



# Information and communication technology for managing pain in palliative care: a review of the literature

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## ABSTRACT

**Background** Information and communication technology (ICT) systems are being developed for electronic symptom reporting across different stages of the cancer trajectory with research in palliative care at an early stage.

**Aim/design** This paper presents the first systematic search of the literature to review existing ICT systems intended to support management of pain in palliative care patients with cancer. The review was conducted according to Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines for systematic reviews and meta-analyses.

**Data sources** Four databases (Embase, MEDLINE, PsycINFO and Healthcare Management Information Consortium) from 1990 to December 2012 were searched, with exclusion of papers based on their description of ICT systems and language used.

**Results** 24 articles met the inclusion criteria, many of which reported the use of non-experimental research designs. Studies were identified at different stages of development with no systems having reached implementation. Most systems captured pain as part of quality-of-life measurement with wide variation in approaches to pain assessment.

**Conclusions** ICT systems for symptom reporting are emerging in the palliative care context. Future development of ICT systems need to increase the quality and scale of development work, consider how recommendations for pain measurement can be integrated and explore how to effectively use system feedback with patients.

## INTRODUCTION

Information and communication technology (ICT) includes all digital technologies that facilitate the electronic capture,

processing, storage and exchange of information.<sup>1</sup> The application of ICT in healthcare settings in the UK has been highlighted as a means of improving patient outcomes<sup>2</sup> and ensuring that patients receive high-quality care.<sup>3</sup> Electronic systems have been developed that use ICT to facilitate the capture of clinical data directly from patients, with early indications of patient acceptance of this approach.<sup>4</sup>

While systems are being developed to support different stages of the illness trajectory in cancer, the use of ICT to capture clinical data specifically in palliative care is at an early stage.<sup>5</sup> Patients engaged with palliative care experience multiple physical symptoms,<sup>6</sup> which affect their quality-of-life and psychological well-being.<sup>7</sup> Pain is reported by 64% of patients with advanced cancer,<sup>6, 8</sup> but undertreatment is common.<sup>9</sup> Frequently cited barriers to adequate pain management include knowledge deficits, inadequate pain assessment and misconceptions regarding pain.<sup>10</sup> The use of ICT could be seen as an approach to address pain management barriers by facilitating greater communication between patients and health professionals contributing to the delivery of palliative care.<sup>11</sup> There is scope for the development and implementation of online palliative care symptom reporting systems in which such timeliness and methods of communication can be explored, with exciting opportunities for future development.<sup>12</sup>

This paper presents a systematic search of the literature to review existing ICT systems intended to support management

of pain in palliative care patients with cancer. The identification of implemented systems or those under development to support pain reporting by palliative care patients will indicate the status of system development at present and inform future work to improve palliative pain management using ICT systems. Rather than seeking to review the benefits of ICT systems and the quality of their effectiveness on implementation, this paper seeks to outline their structure. Palliative care has been acknowledged as posing its own specific challenges to systematic review methods, with an evidence base largely unsuitable for traditional forms of review and synthesis.<sup>13</sup> The approach taken by the current review is to better understand the types of available systems through a descriptive analysis, rather than providing an assessment of the levels of quality or bias of available evidence.

## METHOD

A systematic review of qualitative and quantitative literature was undertaken to identify the function and structure of existing ICT systems used in the management of pain in palliative care patients. This review takes a broad search of ICT systems used in patients with cancer with interpretation of findings orientated towards understanding the use of ICT systems in palliative care. The review was undertaken in five stages: (1) development of search strategy; (2) generation of inclusion and exclusion criteria; (3) assessment of relevance; (4) data extraction and tabulation; and (5) overview of system characteristics and descriptive analysis.

### Search strategy

The search strategy was compiled to identify published reports of ICT systems for pain management. MeSH headings and keywords were identified (as outlined in online supplementary appendix A) and relevant databases were selected and searched in consultation with a healthcare information specialist based at the University of Leeds. The databases Embase, MEDLINE, PsycINFO and Healthcare Management Information Consortium were searched for literature published between 1990 and December 2012. The following journals were hand searched for relevant articles: *Journal of Pain and Symptom Management*, *Supportive Care in Cancer*, *European Journal of Pain* and *BMJ Supportive & Palliative Care*. Potentially relevant references from bibliographies and citation indices were identified and abstracts assessed against selection criteria. The literature search was carried out during December 2012.

### Inclusion and exclusion criteria

Inclusion criteria were developed through consensus by the research team. To be included articles had to describe the use of ICT in the management of pain in patients with cancer. The term ICT was chosen

intentionally as a broad term applying to a wide range of technology use in healthcare to allow capture of existing systems documented in published literature. Management in the current search refers to the identification, assessment or monitoring of pain in patients with cancer. To be considered a management tool, the ICT system must capture information generated by patients, which is shared, reviewed or assessed by a health professional.

Papers were excluded that (i) provide no description of system structure and content; (ii) describe systems that were not designed for, or used by, patients with cancer pain; and (iii) discuss cancer pain, but not involving the use of ICT in pain management. Due to resource limits, it was intended that non-English articles be removed during the assessment of article relevance.

### Study selection

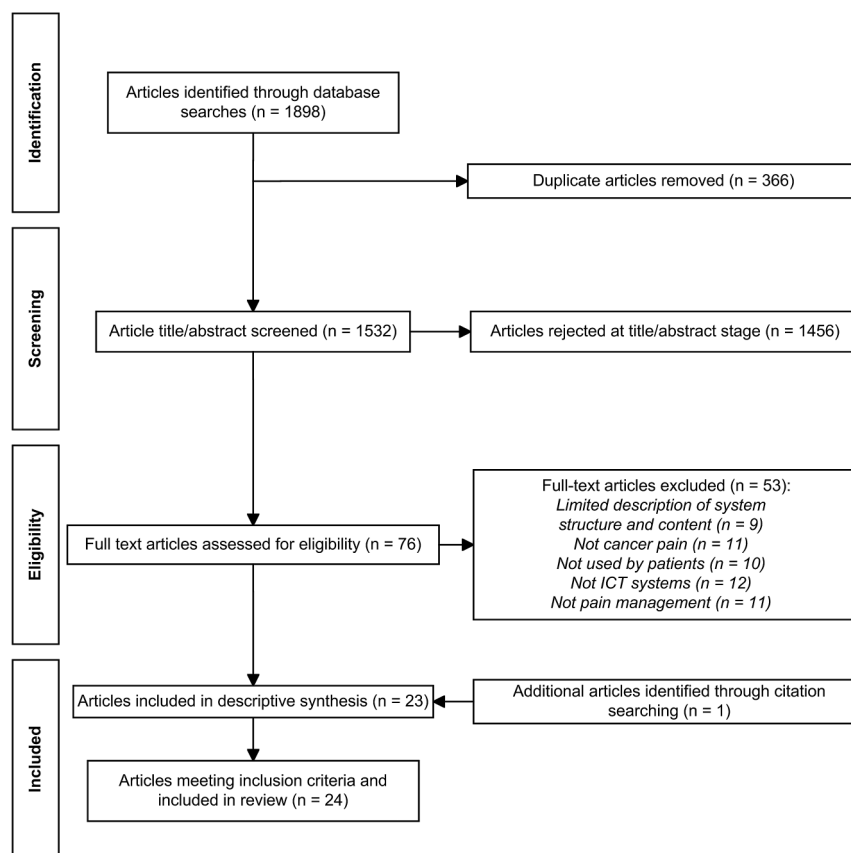
Titles and abstracts were screened for relevant articles, for which full-text reports were sought. Full-text reports were assessed against the inclusion/exclusion criteria to identify eligible reports for the descriptive analysis. Details of the study identification and selection process are shown in the flowchart in figure 1, developed using Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines.<sup>14</sup>

