checkbox"/>	16
20.	Conflict of interest	<input checked="" type="checkbox"/>	18
21.	Funding	<input checked="" type="checkbox"/>	18

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6 2 **Title:**  
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9 3 Exploration of pain assessment and management processes in oncology outpatient services  
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11 4 with healthcare professionals: a qualitative study  
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17 6 **Authors:**  
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20 7 Robinson, OC<sup>1</sup>. Pini, S<sup>1</sup>. Flemming, K<sup>2</sup>. Campling, N<sup>3</sup>. Fallon, M<sup>4</sup>. Richards, SH<sup>1</sup>.  
21  
22 8 Mayland, CR<sup>5,8</sup>. Boland, E<sup>6</sup>. Swinson, D<sup>7</sup>. Hurlow, A<sup>7</sup>. Hartup, S<sup>7</sup>. Mulvey, MR.<sup>1</sup>  
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33  
34 12 Clarendon Way, Leeds, LS2 9NL, UK.  
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56 21 <sup>8</sup>Sheffield Teaching Hospitals, NHS Foundation Trust.  
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13 26 Email: [o.c.robinson@leeds.ac.uk](mailto:o.c.robinson@leeds.ac.uk).

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16 27 **Key words**

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19 28 Pain Assessment, Oncology, Outpatient, Cancer Pain, Pain Management, Qualitative,  
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22 29 Semi-structured interviews.

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25 30 **Abstract**

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28 31 **Objectives:** This study explored cancer pain management practices and clinical care  
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30 32 pathways used by healthcare professionals (HCPs) to understand the barriers and  
31  
32 33 facilitators for standardised pain management in oncology outpatient settings (OS).

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35 35 **Design:** Data were collected using semi-structured interviews that were audio-  
36  
37 36 recorded and transcribed. The data was analysed using Thematic Analysis.

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40 38 **Setting:** Three NHS trusts with oncology OS in Northern England.

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44 40 **Participants:** Twenty HCPs with varied roles (e.g. oncologist, nurse) and experiences  
45  
46 41 (e.g. registrar, consultant) from different cancer site clinics (e.g. breast, lung). Data  
47  
48 42 were analysed using Thematic Analysis.

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51 44 **Results:** HCPs discussed cancer pain management practices during consultation and  
52  
53 45 supporting continuity of care beyond consultation. Key findings included: (1) HCPs'  
54  
55 46 level of clinical experience influenced pain assessments; (2) remote consulting  
56  
57 47 impeded experienced HCPs to do detailed pain assessments; (3) diffusion of HCP  
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59 48 responsibility to manage cancer pain; (4) nurses facilitated pain management support

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4 49 with patients; and, (5) continuity of care for pain management was constrained by the  
5 50 integration of multi-disciplinary teams.

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9 52 **Conclusions:** These data demonstrate HCP cancer pain management practices varied  
10 53 and were unstructured. Recommendations are made for a standardised cancer pain  
11 54 management intervention: (1) detailed evaluation of pain with a tailored self-  
12 55 management strategy; (2) implementation of a structured pain assessment that  
13 56 supports remote consultations, (3) pain assessment tool that can support both  
14 57 experienced and less experienced clinicians. These findings will inform the  
15 58 development of a cancer pain management tool to integrate within routine oncology  
16 59 OS.  
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### 26 61 Strengths and Limitations of this study

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29 62 - To our knowledge, ~~this study~~ this is is the one of the first to qualitative  
30 63 study qualitative studies that has ~~explored in depth~~ provided a descriptive  
31 64 account of cancer pain management processes and experiences in oncology  
32  
33 65 outpatient settings from the perspective of healthcare professionals.  
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39 67 —A structured sampling framework was used to ensure a  
40 68 ~~heterogeneous~~ heterogeneous sample of roles, seniority and clinical speciality  
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42 69 were recruited to the study. ~~I~~ This enabled a detailed understanding to different  
43  
44 70 types of pain prevalence patients experienced.  
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51 73 - ~~Our methodological approach to~~ Our recruitment strategy (i.e. self-referral  
52 74 sampling after receiving an information pack) —may have led to bias, as  
53  
54 75 ~~participants individuals~~ with strong negative or positive views may have been  
55  
56 76 more likely to self-refer and agree to participate to the study.  
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## 78 Introduction

79 In the UK, approximately 167,000 people die of cancer each year (1) of whom half will  
80 experience moderate to severe pain, and a third are undertreated for their pain (2, 3).  
81 Under-treatment of cancer pain reduces patients' quality of life and increases  
82 healthcare service use and costs (3). For patients, the burden of chronic cancer-pain  
83 is associated with anxiety, depression (4) and significantly reduces physical and  
84 emotional wellbeing (5).

85 The underlying pathophysiology of cancer pain is complex; nociceptive, inflammatory,  
86 and neuropathic mechanisms exist in concert with psychological and emotional  
87 components of chronic pain, making cancer pain challenging to manage clinically (6)  
88 (7). Historically, the management of cancer pain has been based on evaluating the  
89 subjective intensity of pain (via 0-10 Likert scales) (8) which do not evaluate aetiology,  
90 mechanisms or psychological components of pain (9). In addition, the challenging  
91 clinical environment within an oncology outpatient department means that cancer pain  
92 management is one of many competing priorities that healthcare professionals (HCPs)  
93 must manage during a time-limited consultation.

94 In the UK and Europe, cancer patients are mainly treated at oncology outpatient  
95 services (OS), within secondary or tertiary healthcare systems. Care in OS differs from  
96 inpatient hospital settings; outpatient clinics are dedicated services patients visit for  
97 specific appointments, so their care can be monitored, reviewed and treated by HCPs  
98 healthcare professionals (HCPs) (i.e. oncologists, nurses). Despite support given to

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4 99 cancer patients at outpatient clinics, uncontrolled cancer pain is the most common  
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6 100 reason for contacting GP out-of-hours services (10).  
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9 101 When cancer pain is routinely assessed on hospital wards or in outpatient clinics, this  
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12 102 improves pain control for patients (11). The UK Faculty of Pain Medicine has published  
13  
14 103 Core Standards for cancer pain management (12) which state that cancer patients  
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17 104 should receive a pain assessment at each encounter with an oncology clinician that  
18  
19  
20 105 covers intensity, mechanisms, aetiology and impact. Yet, oncology literature shows  
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23 106 there is currently no standardised procedure for managing pain in an outpatient setting  
24  
25 107 (13). Despite decades of national and international guidelines on cancer pain  
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28 108 management (6, 8) inadequate pain assessment continues to be a barrier to good pain  
29  
30 109 control for patients with cancer. Wider oncology literature has suggested HCPs  
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33 110 required more educational opportunities for prescribing complex pain relief  
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36 111 medications to cancer patients (14).  
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39 112 External factors can also influence effective pain management processes. In the UK,  
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41 113 referral to oncology begins in primary care, this is community-based care provided by  
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44 114 general practitioners (GPs). Reduced referrals from primary care during the COVID-  
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47 115 19 pandemic has led to an increase in the numbers of patients diagnosed with  
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50 116 advanced cancer post-pandemic. This has been compounded by staff shortages in  
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53 117 oncology OS and increasing levels of sickness absence and burnout in the workforce  
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55 118 (15). In the UK, minimal qualitative studies have explored current pain management  
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57 119 practices for people with cancer in oncology OS. The aim of this qualitative  
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4 120 investigation was to describe cancer pain management practices and clinical care  
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6 121 pathways for cancer pain management used by ~~healthcare professionals (HCPs)~~  
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8 122 HCPs) to understand the barriers and facilitators for standardised pain management  
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11 123 in oncology outpatient settings OS.  
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## 17 125 Methods

