

Identifying professionals' needs in integrating electronic pain monitoring in community palliative care services: An interview study

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Abstract

Background: Poor pain assessment is a barrier to effective pain control. There is growing interest internationally in the development and implementation of remote monitoring technologies to enhance assessment in cancer and chronic disease contexts. Findings describe the development and testing of pain monitoring systems, but research identifying the needs of health professionals to implement routine monitoring systems within clinical practice is limited.

Aim: To inform the development and implementation strategy of an electronic pain monitoring system, PainCheck, by understanding palliative care professionals' needs when integrating PainCheck into routine clinical practice.

Design: Qualitative study using face-to-face interviews. Data were analysed using framework analysis

Setting/participants: Purposive sample of health professionals managing the palliative care of patients living in the community

Results: A total of 15 interviews with health professionals took place. Three meta-themes emerged from the data: (1) uncertainties about integration of PainCheck and changes to current practice, (2) appraisal of current practice and (3) pain management is everybody's responsibility

Conclusion: Even the most sceptical of health professionals could see the potential benefits of implementing an electronic patient-reported pain monitoring system. Health professionals have reservations about how PainCheck would work in practice. For optimal use, PainCheck needs embedding within existing electronic health records. Electronic pain monitoring systems have the potential to enable professionals to support patients' pain management more effectively but only when barriers to implementation are appropriately identified and addressed.

Keywords

Pain, cancer, palliative care, e-technology, clinical acceptability

What is already known about this topic?

- At least one-third of patients with cancer pain are undertreated, and in some cases, not treated at all.
- Lack of coordination across care providers has been identified as a barrier to effective pain management and patient screening using a self-report measure could help to address this problem.

What this paper adds?

- Provides a detailed account of health professionals' perspectives of integrating routine monitoring into clinical practice.
- Health professionals can see the potential benefits of electronic patient-reported pain monitoring, but they have reservations about how it would work in practice.

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- Health professionals' misconceptions about the purpose of electronic pain monitoring may hinder successful adoption in clinical practice.

Implications for practice, theory or policy

- For optimal use, the system should be embedded into existing electronic health records.
- The user-centred design approach should be adopted when developing interventions for clinical practice as this method will ease the process of integration in the future.
- Electronic pain monitoring systems have the potential to enhance patient–professional relationships, but only once barriers to implementation have been identified and fully addressed.

Introduction

Approximately 65% of advanced cancer patients experience pain, and around half of all patients report pain of moderate or severe intensity.^{1,2} One-third of patients with cancer pain are undertreated,³ and in some cases, not treated at all.⁴ Barriers to successful pain management are patient, family caregiver, health professional and systems related.^{5–8} Poor pain assessment is one of the biggest barriers to adequate pain control.^{9,10}

There is growing interest internationally in the development and implementation of remote monitoring technologies for use in cancer and other chronic conditions.¹¹ The literature describes development and testing of pain monitoring systems,^{12–14} but research detailing the needs of health professionals in integrating routine monitoring into clinical practice is limited.

As part of a larger programme of work, we aimed to develop an electronic pain monitoring system (PainCheck). PainCheck is a web-based system which allows patients with advanced cancer based at home to communicate pain to their healthcare professional. Patients and health professionals can access PainCheck from any electronic device that has Internet connection (smartphone, PC, tablet etc.).

To inform the development and implementation strategy for PainCheck, we wanted to understand how palliative care professionals might engage with PainCheck and identify their needs in integrating the system into routine clinical practice. We adopted a user-centred design approach¹⁵ to engage health professionals in the design and development process. Involving users throughout this process improves the quality of the system and increases its level of acceptability^{12,16} and therefore increases the likelihood that it will be adopted and successfully integrated into practice.¹⁷ Patients were also involved throughout the development process. They completed pain diaries and participated in semi-structured interviews. After this initial developmental stage, patients and health professionals were presented with prototype PainCheck systems and were asked to use them in think aloud interviews. The results of this stage and the patient development work will be presented elsewhere.