### Data extraction, appraisal and synthesis

Data were extracted by MJA (lead author) into a tabulated form (see online supplementary appendix B) and checked by a second reviewer. Data were extracted from full-text reports meeting the inclusion criteria. To describe the stage of system development, the human-centred systems development methodology<sup>15</sup> was used for categorising identified studies. This methodology comprises (i) planning and project selection, (ii) analysis, (iii) design and (iv) implementation. *Planning and project selection* refers to defining the problem and considering possible solutions. *Analysis* relates to examination of patient expectations and requirements for a proposed system, including early usability work. The *design stage* involves testing systems with patients and evaluating ease of use and preferences for layout. The *implementation stage* refers to an evaluative component of development and as such is referred to as the *evaluation stage* in the article, which includes pilot studies using a system in clinical practice (eg, in cancer centres) and summative evaluations of patient experience of using systems as part of their care.

## RESULTS

The search identified 1898 citations initially, of which 24 articles met the inclusion criteria (see figure 1). A large proportion of studies were rejected following title and abstract screening (n=1456). As shown in figure 1, several full-text sources (n=76) were



**Figure 1** Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram of articles identified for use in the review.

examined, from which  $n=53$  studies were excluded. Reasons for exclusion of full-text sources included not focusing on cancer pain, discussion of systems that were not designed for communication of pain data (eg, virtual reality simulators) and systems that did not involve any interaction with a patient. Our assessment of titles and abstracts identified no non-English papers that met the inclusion criteria. Online supplementary appendix B contains an overview of all included papers and outlines the various ICT systems described. The descriptive analysis of included articles is organised into three categories: (i) study design, location and population; (ii) system design and development; and (iii) communication facilitation.

### Study design, location and population

#### Study design

Of the 24 included studies, 7 unique study designs were described: randomised experiment,<sup>16–19</sup> non-randomised experiment,<sup>5</sup> observational,<sup>20</sup> survey design,<sup>21–22</sup> system description,<sup>23–24</sup> expert opinion<sup>25</sup> and a non-specified non-experimental study design.<sup>26–38</sup> The largest proportion of included papers used a non-specified non-experimental study design,<sup>34–46</sup> including reports of patients completing usability evaluations or providing feedback on specific system features

using a range of methods including qualitative interviews and descriptive evaluation.

#### Location of system

Of the 24 included studies, 17 independent systems were identified. As shown in table 1, the majority of systems ( $n=10$ ) were identified from research that was conducted in the USA.<sup>16–19 22–24 26–28 30 31 36–38</sup> Other countries in which systems were identified include Sweden,<sup>33–35</sup> the UK,<sup>25 32</sup> Austria,<sup>20</sup> Germany,<sup>21</sup> Japan<sup>29</sup> and Norway.<sup>5</sup>

#### Target population for system

Of the 24 included studies, the target population or intended users of systems were oncology patients,<sup>18 22 26 28–30 36</sup> palliative home care patients,<sup>33–35</sup> oncology outpatients,<sup>27 37</sup> hospice and palliative care patients,<sup>24 31</sup> patients undergoing palliative radiotherapy,<sup>17 25</sup> a mix of palliative care patients, carers and health professionals,<sup>23</sup> brain tumour outpatients,<sup>20</sup> patients requiring surgery for cancer,<sup>16</sup> patients with cancer with incurable metastatic or locally advanced disease,<sup>5</sup> patients receiving chemotherapy for cancer,<sup>32</sup> breast cancer survivors,<sup>21</sup> patients with cancer with depression and/or pain,<sup>19</sup> and a mix of members of the public with pain and people with cancer pain.<sup>38</sup>

**Table 1** Countries from which the identified papers originate

Country	Reference	System name	Number of articles	Systems identified
USA	17	INCPAD	15	10
	18	INCPAD		
	19	INCPAD		
	22	PACE System		
	26	PACE system		
	36	PACE system		
	30	PAINReportIt and PAINConsultN		
	38	PAINReportIt & PAINConsultN		
	23	SIAM-PC		
	37	SymptomReport and SymptomConsult		
	24	Tell Us		
	16	No name 1		
	27	No name 2		
	28	No name 3		
	31	No name 4		
Sweden	33	Anoto Technology	3	1
	34	Anoto Technology		
	35	Anoto Technology		
UK	25	HealthHUB and CareHUB	2	2
	32	ASyMS		
Austria	20	No name 6	1	1
Germany	21	No name 7	1	1
Japan	29	No name 8	1	1
Norway	5	EPCRC-CSA	1	1
Total			24	17

INCPAD, Indiana Cancer Pain and Depression; PACE, Patient Assessment, Care and Education; SIAM-PC, System for Interactive Assessment and Management in Palliative Care.