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### 22 127 **Design**

25 128 Qualitative interview study exploring pain management practices for people with  
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27 129 cancer in oncology OS from the perspective of ~~healthcare professionals (HCPs)~~.  
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30 130 HCPs.  
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### 36 132 **Research participants**

38 133 HCPs were recruited from oncology OS in three National Health Service (NHS) trusts  
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41 134 in Northern England. Eligible HCPs were required to have at least 6-months  
42  
43 135 experience of managing cancer pain in an oncology outpatient setting. Purposive  
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45  
46 136 sampling was used to recruit participants that had varied job roles (oncologist, clinical  
47  
48 137 nurse specialist (CNS)), with a staff sample to reflect different staff grades (consultant,  
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51 138 registrar), working from a range of outpatient sub-specialities (lung, breast, bowel).  
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54 139 This ensured a broad range of experiences of cancer pain assessment, support and  
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56 140 management for patients with differing disease trajectories were included in the  
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59 141 sample.  
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7 143 **Recruitment**

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9 144 Eligible HCPs were identified and recruited ~~through~~ via co-applicant HCPs embedded  
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12 145 within the clinical teams ~~at the respective NHS trusts,~~ who emailed study information  
13  
14 146 packs (i.e. information sheet, consent form) to their entire clinical teams. a written  
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17 147 information sheet explaining the purpose of the study ~~contact~~ information of the  
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20 148 research team (OR/MM) was included in study information packs and potentially  
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23 149 eligible ~~.~~ participants were asked to contact the research team (OR/MM). When  
24  
25 150 potentially eligible ~~eligible~~ participants contacted the research team (OR/MM) the study  
26  
27  
28 151 was discussed in detail, any questions answered, and a date/time arranged for an  
29  
30 152 interview. Interviews were conducted through telephone and video calling software to  
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33 153 suit the participants. Verbal consent was obtained by OR at the beginning of the  
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36 154 interview. The consent audio was recorded and stored separately to the main interview  
37  
38 155 recording.

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43 157 **Patient and Public Involvement**

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47 159 A patient and public involvement (PPI) group was established at the beginning of the  
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49 160 project. Our PPI group included people with personal experiences of managing  
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52 161 cancer pain and one former carer. One PPI member was also a grant co-applicant.  
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55 162 The PPI group met during the study development phase to contribute to all aspects  
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58 163 of the research design and delivery methods. This included providing feedback on the  
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4 164 development of study documents and processes. Once data had been collected,  
5  
6 165 transcribed and summarised the PPI group met to provide feedback on the initial  
7  
8 166 themes and sub-themes identified from the data. ~~It included people with personal~~  
9  
10  
11 167 ~~experiences of managing cancer pain and one former carer. One PPI member was~~  
12  
13  
14 168 ~~also a grant co-applicant.~~  
15

16 169

## 170 Data collection

171 Interviews were conducted by OR between March 2022 and May 2022. Sample size  
172 was determined based on previous qualitative studies conducted in oncology OS (16,  
173 17). Recruitment and analysis continued in tandem until data saturation was reached.  
174 An interview topic guide was informed by existing literature and expert input from the  
175 research and Patient and Public Involvement group (see additional file 1). Participants  
176 were asked about their experiences of cancer pain management in oncology OS. This  
177 included exploring current practice, challenges and identifying what could be done to  
178 improve how pain is managed. OR and MM held weekly meetings to discuss the  
179 interviews and influence of ~~the~~ researcher bias on the dataset was documented.

180

## 181 Data analysis

182 Data analysis was done using Braun and Clark's Thematic Analysis (18). With consent  
183 from participants, interviews were audio-recorded and transcribed verbatim by OR and  
184 LA. Analysis was an inductive-deductive process derived from participant interviews;  
185 ~~to further explore patterns in the dataset~~preliminary analyses was undertaken  
186 throughout the data collection process and the topic guide was adjusted accordingly

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4 187 to explore existing and new patterns identified within the data. After familiarising  
5  
6 188 themselves with the transcripts, ~~initial coding and development of themes was done~~  
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8  
9 189 by OR, MM and SP. Through a series of data analysis meetings, the initial themes and  
10  
11 190 sub-themes were ~~This- presented to was shared with~~ the wider research team and our  
12  
13  
14 191 Patient and Public Involvement and Engagement PPI group to explore their meaning  
15  
16 192 and significance. During these data analysis meetings each theme and sub-theme  
17  
18  
19 193 was described in detail and supporting evidence (codes and quotes) was presented  
20  
21  
22 194 and discussed. ~~Following each data analysis meeting the themes and sub-~~  
23  
24 195 themes were further developed using ~~were refined - feedback from the wider research~~  
25  
26  
27 196 team and PPI group in an iterative process until the themes were agreed to develop,  
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30 197 review and refine themes. Anonymised verbatim quotes from the data were used to  
31  
32 198 illustrate and give credibility to findings.  
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4 200 **Results**

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6 201 Interviews were conducted with 20 HCPs from three NHS trusts, lasting between 30-  
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9 202 minutes to 45-minutes (Table 1. Participant characteristics).

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15 204 *Table 1. Participant characteristics (N=20)*

Participant characteristics	
<i>Healthcare professionals (n=20)</i>	
Male	8
Female	12
Role	
Consultant	12
Clinical Nurse Specialist (CNS)	3
Registrar	4
Pharmacist	1
<i>Cancer sub-speciality area</i>	
Urology	2
Prostate	2
Skin	2
Upper Gastrointestinal tract (GI)	2
Haematology	5

Lung	6
Breast	1

205

206

## 207 Thematic analysis

208 Thorough analysis of the transcripts produced two primary themes: (1) *current pain*  
 209 *management practices during oncology outpatient consultations* and (2) *delivering*  
 210 *continuity of care beyond the oncology outpatient consultations* (table 2). Each theme  
 211 contained four sub-themes to further describe the specific elements of each.