Method

Participants

Participants were recruited from a pool of health professionals ($n=105$) from West Yorkshire, United Kingdom who had completed an online pain management survey. The survey explored current practice of pain management and examined which aspects of pain management were seen as important. It included three scenarios (Figure 1) where health professionals were presented with an example of a pain report that could be generated through PainCheck. Health professionals were asked whether they would take action as a result of reviewing the patient-generated data and were asked to rate the importance of the scenario items. The scenarios represented patients with different levels of pain. A subsample of the health professionals who had given consent for further contact was approached to take part in an interview. Figure 2 provides a detailed explanation of the recruitment process. We aimed to recruit 15–20 health professionals. Purposive sampling was used to recruit health professionals with a diverse range of opinions based on survey responses (Figure 3). A total of 23 health professionals were approached. In all, 15 participated, 2 declined (2 general practitioners (GPs)) and 6 (1 clinical nurse specialist (CNS), 5 district/community nurses) did not respond. Demographics are presented in Table 1. The study was approved by the South Yorkshire NHS Research Ethics Committee. Participants provided informed consent.

Data collection

A semi-structured interview was conducted with a single female researcher (S.T.). S.T. has 10 years experience of conducting qualitative research with oncology patients and health professionals. Interviews were the chosen method of data collection because we wanted to explore individual experiences and understand why individuals had responded in a particular way to the scenarios. Focus groups would not have given the same opportunity to explore detailed individual accounts.¹⁸ Interviews were conducted in a

Example B
Patient B:
Date and time recorded: 10-04-2013 16:06
Patient reported pain data:
1. Pain intensity (0 (no pain)- 10)(pain as bad as you can imagine):
- Pain intensity in the last 12 hours: 2
- Current pain intensity: 1
2. Changes in pain (location or type): <i>Pain from lower back is climbing into shoulders</i>
3. Pain interference with daily activities (0 (no interference)- 10 (Unable to carry on any activities)): 3
4. Additional actions by patient: no
5. Free text entry by patient:
6. Perceived control of pain(0 (No control) - 6 (complete control)): 4
7. Perceived ability to decrease pain (0 (No decrease) - 6 (complete decrease)): 1
Additional comments added by patient:

Figure 1. Example of one of the scenarios included in the health professional survey. Health professionals were asked whether they would take action in response to reading the report and how they would rate each item on a scale of 0–10 in terms of importance.

Online survey
<ul style="list-style-type: none"> • Recruitment emails sent to CNS, district and community nurses and palliative care doctors by coordinators and team leaders • GPs contacted through the Primary Care Research Network • Health professionals were given information and a link to the online survey • Estimated that survey was distributed to 634 health professionals • 105 professionals completed the survey • The survey included three scenarios where health professionals were presented with an example of a pain report that could be generated by patient self-reported data. Health professionals were asked if they would take any action as a result of reviewing the patient generated data and were asked to rate each of the items included in the scenario in terms of their importance.
Follow up interviews
<ul style="list-style-type: none"> • Survey participants were asked to indicate if they were happy to be contacted about future research • 66 professionals agreed to be contacted • A selection criteria was devised based on their responses to the survey (Figure 3) • 23 health professionals were approached by email or telephone: 15 were interviewed, one agreed but a suitable time for interview could not be arranged, one declined and six did not respond or could not be contacted

Figure 2. Recruitment procedure for survey and interviews.