#### Sample population

Fifteen of the twenty-four included studies recruited patients with cancer only.<sup>5 16–21 26–30 34 35 37</sup> The

remaining articles recruited mixed groups of health professionals and patients,<sup>22 31 32</sup> health professionals only,<sup>33 36</sup> patients with cancer and the general public,<sup>16</sup> and clinicians.<sup>25</sup> In the two studies that provided overviews of new and emerging systems, no research participants were involved.<sup>23 24</sup>

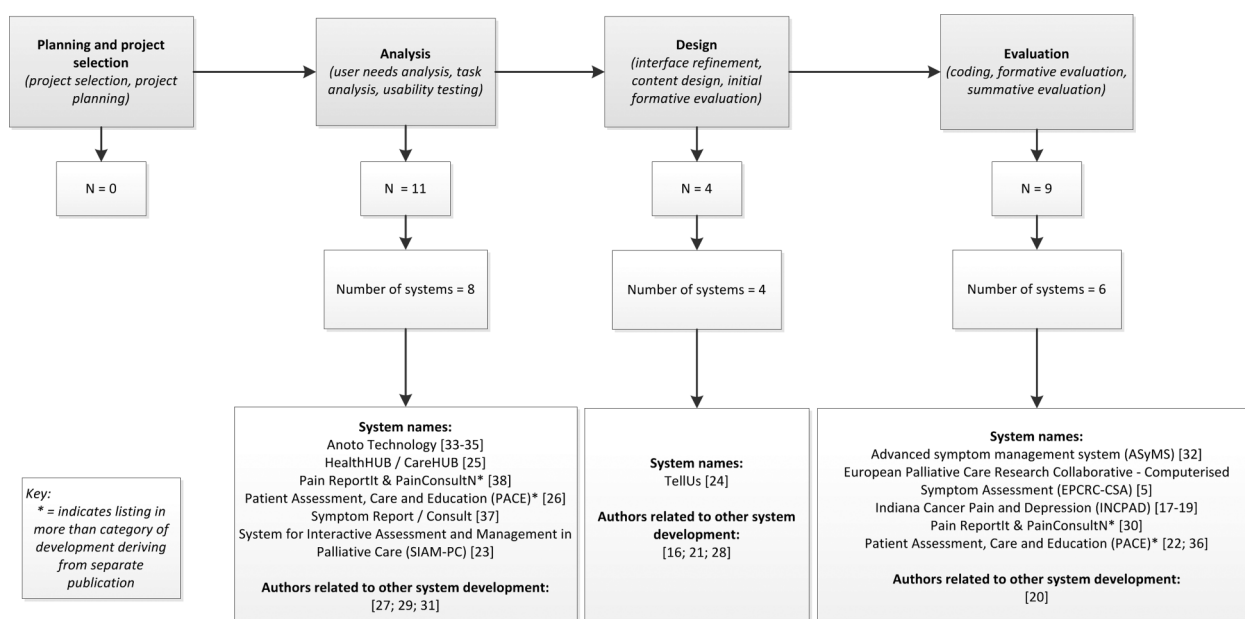
#### System design and development

Figure 2 outlines the classification of included articles in the stages of system development. Of the 24 included studies, no papers discussed the planning stages of systems, 11 studies detail systems in the analysis stage,<sup>23 25–27 29 31 33–35 37 38</sup> 4 studies described the design stage<sup>16 21 24 28</sup> and 9 studies described the evaluation stage.<sup>5 17–20 22 30 32 36</sup> Only two systems, from across five articles,<sup>22 26 30 36 38</sup> are represented at more than one stage of development, classified in both analysis and evaluation stages. There are a number of systems (n=4) in the evaluation category that do not have representation in earlier categories.

#### System focus and the measurement of pain

The focus of systems differed across the 24 included studies. Six studies documented systems that focused on the capture of pain information only,<sup>21 30 33–35 38</sup> while three systems considered the management of pain and depression together as part of a collaborative care approach.<sup>17–19</sup> The remaining 15 studies outlined systems that considered pain amid a wider range of symptoms in the context of quality-of-life measurement.<sup>5 16 20 22–29 31 32 36 37</sup>

A variety of measures to capture pain information were incorporated into systems described in the included articles as outlined in table 2. Systems only considering pain incorporated the McGill Pain Questionnaire,<sup>30 38</sup> bespoke visual analogue scales



**Figure 2** Stage of development for systems outlined in included articles.

**Table 2** Overview of tools used for pain measurement in the identified systems

System focus	Reference	Measure(s) used to capture pain reports from a patient
Pain	30	Computerised extension of the MPQ
	21	Areas of pain and no pain were digitised into a summation image of a female torso, with blackened areas indicating pain areas and white indicating no pain
	33	A pain diary form consisting of a VAS (0–100 mm) for pain intensity and boxes for the number of consumed extra doses of analgesics
	34	<i>Not described in paper</i>
	35	The pain diary included a unidimensional tool for assessment of pain intensity using a 100 mm VAS where the scale was anchored by the words 'No pain' (VAS 0 mm) and 'Severe pain' (VAS 100 mm). It also included a question about consumed extra doses of analgesics
Pain and depression	38	Computerised extension of the MPQ and 16 additional items: two items related to the body outline, three 0–10 items related to current pain, least pain and worst pain intensity, three items measuring goals for pain levels and amount of time pain greater than tolerable level, one item measuring patient satisfaction with pain level, and one item addressing a range of concepts (expectations about the pain, effectiveness of previous pain treatments, pain medication treatment pattern, non-drug treatments used for pain, tendency to tell or not tell others about the pain, onset of pain and beliefs about the cause of the pain)
	18	7 core items, 2 items from PHQ-9, average pain from BPI, single items about global improvement, medication adherence, side effects and whether a call from a nurse was required. Additional BPI questions were included for patients with pain, and additional PHQ-9 questions for those with depression
	19	As above
	17	As above
Quality-of-life	26	86 items, reflecting common cancer-related and treatment-related symptoms, including pain
	27	An 11-point (0–10) pain-intensity numerical scale as an additional item
	23	<i>Not described in paper</i>
	16	MDASI, a brief, validated measure of 13 common cancer-related symptoms over the previous 24 h. Each symptom is rated on an 11-point scale, with 0 being 'not present' and 10 being 'as bad as you can imagine'
	25	ESAS to be completed daily and the EQ-5D weekly
	24	Symptom-specific questions, including an 11-point scale for reporting pain level
	20	QOL assessment EORTC QLQ-C30 and the EORTC BN20
	28	EORTC QLQ-C30
	29	Intensity of symptoms (pain, fatigue, nausea, anxiety, depression and drowsiness) rated using a 0 to 100 VAS
	5	ESAS, EORTC QLQ-C30, screening item about pain intensity at its worst in the last 24 h (taken from BPI), 15 items on physical function, PHQ-9, two questions from the SGA, five questions related to need for assistance, patients' opinions on time expenditure and preferences for computerised vs paper and pencil-based assessment, and a computerised pain body map.
	31	Visual display of relevant information from multiple sources can be captured including PRO assessments, patient history and notes
	32	Aches and pain captured as part of C-SAS
	36	A patient-reported symptom severity screening scale that generates a real-time, point-of-care report. Contains 38 items that produce scores for individual patient-reported problems
	22	As above
	37	An electronic version of the 1970 edition of the MPQ, a pain barriers questionnaire and the SCFS-6