212

213

214 *Table 2. Thematic analysis themes and sub-themes*

### Theme 1: Pain management practices during oncology outpatient consultations

#### Sub-themes:

#### 1.1 Staff background experience influences pain assessment practice

- Assessment of pain was influenced by HCPs seniority and experience, often using clinically based judgements to manage pain.

#### 1.2 Variation in pain management practice

- There was variation in when and how HCPs approached cancer pain management during consultations, related to time and rapport.

#### 1.3 Remote consulting impacted on pain assessment



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-HCPs felt remote consultations impeded even experienced HCPs ability to deperform -a detailed pain assessment.

#### **1.4 HCP's roles and responsibilities.**

There was ~~variation in the extent to which HCPs felt~~ responsible ~~felt by HCPs to~~ manage cancer pain.

### **Theme 2: Continuity of care following oncology outpatient consultations**

#### **Sub-themes:**

#### **2.1 Utilisation of outpatient oncology clinical nurse specialistss pecialist nursesCNS.**

-HCPs felt oncology CNS-speciality nurses had more time to build rapport with patients outside the consultation, and enable ~~provide a personalised continuity of care making patients more~~ willing to openly disclose their experience of cancer pain.

#### **2.2 Integration of supportive services.**

-Optimal pain management involved ~~HCPs identifying and monitoring pain whilst~~ utilising supportive services (i.e. pain management teams) for advice and guidance to develop appropriate treatment pathways.

#### **2.3 Re-assessment and monitoring of cancer pain between primary and secondary care.**

-Outpatient clinicians' opportunity to re-assess and monitor cancer pain is constrained by the frequency of appointments.

#### **2.4 Providing patients with supported Sself-management plans to manage cancer pain at home.**

-HCPs created self-management plans for patient to ensure their cancer pain was adequately reviewed.

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4 216 PCurrent pain management practices during oncology in outpatient consultations

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6 217 Participants reported factors such as time, rapport, mode of assessment (i.e.  
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9 218 telephone) and diffusion of responsibility influenced the extent pain management was  
10  
11 219 explored with patients.

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15 220 Staff background experience influences pain assessment practice

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17 221 Assessment of pain in outpatient clinics was influenced by individual HCP's seniority  
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20 222 and experience. Experienced consultants expressed confidence assessing and  
21  
22 223 treating cancer pain because it was an area of care they "do a lot of"-[P012].  
24  
25 224 Experienced HCPs stated "I don't use any pain guidelines"-[P011] or "I just pull on my  
26  
27 225 own experience"-[P013] to describe how pain was assessed in practice. Senior staff  
28  
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30 226 appeared more likely to use tacit knowledge in addition to drawing on clinically based  
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32 227 observations (i.e. non-verbal behaviours) and conversations with the patient before  
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35 228 determining an appropriate treatment plan:

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39 229 "They [the HCP] might be looking at how far can you lift the leg, the pressure  
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41 230 that they can put on the leg and how much feeling there is on the leg" P004  
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44 231 [CNS, haematology clinic]

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47 232 HCPs used open-ended questions that "triggered"-[P011] patients to discuss pain or  
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50 233 discomfort followed by an assessment for severity of pain. Using a verbal description  
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52 234 of a numerical pain intensity scale encouraged patients to "score it, 0-10"-[P009]. Yet,  
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55 235 several HCPs felt pain scales did not provide a valid representation of a patient's pain  
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58 236 because the subjective nature of pain made it "difficult to apply to numbers"- [P006].  
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4 237 Asking questions associated with the type of cancer, initiated patients to think in-depth  
5  
6 238 about the context, triggers, occurrences and nature of the pain:  
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9 239 *“Thoracic cancers I’d always ask about chest pain specifically and risk of pain*  
10  
11  
12 240 *or swelling outside of the chest and with gynaecological cancers I’d say “have*  
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14  
15 241 *you had any abdominal pain or bloating” P008 [Registrar, lung clinic]*  
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21 243 Variation in pain management practice  
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24 244 There was variation in when and how HCPs approached cancer pain management  
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26 245 during consultations, related to time, rapport and location. Participants stated pain  
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29 246 management conversations required *“empathy and sensitivity”* – [P001], yet  
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31  
32 247 developing the necessary rapport took time. Participants suggested patients received  
33  
34 248 pain assessments at different points in a care journey, i.e. initial or follow-up  
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36  
37 249 consultations. HCPs acknowledged the extent to which pain management was  
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40 250 approached and communicated to patients depended on specific diagnosis groups  
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42 251 with differing levels of associated pain. If HCPs were seeing a *“new cancer patient*  
43  
44  
45 252 *with less pain”- [P008]* consultants prioritised other areas of the patient’s care (i.e.  
46  
47  
48 253 arranging treatment, discussing patient concerns):  
49

50 254 *“If I’m consenting them for radiotherapy a lot of them won’t really be having any*  
51  
52  
53 255 *pain, so you know I’ll ask, and if they’re saying no, then that’s fine” P008*  
54  
55  
56 256 *[Registrar, Lung clinic]*  
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4 257 HCPs suggested discussing other areas of cancer-related care meant opportunities  
5  
6 258 for an in-depth, detailed pain assessment were potentially lost. For patients with  
7  
8  
9 259 specific cancer types, where pain was highly prevalent, HCPs tacit pain assessment  
10  
11 260 identified pain management as a priority. HCPs made clinical judgements on the  
12  
13  
14 261 extent and timing of pain management discussions. This included recognising when  
15  
16  
17 262 external factors could potentially exacerbate pain, for example, "*frailty in older patients,*  
18  
19 263 *comorbidities or smoking*"- [P003].

22 264 *"Some patients are straightforward. Whereas a lot of lung patients have been*  
23  
24  
25 265 *heavy smokers. They've got COPD and ischemic heart disease...where you*  
26  
27  
28 266 *really have got to get into conversations about pain in a big way"* P003  
29  
30 267 *[Consultant, haematology clinic]*

32  
33 268 HCPs suggested follow-up consultations were variable and depended on the care  
34  
35  
36 269 needs and severity of the patient's cancer. For patients with advanced cancer that  
37  
38  
39 270 were seen weekly it could be easier to monitor and explore pain. HCPs described  
40  
41 271 difficulties with building rapport to explore pain when appointments were infrequent  
42  
43  
44 272 and patients did not see the same HCP at follow-up appointments.