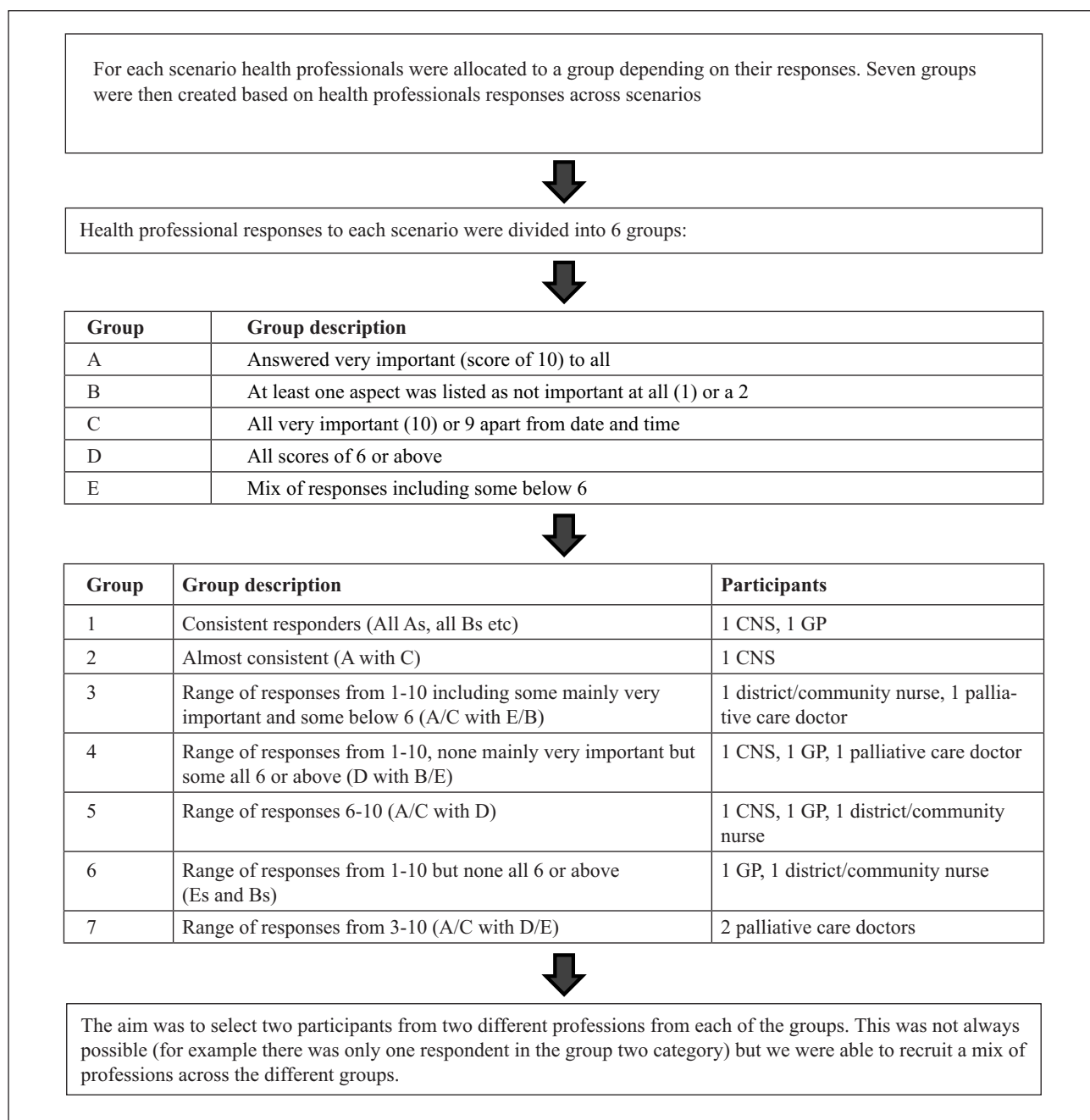


Figure 3. Participant selection process.

Table 1. Health professional demographics.

Sex	
Female (n)	12
Male (n)	3
Age (median, range)	43 (28–59)
Number of years experience in current role (median, range)	6 (1–17)
Professional group	
Palliative care doctor (n)	4
Clinical nurse specialist (n)	4
General practitioner (n)	4
Community/district nurse (n)	3

quiet room at the participant's place of work. Interviews were audio-recorded and transcribed verbatim. Interviews lasted between 16 and 50 min. The topic guide (Table 2) was developed by S.T. and B.M.B. The focus of the topic guide was driven by the aims of the research programme, the literature and the results of the survey.