BPI, Brief Pain Inventory; C-SAS, Chemotherapy Symptom Assessment Scale; EORTC BN20, European Organisation for Research and Treatment of Cancer brain cancer module; EORTC QLQ-C30, European Organisation for Research and Treatment of Cancer Quality-of-Life Questionnaire; EQ-5D, EuroQol European Quality-of-Life-5 Dimensions; ESAS, Edmonton Symptom Assessment Scale; MDASI, M.D. Anderson Symptom Inventory; MPQ, McGill Pain Questionnaire; PHQ-9, Brief Patient Health Questionnaire for depression; PRO, patient-reported outcome; SCFS-6, Schwartz cancer fatigue scale; SGA, Subjective Global Assessment of Nutritional Intake; VAS, Visual analogue scale.

asking patients to measure pain intensity<sup>35</sup> and presentation of visual images of an affected region of the body for patients to indicate the location of pain.<sup>21</sup> Papers outlining a system for capturing pain and depression<sup>18 19</sup> comprised a mix of items taken from the PHQ-9<sup>39</sup> depression scale, Brief Pain Inventory (BPI)<sup>40</sup> and single questions addressing medication adherence, adverse effects, global improvement and whether the patient wanted to be contacted by a nurse.

Systems measuring pain as part of a wider collection of symptoms used a variety of existing and bespoke symptom and quality-of-life measurement tools. The C-SAS,<sup>41</sup> EORTC QLQ-C30,<sup>42</sup> EORTC BN20,<sup>43</sup> EQ-5D,<sup>44</sup> ESAS,<sup>45</sup> MDASI,<sup>46</sup> SCFS-6,<sup>47</sup> and SGA,<sup>48</sup> are among measures used alone or in combination with other measures in the identified systems. Systems

measuring pain as part of a wider collection of symptoms also used numerical scales and five-point response items to capture pain intensity or the impact of cancer on components such as sexual interest and function. No consistency in the use of measures for capturing pain reports from patients was evident, and there was variation in the compilation and presentation of measures of pain across all systems independent of the system focus.

#### Communication facilitation

As shown in table 3, of the 24 included studies, the intended location of use of systems for patients varied between waiting room (n=12), home setting (n=8) and remote use in the community (n=4). Systems intended for use in the waiting room capture and collate information for review by a health



professional, typically prior to consultation. Where the intended location for patients is the home setting,<sup>16 23 25 29 32–35</sup> ICT systems add to an existing dialogue about pain or its changing nature. Systems in this category typically involve the monitoring of pain symptoms, either actively by nursing staff or through thresholds that generate alerts to health professionals when patient scores are reported outside of a pre-determined acceptable range. Systems intended for remote use by patients<sup>17–19 24</sup> provide flexibility in ways to report pain using web-based systems alongside automated or patient-initiated symptom reporting via landline or computer. One system<sup>24</sup> was specifically designed for use with hospice and palliative care patients to accommodate a situation where patient status may change rapidly and/or need regular monitoring.

### System feedback

Systems described in the included studies facilitated two forms of communication: patient to health professional (n=15) (where a patient enters data that are sent directly to a health professional without receiving feedback),<sup>5 16 18–23 26 27 29 31 33 35 36</sup> and feedback of information presented to patient and health professional following patient entry of information (n=8).<sup>17 24 25 28 30 32 34 37</sup> One paper<sup>38</sup> did not report on the feedback provided by the system.

Systems facilitating patient to health professional communication<sup>5 16 18–23 26 27 29 31 33 35 36</sup> did not create any additional dialogue between these two groups. Systems informed or alerted health professionals to the experience of pain in a patient, which may be used to impact on decision making regarding pain management. This feedback provided only to the health professional was in the form of patient score summaries that could be printed, quality-of-life profiles showing longitudinal charts or graphical summaries for patients, and summation pictures of areas where pain is reported. The modes of technology that were used to capture data from patients for this purpose included landline and mobile telephone, and handheld devices (such as tablet computers).

Systems providing feedback to patients and health professionals (n=8) provided different forms of output for each group. For patients, these systems

reported one or more of the following types of feedback:

1. specific self-care advice when symptoms are reported out of a predefined range
2. graphical display of scores over time
3. tailored educational materials relating to symptoms
4. personalised feedback from a nurse (via phone or online)

A combination of these types of feedback was present in one system,<sup>24</sup> which provided presentations of scores over time and tailored educational materials. For health professionals, the types of information provided through this category of system are similar to those providing information from a patient to a health professional only. For example, patient scores can be printed out and reviewed by a health professional or used during a consultation with a patient. Additional features were also identified in this category of systems, with the use of predefined ranges set to prompt email alerts. One system<sup>20</sup> used the information reported by a patient to produce summaries of pain data and an evidence-based treatment plan to support clinical management decisions.

### DISCUSSION

This review has found that few ICT systems for pain reporting in palliative care patients are evaluated in the context of experimental research and no systems are reported to be implemented in clinical practice. Over half of the articles reviewed describe systems that were in the early stages of design and provided little detail on the overall development approach being taken. When identifying how ICT systems facilitate pain management, it was found that most ICT systems conduct pain assessment in the context of wider quality-of-life measurement in patients with cancer. A focus only on pain symptoms was seen in a small proportion of the included ICT systems, where reports were collected directly from the patient for use by a health professional with no feedback provided to the patient. The possibilities of feedback that can be generated by ICT systems have only begun to be explored with patients and health professionals with a small number of systems.

ICT system development is an emerging area of research in healthcare that may reflect the low numbers of systems identified across the stages of

**Table 3** The location for systems to be used by patients and health professionals in the identified articles (numbers correspond to study number in online supplementary appendix B)

		Location for patient		
		Clinic waiting room	Home setting	Remote use in community
Location for Health Professional	Clinical environment	(n=12) <sup>5 20–22 25 26 28 30 31 37 38 48</sup>	(n=5) <sup>25 32–35</sup>	(n=4) <sup>17–19 24</sup>
	Remotely (eg, web-based systems)	No articles	(n=2) <sup>16 23</sup>	No articles
	No setting defined	No articles	(n=1) <sup>29</sup>	No articles

system development. This is highlighted through the generally low quality of development research found in symptom-reporting systems.<sup>49</sup> Concerns have been raised about the use of technologies in cancer care when implementation occurs prior to established clinical efficacy or use.<sup>50</sup> Encouraging structured development of ICT systems with continued dissemination of findings is a strategy that can support high-quality research generation across all areas of application in healthcare.