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48  
49  
50 274 Remote consulting impacted ~~on~~ pain assessment

51  
52 275 Management of oncology outpatient care has changed since COVID-19 pandemic and  
53  
54  
55 276 more consultations are conducted remotely. HCPs described advantages to remote  
56  
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4 277 consulting as it enabled easier, more frequent contact with patients and supported  
5  
6 278 continuity of care:  
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8  
9 279 *"We would, you know put that as part of our diary for the following day to call*  
10  
11  
12 280 *back and see. Make sure that it was working"* P005 [CNS, upper GI clinic]  
13

14  
15 281 However, some HCPs found remote consulting prevented non-verbal observations of  
16  
17  
18 282 pain and experienced clinicians recognised that this impeded their ability to do a  
19  
20  
21 283 detailed pain assessment:  
22

23  
24 284 *"And saying to a patient, is it the lumbar region? Why would they know that"*  
25  
26 285 *P004 [CNS, haematology clinic]*  
27

28  
29  
30 286 HCPs described a risk of patients misattributing cancer-related pain for side effects  
31  
32  
33 287 and symptoms during remote consultations, making it challenging to provide  
34  
35 288 appropriate treatment. HCPs had to *"take [it] on the patient's own word"*-[P002]feeling  
36  
37  
38 289 there was *"no other option"*- [P002]. Some HCPs felt pain assessments began from  
39  
40  
41 290 observations of non-verbal cues when *"they call the patient from the waiting room"*-  
42  
43 291 *P011*, which was not possible in telephone consultations. This contributed to the  
44  
45  
46 292 overall judgement of the patient's pain:  
47

48  
49 293 *"You notice whether they're in a wheelchair, how they're able to get out of their*  
50  
51  
52 294 *chair, whether they can walk down the corridor as fast or slower than you can"*  
53  
54 295 *P018 [Consultant, breast clinic].*  
55

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4 297 Healthcare professional's roles and responsibilities

5  
6 298 There was a diffusion of responsibility when HCPs discussed pain management. Due  
7  
8  
9 299 to other community-based HCPs (i.e. GPs, palliative care teams) also being able to  
10  
11 300 monitor and manage a patient's pain, some oncologists in secondary care felt it was  
12  
13  
14 301 not their responsibility therefore did not engage in detailed pain conversations, e.g. it  
15  
16 302 was a "*community palliative nurse's job to manage pain*"- [P003]. However, HCPs did  
17  
18  
19 303 not want to put a patient at risk of uncontrolled pain whilst they were waiting to discuss  
20  
21  
22 304 this pain with the patient's community teams and thus developed a self-management  
23  
24 305 plan for the patient to follow:

25  
26  
27 306 *"You're thinking about, well, the patient could be suffering tonight. You know, I*  
28  
29 307 *can maybe address some of these issues now"* P003 [Consultant, haematology  
30  
31  
32  
33 308 *clinic].*

34  
35  
36 309 Some HCPs described how patients needed to take "*ownership*"-[P014] and  
37  
38 310 "*responsibility*"-[P003] to disclose if they were experiencing pain because patients  
39  
40  
41 311 often withheld the extent of their pain due to "*fears of bothering the clinician*"- [P008]  
42  
43  
44 312 making it more challenging to accurately assess and manage. In some instances,  
45  
46  
47 313 HCPs felt patients needed to provide honest opinions to support a thorough  
48  
49 314 assessment and avoid uncontrolled pain:

50  
51  
52 315 *"You know autonomy to the patient and responsibility to the patient to tell you if*  
53  
54 316 *there's a problem you know"* P014 [Registrar, upper GI clinic]

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4 318  
5  
67 319 Continuity of care following [oncology](#) outpatient consultations  
8

9 320 Participants indicated continuity of care for pain management was facilitated by CNS,  
10  
11 321 relationships between oncology HCPs and supportive services (i.e. palliative care  
12  
13 322 teams, pain management services), re-assessment and monitoring of cancer pain  
14  
15 323 between primary and secondary care and self-management plans to manage cancer  
16  
17 324 pain at home.

23 325 Utilisation of outpatient oncology CNS  
24

25 326 Most registrars and consultants entrusted CNS with following up patients and  
26  
27 327 providing pain management support beyond their initial consultation with an  
28  
29 328 oncologist. This was a component of the CNS role to undertake follow-up remote  
30  
31 329 consultations (i.e. telephone or video call) including the re-assessment of pain and  
32  
33 330 other symptoms:

39 331 *"I have the support of CNSs, it will be within days [referring to follow-up calls],*  
40  
41 332 *you know hopefully within a week then I have somebody else checking in on*  
42  
43 333 *them as to whether medication levels need increasing" P007 [Consultant,*  
44  
45 334 *prostate clinic].*

50 335 Consultants reflected on a CNS ability to build rapport with patients and provide a  
51  
52 336 personalised continuity of care making patients more willing to openly disclose their  
53  
54 337 pain. One example showed CNS identifying problematic pain with a patient and  
55  
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4 338 escalating this to the consultant to be explored further at follow-up consultations so  
5  
6 339 changes can be made to medication:  
7  
8

9 340 *"If there's a note or a, verbal reminder [referring to a nurse providing notes to a*  
10  
11 341 *consultant about a patient's pain]. Actually, they have had some problems with*  
12  
13 342 *pain or this particular issue then that definitely works well" P011 [Consultant,*  
14  
15 343 *haematology clinic].*  
16  
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18  
19

20 344 If there were little or no CNS staff available to support the management of pain  
21  
22 345 following consultations with an oncologist, participants suggested it placed strain on  
23  
24 346 other HCPs to fulfil this role. Consultants and registrars expressed concerns for having  
25  
26 347 *"triple booked clinics"- [P003] and calling patients "three hours after their appointment*  
27  
28 348 *time"-[P003] when there were no CNS staff to support clinics.*  
29  
30  
31  
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36  
37 350 Integration of supportive services  
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39  
40 351 Relationships between supportive services (i.e. palliative care, community nursing  
41  
42 352 teams and pain team) and oncology HCPs were essential to cancer pain management.  
43  
44 353 While HCPs expressed confidence in their ability to identify and treat cancer pain,  
45  
46 354 there were circumstances where HCPs described *"reaching their limits"- [P012] on*  
47  
48 355 providing recommendations on complex opioid medication and required specialist  
49  
50 356 support:  
51  
52  
53  
54

55  
56 357 *"we're used to drugs like Gabapentin, Amitriptyline but when patients are still*  
57  
58 358 *having pain, that's when you need help and we're lucky, we can ring the palliative*  
59  
60



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4 359 *care team and there is somebody that can review the patient...usually you can get*  
5  
6 360 *access to that specialist advice if you need".P012 [Consultant, lung clinic]*  
7