Data analysis

Transcripts were analysed using framework analysis. After familiarisation with all transcripts, four transcripts were analysed (one from each professional group); the initial

Table 2. Topic guide for interviews.

Topic guide for healthcare professional interviews		
Theme	General questions	Prompt items
Introduction	Introduce Research Consent	Introduce self Introduce research (funding, research design, outputs) Explain: confidentiality, length of interview, nature of discussion (specific topics to address, free to converse, in your own words, no right or wrong answers), reporting and data storage/archiving Any questions Obtain written consent Start recording
Background	Please describe your role	Their role Typical day/week Number of patients seen Time spent with each patient Nature of their contact with patient Is pain assessment part of your role?
Current assessment of pain	Can you describe how you currently assess pain?	How do you assess pain speaking to the patient, physical examination? What aspects of pain do you assess? How often do you assess pain? Do you keep a formal record of assessments? Do you keep paper or electronic records? How do you manage pain?
Content of assessment	Outline of the system. You may remember we presented you with three scenarios and asked which issues were important What should the assessment include?	Link to survey results In the survey you indicated that ... and ... were important. Can you explain a bit more about this? You did not think that ... was an important issue for pain assessment, why is that? Should a pain assessment include any additional information to that included in the scenarios covered in the questionnaire?
Use of electronic remote monitoring in practice	The proposed system will be patient-led and will allow patients to report pain remotely from the community How might remote monitoring of pain fit with your current practice?	What would you do with patient reports? What actions might you take as a result? How often do you think patients should complete the reports in order for it to be most useful and be manageable for healthcare professionals?
Wider practice	How might this type of assessment fit with the wider practice in the healthcare system?	Whose responsibility is it to respond to patient-generated reports? To whom will the reports be most useful for? How should actions taken be recorded? Who needs to know about actions taken? Given busy schedules, how should the need for action or response be flagged or prioritised, for example, email alerts Who would be responsible for receiving alerts and responding to them?
Closing	Do you have anything else you would like to say? Future involvement Thank you for participating	Next research will be determined by this work If opportunity arises to participate further and you are interested, we can get in touch then

framework was created and discussed. This framework was applied to the remaining transcripts. Any ambiguity about coding was discussed. Three new codes were added after coding the fifth transcript; then, no new codes were required suggesting the framework was robust, and we had reached data saturation.

Results

We identified three meta-themes: (1) uncertainties about integration of PainCheck and a change in current practice, (2) appraisal of current practice and (3) pain management is everybody's responsibility (Figure 4).