Many systems identified in this review were designed to capture information from a patient for use by a healthcare professional in a clinical setting, with a patient relaying symptom reports without engaging in active forms of communication. Although cancer symptom reporting tends to occur inside healthcare institutions,<sup>51</sup> the unidirectional provision of pain reports to a health professional (via ICT systems) ignores the benefits to both parties (particularly the patient) that could derive from feedback or tailored support in response to data entered into an ICT system. Although feedback was provided by some of the systems identified here, there is now a clear need for future research to explore how ICT system feedback can be used to improve pain management in palliative care.

The lack of consistency in pain measures identified in ICT systems may impact on the assessment and management of patients in palliative care. When used in palliative care, pain assessment tools can include dimensions and items of limited relevance for patients with advanced cancer.<sup>52</sup> This can negatively influence patients, such as reducing compliance to assessment, and should be considered to ensure clinical relevance of selected tools and measures. Well-validated, multidimensional assessment tools such as the BPI<sup>43</sup> and McGill Short Form Questionnaire<sup>53</sup> have been suggested for use in capturing the experience of pain.<sup>54</sup>

A descriptive analysis of the literature was chosen as a tool for understanding the current state of ICT system development in the literature to inform thinking for future areas of research and development. The scope of systems included in the review was limited to systems reported in research literature. Inclusion of systems was reliant on developers and researchers disseminating the design processes of an ICT system in the research literature. In order to counter this limitation, the search strategy was broadened to include all cancer not just advanced cancer (ie, palliative care). The strength of this is that we are likely to have broadened the search and captured a greater number of ICT systems, but not all included systems have been developed and validated in palliative sample populations that may not accurately reflected our target population (palliative care patients with advanced cancer and pain) in terms of their needs, experiences and symptom profiles.

The use of ICT systems presents an approach to improving the management of pain in palliative care patients with cancer. This is the first review of ICT systems used to manage pain in palliative care. A number of systems were identified in this systematic review of the literature, with systems focusing specifically on pain alongside those capturing more varied measures of quality-of-life. Future ICT system development needs to consider the palliative care context closely to assess how existing and emerging systems can be integrated effectively. ICT systems in palliative care need to increase the quality and scale of development work, adhere to recommended pain measure use and consider how to effectively use feedback to patients. If achieved, ICT system development in palliative care promises a platform on which patients and health professionals can engage in an efficient and meaningful dialogue to improve the management of pain.

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## **APPENDIX A – SEARCH TERMS**

### **MeSH terms used (Medline terms used as an example)**

#### **Technology:**

Technology, Telemedicine, Computing Methodologies, Information Services, Medical Informatics Applications, Medical Records Systems Computerized, Patient Identification Systems

#### **Cancer Pain:**

Neoplasm, Pain, Analgesics

#### **Management:**

Pain Measurement, Pain Management, Drug Therapy

### **Keyword combinations**

#### **Technology:**

Technolog\* OR information system\* OR medical record\* OR patient system\* OR (telemedicine or telehealth) OR (ict or information communication technolog\*) OR (remote communication\* OR remote consultation\*) OR (ehealth OR e-health) OR (internet OR email OR www OR world wide web OR virtual OR web site OR website) OR (e-learning OR elearning OR telecommunicat\*)

#### **Cancer Pain:**

(neoplasm\* OR cancer\* OR carcino\* OR malignan\* OR tumor\* OR tumour\*) OR pain OR breakthrough pain OR acute Pain OR Analgesic\* OR Opioid\*

#### **Management:**

Monitoring OR management OR support

## APPENDIX B – OVERVIEW OF INCLUDED ARTICLES

Reference	System name	Country	Target Population	Study Sample Population	Study Design	Goal of System	Aim of article	Mode(s) of technology used to gather patient data	Content of patient system	Information provided to patient	Information provided to health professional	Symptom focus
[26]	PACE (Patient Assessment Care and Education) System	USA	Oncology patients	73 breast cancer patients, referred by their oncologists	Non-experimental design	Gather patient reported demographics, illness, symptoms, performance status, and QOL data	Determine the feasibility and acceptability of tablet computers as a method for delivering standard validated assessment instruments, and for gathering symptom and QOL data directly from patients in the academic setting	A tablet computer (a notebook-and-pen-style personal computer on which the patient answers a set of predefined questions)	86 items, reflecting common cancer- and treatment-related symptoms (e.g., fatigue, nausea, weight loss, rash), psychological concerns (e.g., feeling helpless, feeling guilty), functional concerns (e.g., bathing, dressing, running, driving), and social concerns (e.g., attending social activities, performing a paid job). Responses are scored on 11-point scales anchored at 0 ("not a problem") and 10 ("as bad as possible"), and referenced to the past week	Once the patient completed all electronic surveys, she was able to browse the Cancer Support Network educational library available on PACE	A report is generated and printed at a clinician's workstation, reflecting the patient's symptoms, psychological distress, QOL, and performance status. This presents an individual patient's responses from the most recent four surveys. It is color-coded so that the oncologist can quickly identify trends of worsening or improving problems and symptom severity	Range of cancer-related symptoms (including pain)
[27]	<i>No name</i>	USA	Outpatients from oncology radiotherapy who were newly evaluated for radiation therapy	101 outpatients who were newly evaluated for radiation therapy	Non-experimental design	Computerise QOL and symptom assessment in an outpatient clinical cancer setting	Report on development and testing of an innovative computerised symptom and QOL assessment for patients with cancer who are evaluated for and treated with radiation therapy	Web application with software that runs on a secure, centrally located server that can be accessed by any Internet-enabled computer	SF-8, a short-form, multipurpose health survey developed by Ware (2000) based on work with the SF-36 and SF-12. SDS, a 13-item, cancer-specific symptom assessment. Three additional items included an 11-point (0–10) pain-intensity numerical scale and two 5-point response items related to fever and chills and the impact of cancer on sexual interest and function.	The application provides a Web-based graphic user interface for the patient and survey assistant. No output for the patient is described.	A paper report for the clinician to review prior to or during the visit by a patient. The software can also for clinical reporting and research use.	Range of cancer-related symptoms (including pain)
[23]	SIAM-PC (System for Interactive Assessment and Management in Palliative Care)	USA	Palliative care patients, carers and health professionals	<i>No patients</i>	Description and overview of a new system	To assess and support management in palliative care	Describe the SIAM-PC system	Mobile or fixed telecommunication technologies (including telephone, computer and handheld device)	A computerized adaptive testing component that administers tailored assessments. The system can be used by multiple users (patients, caregivers).	Medical guidance based on their responses.	Patient scores from an array of measures (e.g., QOL domains) are calculated and paired to other clinical and demographic characteristics. There is also a clinical decision support system that aids clinicians in making diagnostic and therapeutic decisions in patient care. Data can also be used for research and audit.	Range of cancer-related symptoms (including pain)
[25]	HealthHUB and CareHUB	UK	Patients receiving palliative radiotherapy for lung cancer	13 clinicians, 0 patients	Expert opinion / consensus	To use e-technology as an assessment and monitoring tool in palliative care in the UK	This study had two aims: (1) to test and evaluate the support provided to patients by the computerised assessment tool (the HealthHUB); and (2) to determine the clinical acceptability of the technology in a palliative care setting.	Landline in patient home	ESAS to be completed daily and the EQ-5D weekly	HealthHUB (patient system) offers the patient and their carer/s instant advice specific to their symptom reports and if their scores fall outside a predetermined range. It also contains an information bureau that synthesises comprehensive information on the symptoms associated with lung cancer. Individualized emergency contact information is also provided.	The patient's information is sent to the CareHUB (health professional system). The information should be monitored on a daily basis to ensure a prompt response to symptom needs. Alerts are sent to CareHUB if patient symptom scores fall outside a predetermined range	Range of cancer-related symptoms (including pain)