8  
9 361 In some cases, the level of responsibility and expertise the clinician felt they had over  
10  
11 362 managing a patient's pain (i.e. pain was important part of consultation discussions)  
12  
13 363 influenced whether a patient would be referred to another team or managed by  
14  
15 364 themselves. Data suggested optimal pain management often involved HCPs  
16  
17 365 identifying and monitoring pain whilst utilising supportive services for advice and  
18  
19 366 guidance to develop appropriate treatment pathways.  
20  
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25 367

26  
27  
28 368 Re-assessment and monitoring of cancer pain between primary and secondary  
29  
30  
31 369 care

32  
33 370 Inpatient ward settings enabled HCPs to regularly re-assess cancer pain and make  
34  
35 371 amendments to medication more frequently. In OS a clinicians' opportunity to re-  
36  
37 372 assess and monitor cancer pain was constrained by the frequency of appointments on  
38  
39 373 weekly, monthly or greater basis. Some oncology OS support patients from "*large*  
40  
41 374 *geographical areas*"-[P005] therefore patients might not return for consistent follow-up  
42  
43 375 appointments. Participants reported this made it difficult for HCPs to provide continuity  
44  
45 376 of care and put more dependency on managing cancer pain between primary and  
46  
47 377 secondary care:  
48  
49  
50  
51  
52

53  
54  
55 378 *"What we don't have a mechanism like we do on the ward... We simply don't*  
56  
57 379 *have that contact, so we are next seeing the patients usually in three or six*  
58  
59  
60

1  
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4 380 *weeks' time. So the pattern of medical interaction it simply doesn't map on to*  
5  
6 381 *pain relief" P018 [Consultant, breast clinic]*  
7  
8

9 382 HCPs emphasised pain management decisions needed to be made in line with the  
10  
11 383 patient's needs and their ability to conveniently access primary care. As a result of  
12  
13 384 this, patients and HCPs often had to "rely on the GPs to issue drugs and escalate pain  
14  
15 385 control"- [P014].  
16  
17  
18

19  
20 386 *"We would also encourage patients to seek support from the GP and there will*  
21  
22 387 *come a time when it's beyond our scope" P005 [CNS, upper GI clinic]*  
23  
24  
25

26 388

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29  
30 389 [Providing patients with supported s](#)Self-management plans to manage cancer  
31  
32 390 pain at home  
33

34  
35 391 Due to the challenges with assessment and re-assessment in OS, some HCPs  
36  
37 392 suggested providing a "safety net"-[P016]for the patient was a crucial aspect to ensure  
38  
39 393 cancer pain was adequately reviewed. This involved developing a strategy so a patient  
40  
41 394 knew what to do if the pain relief was not effective or if they were still experiencing  
42  
43 395 severe pain:  
44  
45  
46

47  
48 396 *"I want you to see how those go and then perhaps give them a time period, so this*  
49  
50 397 *is gonna take a few days for this to start to work better. If things are not any better,*  
51  
52 398 *then to call us back" P016 [Consultant, haematology clinic]*  
53  
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55  
56 399 Some HCPs provided patients with documentation that included information on how,  
57  
58 400 when and what medication to take, as well as contact information for the OS and out-  
59  
60

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4 401 of-hours services. This was one-way HCPs ensured patients were supported to self-  
5  
6 402 manage cancer pain at home:  
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8

9 403 *"If there is anything of concern there is a number that you can call 24 hours a*  
10  
11  
12 404 *day, 7 days a week, 365 days a year and then we can see them on the acute*  
13  
14 405 *unit and take it from there" P006 [Registrar, urology clinic]*  
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For peer review only

## 406 Discussion

407 We found an unstructured and variable approach to pain management affected  
408 multiple components of a patient's outpatient cancer care. Firstly, HCPs used clinical  
409 judgement in place of a structured assessment to manage a patient's pain. This  
410 explains why HCPs might not use pre-existing guidelines and tools that have been  
411 published (6, 8). Research has highlighted disadvantages to using pain assessment  
412 tools, such as oversimplification of the multi-dimensional pain experience and not an  
413 appropriate reflection of a patient's pain (19). Pain management tools can be efficient  
414 especially when HCPs have limited time or when pain assessments are combined with  
415 [an](#) individualised assessment to fully understand how pain is affecting the patient  
416 physically, psychologically, socially and culturally.

417 [Our data show that pain management in oncology outpatient services was influenced](#)  
418 [by variation in HCPs' expectation of responsibility for pain management; i.e. it was](#)  
419 [often considered to be someone else or another services' responsibility. This diffusion](#)  
420 [of responsibility is well reported in healthcare settings and is known to lead to](#)  
421 [underperformance of clinical activities and fragmented care in circumstances of](#)  
422 [shared accountability](#) (20) [Fallon et al. \(2018\) showed that when structured pain](#)  
423 [assessment processes are implemented within routine clinical care, this leads to a](#)  
424 [more consistent approach to pain management, a reduction in the diffusion of](#)  
425 [responsibility and improved pain outcomes for cancer patients](#) (11). ~~As shown in this~~  
426 ~~study, the diffusion of responsibility that the respective healthcare professional placed~~  
427 ~~on managing a patient's pain influenced the extent pain was explored with patients.~~

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4 428 ~~However, randomised control trial data show that simple clinician-delivered pain~~  
5  
6 429 ~~assessment processes, implemented via policy level change resulted in broad ation~~  
7  
8  
9 430 ~~of a structured pain assessment used by all HCP uptake, s ensures all patients receive~~  
10  
11 431 ~~a consistent pain assessment for all patients and improved cancer pain outcomes~~  
12  
13  
14 432 ~~[REF]. thorough assessment of pain.~~

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16  
17 433 ~~This could be used in conjunction with the recognition of non-verbal cues and open-~~  
18  
19  
20 434 ~~ended questions to explore the patient's pain in more detail. Our data showedWe~~  
21  
22 435 ~~found~~ variation across the roles and responsibilities of HCPs supporting the continuity  
23  
24  
25 436 of pain management. Oncology outpatient literature suggests some HCPs perceived  
26  
27  
28 437 their primary duty was to provide patients with their disease status and have  
29  
30  
31 438 conversations around treatment (21). However, our data shows that HCPs who  
32  
33  
34 439 expressed clinical responsibility around pain management were inclined to develop  
35  
36  
37 440 self-management plans to support patients to manage cancer pain at home.

38  
39 441 This study aimed to describe current pain management and thus the interview topic  
40  
41  
42 442 guide was not developed to explored nuances of self-management practices.  
43  
44  
45 443 However, we know from previous studies there is variation in self-management  
46  
47  
48 444 approaches (22). In OS, development of self-management support for patients is  
49  
50  
51 445 crucial to a continuity of care. This includes providing elements of educational  
52  
53  
54 446 interventions to facilitate problem solving and adequate decision-making skills and  
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56  
57 447 tailoring recommendations to the individual's situation and defining goals with action  
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59  
60 448 plans (22). By developing supportive plans, it ensures patients understand what to do

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4 449 if pain escalates or becomes unmanageable. Subsequently, it could encourage  
5  
6 450 patients to initiate re-assessment of their pain at primary and secondary care services.  
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9 451 We found system-level challenges impacted the extent to which pain was explored  
10  
11  
12 452 with patients and monitored by outpatient HCPs. Exacerbated by the impact of the  
13  
14 453 COVID-19 pandemic, clinics are often over-booked, short staffed, and have long  
15  
16  
17 454 waiting lists (15). In addition, our data show that the complexity surrounding the  
18  
19  
20 455 interface between primary and secondary care and challenges with integration of  
21  
22  
23 456 multi-disciplinary teams meant continuity of care, in particular re-assessment and  
24  
25 457 monitoring of pain, was difficult as patients were referred back to primary or community  
26  
27  
28 458 care teams.

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30  
31 459 Oncologists found it difficult to build rapport with patients that might not return to  
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34 460 outpatient appointments and felt they had to prioritise topics of care with the limited  
35  
36 461 time they had. Consultations take a patient-centred approach that prioritises care  
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38  
39 462 practices that are responsive to a patient's preferences and values and thus not  
40  
41 463 focusing on pain management may be appropriate for some patients. However, this  
42  
43  
44 464 study and previous research has highlighted patients can often be reluctant to express  
45  
46  
47 465 their concerns and preferences without prompting (13). This suggests the  
48  
49 466 development of rapport with patients is essential to gain full understanding of a  
50  
51  
52 467 patient's care needs. We found CNS had more opportunities to build rapport and have  
53  
54 468 discussions about pain with patients. However, in line with previous studies (14)  
55  
56  
57 469 opportunities for pain management discussions are often missed if there are nurses  
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4 470 with less experience and confidence to conduct pain assessments. Recommendations  
5  
6 471 from this study highlight the benefit of providing training for HCPs to support pain  
7  
8  
9 472 management conversations and embedding this within routine clinical practice.

10  
11  
12 473 Oncology literature has highlighted the benefits for the use of remote consultations in  
13  
14 474 cancer pain management, where it is used appropriately. For example, reduction in  
15  
16  
17 475 pain severity scores, cost-effective, improved accessibility for patients to receive HCP  
18  
19  
20 476 advice and treatment of symptoms and aided monitoring and re-assessment of  
21  
22  
23 477 symptoms (23, 24). We found adaptations to pain assessments for remote care  
24  
25 478 impeded experienced HCPs to do a detailed thorough pain assessment, especially if  
26  
27  
28 479 not Audio Visual (AV) facilitated. HCPs become experts in their field through  
29  
30  
31 480 knowledge, skill, training and experiential learning (25). Since COVID-19 the increased  
32  
33 481 use of remote consultations has meant HCPs have to spend more time doing pain  
34  
35  
36 482 assessments remotely. However, due to a lack of experiential learning for conducting  
37  
38 483 pain assessments through remote consultations, this potentially made even  
39  
40  
41 484 experienced HCPs feel like a novice. This coincides with the novice to expert theory  
42  
43  
44 485 (25). Similarly, for those with less experience a change in mode-of-consulting could  
45  
46 486 further impede thorough pain assessments for patients. Without additional support and  
47  
48  
49 487 structured guidance on how to conduct remote consultations there is a risk that  
50  
51 488 patients' pain will not be appropriately managed and key components of a detailed  
52  
53  
54 489 pain assessment potentially missed. Previous research has shown even when pain  
55  
56  
57 490 assessments are standardised and detailed, only modest improvements in pain for  
58  
59 491 patients with cancer are observed, largely because of low delivery fidelity and poor  
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4 492 implementation (6). However, Fallon et al. (2018) demonstrated that when  
5  
6 493 standardised pain assessment processes are integrated within routine clinical practice  
7  
8  
9 494 at the level of the service (rather than at an individual clinician level) this leads to  
10  
11 495 greater improvements in pain outcomes for patients and more appropriate analgesic  
12  
13  
14 496 prescribing. This suggests an in-depth implementation plan at service-level would be  
15  
16 497 crucial to the success of a structured pain management intervention.  
17  
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20 49821  
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23 499 Strengths and limitations

24  
25 500 A structured sampling framework was developed by the research team which may  
26  
27  
28 501 have resulted in potential bias. However, this approach provided a heterogeneous  
29  
30  
31 502 sample of staff roles, seniority and clinical speciality that gave a greater understanding  
32  
33 503 to the management of different types of pain prevalence patients experienced. All  
34  
35  
36 504 participants were from Northern England; therefore, the study's findings may not be  
37  
38  
39 505 generalisable to other regional oncology outpatient settings or international healthcare  
40  
41  
42 506 systems. One A limitation of our methodological approach is related to our  
43  
44 507 recruitment strategy recruitment bias(i.e. self-referral sampling after HCPs received  
45  
46  
47 508 an information pack); due to the nature of the research aims (i.e. pain management in  
48  
49 509 oncology) participants with strong negative or positive views may have been more  
50  
51  
52 510 likely to agree to participate. However, the themes identified from the data indicated  
53  
54  
55 511 broad perspectives of pain management processes and experience, so it is unlikely  
56  
57 512 that we have sampled an exclusively polarised group of participants.  
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4 5135  
6  
7 514 Implications of clinical research and practice8  
9 515 Faculty of Pain Medicine Core standards for cancer pain management (12) state all10  
11  
12 516 patients should receive a pain assessment at each encounter with an oncology13  
14  
15 517 clinician that includes exploration of intensity, mechanisms, aetiology and impact.16  
17 518 Evidence from clinical trials show that standardising pain assessment in oncology18  
19  
20 519 outpatient clinics leads to improvements in patients' pain and quality of life (11). This21  
22  
23 520 research recommends the implementation of a structured routine pain assessment24  
25 521 [that minimises the risk of diffusion of responsibility and encourages HCPs to](#) ~~that~~26  
27  
28 522 [enables all HCPs using different modes of consultations to](#) incorporate the most crucial29  
30  
31 523 components of a pain assessment [into patient consultations \(i.e. exploration of](#)32  
33 524 [intensity, mechanisms, aetiology and impact\).](#) ~~within the limited time they have.~~34  
35 525 Secondly, at a service level, uncontrolled cancer pain remains the most common36  
37  
38 526 reason for contacting GP out-of-hours service (10). Implementing a structured pain39  
40  
41 527 assessment within oncology OS would encourage patients to report pain earlier,42  
43 528 enabling HCPs to manage cancer pain earlier, reducing the burden ~~on~~ GP out-of-44  
45  
46 529 hours service, and minimising the risk of patients living with undertreated cancer pain.47  
48  
49 530 **Conclusion**50  
51  
52 531 This study demonstrates a variable and unstructured approach to pain management53  
54  
55 532 affected multiple components of a patient's outpatient cancer care. We recommend56  
57 533 the need for a cancer pain management intervention that standardises pain