Reference	System name	Country	Target Population	Study Sample Population	Study Design	Goal of System	Aim of article	Mode(s) of technology used to gather patient data	Content of patient system	Information provided to patient	Information provided to health professional	Symptom focus
[24]	Tell Us	USA	Hospice and palliative care patients	No participants	System Description - Overview of a new system	Web-based tool to collect symptoms and additional data to provide feedback to hospice and palliative care patients, caregivers, and health professionals.	Describe the structure and development of the Tell Us system.	<p>The system is accessed via a web browser.</p> <p>Permits patients to enter data on a scheduled basis and providers to view cumulative patient data and receive programmable automated e-mail notifications.</p>	Tell Us includes modules to enrol clinical and research sites, as well as individual patients, and to author and deploy clinical assessments. Accessed through web browser providing.	Targeted educational materials linked to domains in the assessment and a module for patients and family caregivers to use on a scheduled basis to enter data and comments.	E-mail alerts and summary information at the patient or designated population level. The alert e-mail provides information about the patient, the reason for the alert, and patient or caregiver comments and provides a link to Tell Us that provides one click to login. The system also enables health professionals to analyse patient data, author and deploy clinical assessments, and enrol new patients.	Range of cancer-related symptoms (including pain)
[20]	<i>No name</i>	Austria	Brain tumour outpatients in routine clinical practice	110 patients with primary brain tumours	Observational study	Computer-based QOL monitoring tool	Report on the implementation of a computer-based QOL monitoring tool in a neurooncology outpatient unit	Questionnaire presented on a personal computer (PC) to patients in the waiting room while they are waiting for their examinations at a neurooncology outpatient unit	QOL assessment EORTC QLQ-C30 and the EORTC BN20	No information provided to patient	Uses Computer-Based Data Assessment and Evaluation software that presents scales as bar charts, together with reference lines indicating certain percentiles. A flag system marks those patients potentially in need of further medical and/or psycho-oncologic interventions.	Range of cancer-related symptoms (including pain)
[28]	<i>No name</i>	USA	Oncology patients	Usability testing: 1) User-testing on seven men aged 56 – 77 years with prostate cancer; 2) ease of use survey conducted with 60 patients with breast, gastrointestinal, or prostate cancer.	Non-experimental design	To collect quality of life and symptom information from patients with cancer	To report on usability testing of system by patients	A tablet is used by patients with touch-display screen. Questionnaires are displayed as webpages.	EORTC QLQ-C30	Information provided to patient not discussed in the article	Information provided to the health professional not discussed in the article	Range of cancer-related symptoms (including pain)
[29]	<i>No name</i>	Japan	Oncology patients	22 patients (4 patients in phase 1 and 16 patients in phase 2)	Non-experimental design	To act as an electronic diary to collect symptoms in patients with cancer in natural settings to record symptoms at the time of acute exacerbation in addition to regularly scheduled assessments	To develop a PDA system to collect information on symptoms such as pain and mood states in patients with cancer	Sharp Zaurus Model SL-C1000 handheld PDA, using stylus for inputting responses (but a finger can also be used)	Intensity of symptoms (pain, fatigue, nausea, anxiety, depression, and drowsiness) rated using a 0 to 100 VAS. Regular assessments at the sound of an alarm, and asked to complete an entry each time 'rescue medication' was used.	Information provided to patient not discussed in the article	Information provided to the health professional not discussed in the article	Range of cancer-related symptoms (including pain)