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4 534 assessments in oncology OS, which is implemented at the level of the service. This  
5  
6 535 will ensure each patient receives the same detailed evaluation of cancer pain and is  
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9 536 provided with a self-management strategy that facilitates pain management beyond  
10  
11 537 consultations.  
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17  
18 539 **List of abbreviations**

19  
20  
21 540 HCP – Healthcare Professionals

22  
23  
24 541 OS – Outpatient Services

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26  
27 542 CNS – Clinical Nurse Specialist

28  
29  
30 543 Upper GI - Upper Gastrointestinal tract

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32  
33 544 NHS – National Health Service

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35  
36 545 AV – Audio Visual

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44 547 **Declarations**

45  
46  
47 548 **Ethical approval and consent to participate**

48  
49  
50 549 Ethical approval was obtained by University of Leeds, Faculty of Medicine Research

51  
52  
53 550 Ethics Committee and Health Research Authority (21/HRA/5245). Approvals were

54  
55  
56 551 also obtained at each NHS trust.

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58  
59 552 **Consent for publication**

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2  
3  
4 553 Not applicable  
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6

7 554 **Availability of data and materials**  
8  
9

10 555 Not applicable  
11  
12

13 556 **Competing ~~interests~~interest's statement**  
14  
15

16 557 None declared.  
17  
18

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20  
21

22  
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24  
25

26 560 **Authors' contribution**  
27  
28

29  
30 561 MM is the chief investigator for this study; he conceived the project, led the design and  
31

32 562 writing of the study protocol, facilitated data analysis and drafting of this manuscript.  
33  
34

35 563 Methodology (OR, MM). Project administration (OR, MM).  
36  
37

38 564 OR wrote the study protocol, including drafting the topic guide, completed data  
39

40 565 curation, data collection and transcribed interviews. OR led the data analysis and  
41

42 566 interpretation of the data. Review of interpretation of the data and analysis was done  
43

44 567 by MM, SP, KF, SR, NC. OR wrote the first draft of the manuscript. Writing-review  
45

46 568 and editing (OR, MM, SR). All authors (OR, SP, KF, NC, MF, SR, CM, EB, DS, AH,  
47

48 569 SH, MM) contributed to manuscript revision, read and approved the submitted and  
49

50 570 revised version.  
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4 571 ~~MM is the chief investigator for this study; he conceived the project, led the design and~~  
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6 572 ~~writing of the study protocol, facilitated data analysis and drafting of this manuscript.~~  
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9 573 ~~OR facilitated the writing of the study protocol, including drafting the topic guide,~~  
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12 574 ~~completed data collection and transcribed interviews. OR led the data analysis~~  
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14 575 ~~facilitated by MM, SP, KF, SR, NC. OR wrote the first draft of the manuscript. All~~  
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17 576 ~~authors contributed to manuscript revision, read and approved the submitted version.~~

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30 580 NHS Trusts: Leeds Teaching Hospitals, Hull University Teaching Hospital, Sheffield

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33 581 University Teaching Hospital

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583 **References**

- 584 1. Cancer Research UK. Cancer Mortality Statistics. (2017-2019).
- 585 2. van den Beuken-van Everdingen MH, de Rijke JM, Kessels AG, Schouten HC, van Kleef M, Patijn  
586 J. Prevalence of pain in patients with cancer: a systematic review of the past 40 years. *Ann Oncol.*  
587 2007;18(9):1437-49.
- 588 3. Shen WC, Chen JS, Shao YY, Lee KD, Chiou TJ, Sung YC, et al. Impact of Undertreatment of  
589 Cancer Pain With Analgesic Drugs on Patient Outcomes: A Nationwide Survey of Outpatient Cancer  
590 Patient Care in Taiwan. *J Pain Symptom Manage.* 2017;54(1):55-65 e1.
- 591 4. Kroenke K, Zhong X, Theobald D, Wu J, Tu W, Carpenter JS. Somatic symptoms in patients with  
592 cancer experiencing pain or depression: prevalence, disability, and health care use. *Arch Intern Med.*  
593 2010;170(18):1686-94.
- 594 5. Wang HL, Kroenke K, Wu J, Tu W, Theobald D, Rawl SM. Cancer-related pain and disability: a  
595 longitudinal study. *J Pain Symptom Manage.* 2011;42(6):813-21.
- 596 6. Fallon M, Giusti R, Aielli F, Hoskin P, Rolke R, Sharma M, et al. Management of cancer pain in  
597 adult patients: ESMO Clinical Practice Guidelines. *Ann Oncol.* 2018.
- 598 7. Bennett MI. Mechanism-based cancer-pain therapy. *Pain.* 2017;158 Suppl 1:S74-s8.
- 599 8. World Health Organisation. WHO guidelines for the pharmacological and radiotherapeutic  
600 management of cancer pain in adults and adolescents. 2019.
- 601 9. Mulvey MR, Rolke R, Klepstad P, Caraceni A, Fallon M, Colvin L, et al. Confirming neuropathic  
602 pain in cancer patients: applying the NeuPSIG grading system in clinical practice and clinical research.  
603 *Pain.* 2014;155(5):859-63.
- 604 10. Adam R, Wassell P, Murchie P. Why do patients with cancer access out-of-hours primary care?  
605 A retrospective study. *Br J Gen Pract.* 2014;64(619):e99-104.
- 606 11. Fallon M, Walker J, Colvin L, Rodriguez A, Murray G, Sharpe M. Pain Management in Cancer  
607 Center Inpatients: A Cluster Randomized Trial to Evaluate a Systematic Integrated Approach-The  
608 Edinburgh Pain Assessment and Management Tool. *J Clin Oncol.* 2018;36(13):1284-90.
- 609 12. Bennett M, Sharma M. Cancer-related Pain. In: Weiss A, Taylor J, Searle R, editors. Core  
610 standards for pain management services in the UK. 2 ed. London: Faculty of pain medicine of the royal  
611 college of anaesthetists; 2021. p. 88-90.
- 612 13. Chapman EJ, Edwards Z, Boland JW, Maddocks M, Fettes L, Malia C, et al. Practice review:  
613 Evidence-based and effective management of pain in patients with advanced cancer. *Palliative*  
614 *medicine.* 2020;34(4):444-53.
- 615 14. Kasasbeh MAM, McCabe C, Payne S. Cancer-related pain management: A review of knowledge  
616 and attitudes of healthcare professionals. 2017;26(6):e12625.
- 617 15. Levell NJ. NHS outpatient secondary care: a time of challenges and opportunities. *Future*  
618 *healthcare journal.* 2022;9(2):106-12.
- 619 16. Graupner C, Breukink SO, Mul S, Claessens D, Slok AHM, Kimman ML. Patient-reported  
620 outcome measures in oncology: a qualitative study of the healthcare professional's perspective.  
621 *Supportive Care in Cancer.* 2021;29(9):5253-61.
- 622 17. Steven B, Lange L, Schulz H, Bleich C. Views of psycho-oncologists, physicians, and nurses on  
623 cancer care—A qualitative study. *PLOS ONE.* 2019;14(1):e0210325.
- 624 18. Braun V, Clarke, V. Thematic analysis: A practical guide. SAGE publications. 2021.
- 625 19. Ruben MA, van Osch M, Blanch-Hartigan D. Healthcare providers' accuracy in assessing  
626 patients' pain: A systematic review. *Patient Education and Counseling.* 2015;98(10):1197-206.
- 627 20. Marcotte LM, Kimmel-Morrison J, Liao JM. How to Keep Diffusion of Responsibility From  
628 Undermining Value-Based Care. *AMA journal of ethics.* 2020;22(9):E802-7.
- 629 21. Thestrup Hansen S, Kjerholt M, Friis Christensen S, Brodersen J, Hølge-Hazelton B. User  
630 experiences on implementation of patient reported outcome measures (PROMs) in a Haematological  
631 outpatient clinic. *Journal of Patient-Reported Outcomes.* 2020;4(1):87.