Reference	System name	Country	Target Population	Study Sample Population	Study Design	Goal of System	Aim of article	Mode(s) of technology used to gather patient data	Content of patient system	Information provided to patient	Information provided to health professional	Symptom focus
[5]	EPCRC-CSA	Norway	Cancer patients with incurable metastatic or locally advanced disease	965 patients with incurable metastatic or locally advanced disease	Experimental Study without randomisation : Post-trial examination of the EPCRC-CSA tool feasibility	To support patients with advanced cancer in self-reporting of symptoms and other PROs	To identify factors associated with discontinuation, time expenditure, and patient preferences of the computerized symptom assessment used in an international multicentre data collection project	Touch sensitive computers (HP Compaq TC4200L 1200 tablet PCs)	ESAS, EORTC QLQ-C30, screening item about pain intensity (PI) at its worst in the last 24 hours (taken from BPI), 15 items on physical function, PHQ-9, two questions from the SGA, five questions related to need for assistance, patients' opinions on time expenditure, and preferences for computerized vs. paper and pencil-based assessment. A computerised pain body map was also included.	Different paths were automatically selected by the computer based on the patients' responses to the PI screening question.  Dependent on response, questions could be included to capture more information about BTP. Patients who confirmed decreased food intake on the SGA were given one additional question on nutritional intake, before proceeding to the final items	Record of socio-demographic and medical variables, the MMSE for assessment of cognitive function, 16 KPS items, 17 two items related to primary/secondary cachexia, and the ESAS	Range of cancer-related symptoms (including pain)
[30]	PAINReportIt & PAINConsultN	USA	Oncology patients	Two pilot studies in which the system was tested.  Study 1: 5 women and 4 men with bone metastasis-related pain  Study 2: 15 patients with cancer and bone metastasis receiving treatment in the clinic	Non-experimental design	Provide decision support specifically for managing cancer pain	Describe the process of developing the PAINReportIt and PAINConsultN system and present results of two pilot studies with the system:  Study 1: to evaluate the feasibility of using the system in a community radiation oncology setting  Study 2: evaluate patient acceptability and pain outcomes as well as physician outcomes	Interactive touch screen used by patient. Results from system sent to study authors who printed out summary and placed in patient notes for review by doctor	Computerised extension of the MPQ. Questions on pain medications used by the patient, demographic information, computer experience and perceived acceptability of completing the survey via the touch-screen computer.	Option of printing or viewing on-screen a one-page summary report	A summary of the pain data and pharmacologic treatment plans to support the clinician's decisions regarding management of the patient's pain	Only capturing information about pain
[17]	Indiana Cancer Pain and Depression (INCPAD)	USA	Patients receiving palliative radiotherapy for lung cancer	202 cancer patients with pain and / or depression	Experimental study with randomisation	Test effectiveness of a telecare management intervention that combines a centralised nursing team with automated home-based symptom monitoring	Examine the predictors of use and patient satisfaction for two components of a telehealth intervention (nurse care management and automated symptom monitoring)	Interactive Voice Response telephone calls or web-based surveys used according to patient preference	7 core items; 2 items from PHQ-9; average pain from BPI, single items about global improvement, medication adherence, side effects, and whether a call from a nurse was required. Additional BPI questions were included for patients with pain, and additional PHQ-9 questions for those with depression.	4 calls from nurses (baseline and three follow-up calls) and triggered telephone calls that occurred when automated symptom reporting system indicated inadequate symptom improvement, nonadherence to medication, adverse effects, potential suicidal ideation, or a patient request to be contacted	Automated symptom reporting reports generated by the system. System alerts sent to health professional if inadequate symptom improvement, nonadherence to medication, adverse effects, potential suicidal ideation, or a patient requests to be contacted	Capturing information about pain and depression
[21]	No name	Germany	Breast cancer survivors	343 breast cancer patients	Survey design	To establish method for digitally mapping / representing pain reports	Present a method of visualising pain areas and assigning them to a pictogram of the body in a sample of breast cancer patients.	Information entered via a pen tablet - pictogram location was standardised on the pen tablet.	Areas of pain and no pain were digitised into a summation image of a female torso, with blackened areas indicating pain areas and white indicating no pain.	No information provided to patient	Patient data displayed. Pain is visualised by pain maps depicting the location of pain in breast cancer survivors on pictograms of the body. Analysis of the total number of pixels, in which pain was stated, allows comparison of pain areas in several subgroups.	Only capturing information about pain

Reference	System name	Country	Target Population	Study Sample Population	Study Design	Goal of System	Aim of article	Mode(s) of technology used to gather patient data	Content of patient system	Information provided to patient	Information provided to health professional	Symptom focus
[31]	<i>No name</i>	USA	Patients receiving hospice and palliative care	Two studies; 1) usability study involving 8 providers and 18 patients / caregivers  2) a second usability test consisting of 9 providers and 18 patient / caregiver interviews.	Non-experimental design	Evaluate usability of system - not description of development	To determine needs and initial usability of the system prototype involved in the research	A software prototype that gathers clinical data and patient-reported outcomes to be entered and stored in medical records (can be standalone system too)	Computer software for improving communication between health professionals and patients, only accessed by health professionals during a consultation.	No information provided to patient	Assessments, Support, Notes, Summaries and Trends data.	Range of cancer-related symptoms (including pain)
[32]	<i>No name</i>	UK	Patients receiving chemotherapy for cancer	Convenience sample of 18 patients and 9 health professionals at one Scottish cancer centre	Non-experimental design	To assess use of handheld computer in patients receiving chemotherapy	Feasibility study to evaluate the acceptability of using handheld computers as symptom assessment and management tool for patients receiving chemotherapy for cancer	Handheld computers as a symptom assessment and management tool for patients receiving chemotherapy for cancer  Daily reports sent via internet to server.	Patients send daily symptom reports to the cancer centre.	Generates a score for patient which determines specific self-care advice for the patient tailored towards the nature and severity of symptoms that are recorded. If a patients score was out of expected range, a nurse contacts patient to offer further symptom management advice	Daily reports were collated to create a 'cycle symptom report' for each patient - stored in case notes of patient and reviewed by healthcare team prior to patient's subsequent cycle of chemotherapy	Range of cancer-related symptoms (including pain)
[18]	INCPAD	USA	Oncology patients	131 participants with depression only, 96 with pain only and 178 with both depression and pain	Experimental study with randomisation	Designed to improve recognition and treatment of pain and depression	Describes a telecare management intervention delivered by a nurse–psychiatrist team that is designed to improve recognition and treatment of pain and depression	Automated symptom monitoring by either landline telephone or the Internet, depending on patient preferences	7 core items; 2 items from PHQ-9; average pain from BPI, single items about global improvement, medication adherence, side effects, and whether a call from a nurse was required. Additional BPI questions were included for patients with pain, and additional PHQ-9 questions for those with depression	Information provided to patient not discussed in the article	Information provided to the health professional not discussed in the article	Capturing information about pain and depression
[19]	INCPAD	USA	Patients with cancer with depression and / or pain	202 patients with cancer randomly assigned to receive the intervention and 203 to receive usual care were stratified by symptom type	Experimental study with randomisation	Designed to improve recognition and treatment of pain and depression.	Describes a telecare management intervention delivered by a nurse–psychiatrist team that is designed to improve recognition and treatment of pain and depression.	Automated symptom monitoring was performed using either interactive voice–recorded telephone calls or Web-based surveys based on patient preference.	7 core items; 2 items from PHQ-9; average pain from BPI, single items about global improvement, medication adherence, side effects, and whether a call from a nurse was required. Additional BPI questions were included for patients with pain, and additional PHQ-9 questions for those with depression.	4 calls from nurses (baseline and three follow-up calls) and triggered telephone calls that occurred when automated symptom reporting system indicated inadequate symptom improvement, non-adherence to medication, adverse effects, potential suicidal ideation, or a patient request to be contacted	Automated symptom reporting reports generated by the system. System alerts sent to health professional if inadequate symptom improvement, non-adherence to medication, adverse effects, potential suicidal ideation, or a patient requests to be contacted	Capturing information about pain and depression