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2  
3 632 22. Bennett MI, Mulvey MR, Campling N, Latter S, Richardson A, Bekker HG, et al. Self-  
4 633 management toolkit and delivery strategy for end-of-life pain: the mixed-methods feasibility study.  
5 634 Health Technology Assessment Programme. 2017;21 (76).  
6 635 23. Buonanno P, Marra A, Iacovazzo C, Franco M, De Simone S. Telemedicine in Cancer Pain  
7 636 Management: A Systematic Review and Meta-Analysis of Randomized Controlled Trials. Pain  
8 637 Medicine. 2023;24(3):226-33.  
9 638 24. Alese OB, Zhang C, Zakka KM, Kim S, Wu C, Shaib W, et al. A cost analysis of managing cancer-  
10 639 related pain among hospitalized US cancer patients. 2020;38(15\_suppl):7079-  
11 640 25. Guven Ozdemir N. The Development of Nurses' Individualized Care Perceptions and Practices:  
12 641 Benner's Novice to Expert Model Perspective. 2019;12:2-1279.

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For peer review only

Dear Reviewers,

We would like to thank you for taking the time to provide feedback on the submitted manuscript. We hope we have adequately responded to your comments and adjusted the manuscript accordingly.

Comments from reviewers	Response to editor
<p>- Please complete a thorough proofread of the text and correct any spelling and grammar errors that you identify e.g. strengths and limitations section: "To our knowledge, this study is the first to qualitative study.." The 2nd bullet point of this section also needs to be split into two sentences.</p>	<p>A thorough proofread has been conducted on the paper. This has addressed the comments from the editor and reviewers related to spelling and grammar errors.</p>
<p>A study limitation not mentioned is that the entire sample were taken from Northern England. Perhaps other health systems in the UK or internationally may be different and therefore the findings may or may not be generalisable to other services.</p>	<p>An additional limitation has been added to strengths and limitations (pg. 16). This is to acknowledge we have used a sample from Northern England and the associated challenges with generalising the findings to other regional or international services.</p>
<p>Grammar - please check grammar throughout. 3 examples include the first dot point under strengths, on page 15 first line, and on page 19 line 50 - a patients' opportunity should read a patient's opportunity. There may be others so please give it a better review than what was done on submission.</p>	<p>A thorough proofread has been conducted on the paper. This has addressed the comments from the editor and reviewers related to spelling and grammar errors.</p>
<p>Abstract            Lines 28-33, p5: I am surprised that this is the first study to explore in depth pain as it is a cause of emergency presentations. I would suggest that the findings, were more descriptive than in depth.            Lines 49-54, p3: can you be more specific rather than a broad term of "our methodological approach"</p>	<p>P.2. Thank you for highlighting this, we have re-worded the abstract to reflect the descriptive nature of the study.            Lines 69-71. p.3 We have re-worded 'our methodological approach' to be more specific. This includes recognising our recruitment strategy (i.e. self-referral sampling) may have led to bias. This has also been incorporated into the strengths and limitations section (p.16).</p>
<p>Methods:            Generally, can you provide much more detail and granularity about the methods used.            Lines 52-55, p6: can you clarify how participants were identified in more detail            Lines 14-23, p 8: can you provide some further detail on PPI</p>	<p>Lines 132-138 p.56 Added more information about how participants were identified and recruited (i.e. co-applicants embedded within clinician teams emailed study information packs to entire clinical teams)            Lines 144-150 p.5. Added additional information that acknowledges how PPI were involved in the design and delivery of the study (i.e., providing feedback on study documents and processes).</p>

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<p>involvement. I.e., what aspects of design and delivery, how was their input sought and what were their priorities/recommendations.</p> <p>I note later that they referred to additional file 1 – unfortunately I could not see this document, but maybe provide a summary in a text box or similar within the main document</p> <p>17-25, p10: “shared with wider team and PPI to develop review and refine themes” please provide more detail on what is meant by this, how it was done, what was their input and how did they contribute to the final outcome</p>	<p>A supplementary file (Topic guide) was uploaded at the time of submission. We apologise reviewer 2 was unable to see this, we will upload it again.</p> <p>Line 174-176 p6 Provided more detailed information about the refinement and development of themes (i.e., having data analysis meetings to discuss themes and sub-themes)</p>
<p>Results: The themes and sub-themes table was not clear - please consider a different format to the table and lay terms/language</p>	<p>We have edited the layout and content of Table 2 to make the presentation clearer.</p>
<p>Discussion:  Generally, more attention is needed to highlight the complex nature of pain, and, the tension that comes from many competing priorities of HCPs in a busy outpatient unit</p> <p>lines 38-41, p24, “Implementation of a structured pain assessment used by all HCPs ensure all patients receive a consistent thorough assessment of pain” – this is a broad statement about a very complex phenomenon</p>	<p>Line 79-84 P.3 We have added a paragraph into the introduction describing the complex nature of cancer pain pathophysiology and the challenging clinical environment in outpatient departments.</p> <p>Line 374-381. P.15. Agreed. We have re-written this paragraph and provided a supporting reference. The paragraph’s focus was on the concept of ‘diffusion of responsibility in a clinical setting of shared accountability’. We hope our re-write of this paragraph has made this concept clearer.</p>