Reference	System name	Country	Target Population	Study Sample Population	Study Design	Goal of System	Aim of article	Mode(s) of technology used to gather patient data	Content of patient system	Information provided to patient	Information provided to health professional	Symptom focus
[33]	Anoto Technology	Sweden	Palliative home care patients	3 nurses, 2 physicians, and 1 secretary from hospital-based home care clinic	Non-experimental design	To use digital pen technology to capture frequent pain assessments from palliative care patients	Explore and describe professional caregivers' experiences of the use of pain diaries and digital pen technology for frequent pain assessment	Digital pen technology	A pain diary form consisting of a VAS (0 – 100 mm) for pain intensity and boxes for the number of consumed extra doses of analgesics	No information provided to patient	Print out of assessments	Only capturing information about pain
[34]	Anoto Technology	Sweden	Palliative home care patients	12 patients palliative home care patients	Non-experimental design	Use digital pen technology for frequent pain assessment	Explore and describe palliative home care patients' experiences of assessing their pain by using paper pain diaries together with digital pen and mobile Internet technology, and to explore and describe the professional caregivers' experiences of the system and of their patients' use of this pain assessment method.	Pain diary and digital pen technology	Not described in paper	No information provided to patient	Not described in paper	Only capturing information about pain
[35]	Anoto Technology	Sweden	Palliative home care patients	12 palliative patients	Non-experimental design	Use digital pen technology for frequent pain assessment	To explore and describe palliative home care patients' experiences of assessing their pain by using a pain diary together with digital pen and mobile Internet technology	Pain diary and digital pen technology	The pain diary included a unidimensional tool for assessment of pain intensity using a 100mm VAS where the scale was anchored by the words "No pain" (VAS 0mm) and "Severe pain" (VAS 100 mm). It also included a question about consumed extra doses of analgesics.	Health professionals gave the patients feedback on received assessments.	Clinic secretaries checked the system for incoming assessments and printed the assessments during daytime. In the evenings and at weekends, the assessments were examined, printed and signed by the responsible nurse.	Only capturing information about pain
[36]	PACE	USA	Oncology patients	16 providers (physicians, nurses, and physician assistants) at 13 community oncology clinics	Non-experimental design	Use of a pen-based e-tablet to provide educational to patients in text, video, audio and graphic format.	Report the qualitative assessment of the PACE system – particularly the health professional overview from 16 community oncology clinics who were using the system.	e-tablet connected to wireless network and administered in an outpatient oncology clinic and physician offices	Patient Care Monitor survey (psychometrically validated patient-reported symptom severity screening scale). Contains 38 items that produce scores for individual patient reported problems.	No information provided to patient	A real-time, point-of-care report for the provider or clinician that becomes a permanent part of the patients' medical record	Range of cancer-related symptoms (including pain)

Reference	System name	Country	Target Population	Study Sample Population	Study Design	Goal of System	Aim of article	Mode(s) of technology used to gather patient data	Content of patient system	Information provided to patient	Information provided to health professional	Symptom focus
[22]	PACE	USA	Oncology patients	92 providers (at 16 community oncology clinics) and 100 oncology patients	Survey design	Address under-identification and treatment of chemotherapy-related symptoms	Evaluating the PACE system. Specifically, determine provider and patient opinions of the system	Pen-based e-tablet system	A psychometrically validated, patient-reported symptom severity screening scale that generates a real-time, point-of-care report. There were also educational materials in text, video, audio and graphic format.	Once the patient completed all electronic surveys, they are able to browse the Cancer Support Network educational library available on PACE.	A report reflecting the patient's symptoms, psychological distress, QOL, and performance status.	Range of cancer-related symptoms (including pain)
[37]	SymptomReport and SymptomConsult	USA	Outpatients with cancer	41 outpatients with cancer	Non-experimental design	Increase tertiary cancer control efforts by relieving symptoms experienced during curative or palliative phases of cancer treatment	Evaluate the feasibility of the SymptomReport system	Fujitsu 1600 pen tablet computer with the Windows 98-based program.	An electronic version of the 1970 edition of the MPQ, a pain barriers questionnaire, and the SCFS-6	SymptomConsult provided computer games or tailored educational materials based on the patient's SymptomReport responses	Data is captured in Microsoft Access and can be analysed, but not used in clinical systems for the reported study	Range of cancer-related symptoms (including pain)
[38]	PAINReportIt & PAINConsultN	USA	General public with pain and people with cancer pain	Three groups of participants: 1) Outpatients (n=10), were receiving radiation treatments for lung cancer or bone metastasis; 2) Inpatients, (n=106), were hospitalised with a cancer diagnosis; 3) Public (n=97), which included people from the general public who self-selected to complete PAINReportIt.	Non-experimental design	To develop an interactive computerised format for pain assessment	To examine the feasibility of PAINReportIt in terms of the completion time, acceptability, and completeness of data when used by people experiencing pain.	Microsoft Windows 95/98 personal desktop computer with a touch-screen	Computerized extension of the 1970 version of the MPQ and 16 additional items: two items related to the body outline, three 0–10 items related to current-, least- and worst-pain intensity, three items measuring goals for pain levels and amount of time pain greater than tolerable level, one item measuring patient satisfaction with pain level, one item addressing a range of concepts (expectations about the pain, effectiveness of previous pain treatments, pain medication treatment pattern, non-drug treatments used for pain, tendency to tell or not tell others about the pain, onset of pain, and beliefs about the cause of the pain)	Information provided to patient not discussed in the article	Information provided to the health professional not discussed in the article	Only capturing information about pain

**Abbreviations:** QOL = quality of life; SF-8 = short form 8; SF-36 = short form 36; SF-12 = short form 12; SDS = Symptom Distress Scale; RCT = randomised controlled trial; IVR = Interactive voice response; MDASI = M. D. Anderson Symptom Inventory; ESAS = Edmonton Symptom Assessment Scale; EORTC QLQ-C30 = European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire; EORTC BN20 = European Organisation for Research and Treatment of Cancer brain cancer module; PDA = personal digital assistant; PRO = patient reported outcome; BPI = Brief pain inventory; PHQ9 = Brief Patient Health Questionnaire for depression; SGA = Subjective Global Assessment of Nutritional Intake; BTP = breakthrough pain; MMSE = Mini-Mental State Examination; KPS = Karnofsky Performance Status; MPQ = McGill Pain Questionnaire; SCFS-6 = Schwartz cancer fatigue scale.