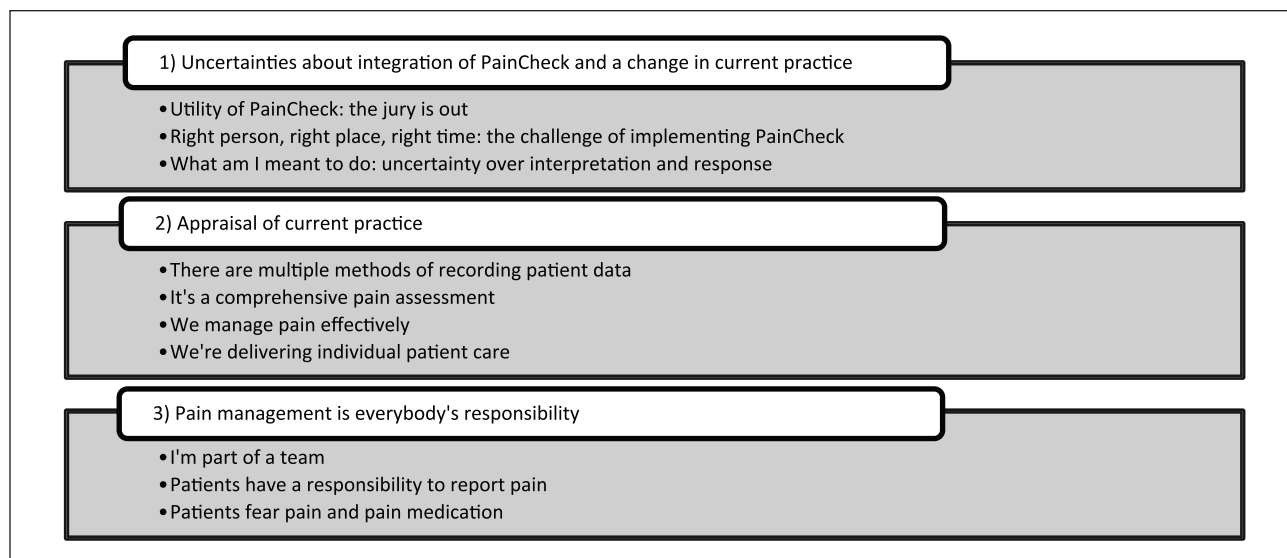


Figure 4. Meta-themes and themes generated from the interviews with health professionals.

1. Uncertainties about integration of PainCheck and a change in current practice

Health professionals had concerns and reservations about integration of PainCheck into routine practice. They were aware that implementing PainCheck would change current practice, but responses were mixed as to whether this would be positive. Health professionals had concerns about the practicalities of using PainCheck such as how the reports would be received, who would have access to them and who would be responsible for reviewing and taking action. They were concerned they would not have the right skills to interpret the reports or the time to address and manage concerns effectively. Health professionals could see the possible benefits of implementing PainCheck, but they were aware of barriers to implementation and were unsure how such a system would improve current practice.

Health professionals expressed a diverse range of opinions when exploring the clinical utility of PainCheck and the potential of the system to change current practice. Many of their apprehensions stemmed from their being unable to fully envisage how PainCheck would work in practice and what its purpose was:

So I think it really depends on what you're going to use it for. If you're using it as a patients ... a way the patients just making contact. If you're just using it as an initial screening, like a patient that's already known to the service ... Who's had a good assessment previously and they just want to let someone know about their pain then I think this is probably fine in a way. (HP12 palliative care doctor)

Health professionals were concerned that PainCheck would replace existing contact with patients. They stressed the importance of face-to-face interactions:

Speak to them and sort of ... you wouldn't just take it from a paper ... assessment. And then hopefully you would have enough time to go out and see them. (HP4 community/district nurse)

Despite reservations, health professionals listed a number of benefits to using PainCheck such as monitoring pain, identifying patterns, improving patient recall and accuracy, improving continuity of care, potential to influence pain management decisions and encourage health professionals to rethink their pain management approach. Health professionals could see the benefits of PainCheck for patients with relatively stable pain as it may reduce the need for health professionals to contact patients. Health professionals could monitor more patients without the same time commitments. The system would also be beneficial for patients who are reluctant to contact health professionals:

But conversely for people who don't normally bother you at all, they may actually feel confident in just doing this because it gives them a list of triggers suggesting well, and particularly for people who find it hard to put pain into words ... Some of them I actually think it would be quite useful. (HP18 palliative care doctor)

In order to implement PainCheck successfully, it has to be targeted at the right people. The report has to be received by a health professional with the knowledge and skills to address the problem, and the patient needs the ability to engage with and use the system. The right health professional might be the GP or a CNS, or the person responsible may change over time. Reports have to be sent to the right place. Health professionals discussed various methods of how reports could be received. A system that could be

integrated into existing electronic health records (EHRs) was preferred, as this would increase the likelihood of integration and would improve accessibility across the multidisciplinary team. Timing is also a key issue. Health professionals were concerned about when they would receive reports and when they would be expected to respond. Patient safety could be compromised if reports were not responded to quickly:

So ... whether there's some way of, because there's the danger as well ... that this could em ... could be relied on! Whereas we would ring someone up and say 'How are you? Or in pain?' You'd think 'oh I'll put in the results on the pain server' you know and then people, people don't ring up. So it could be they put some really important information about 'I'm in absolute agony! But I've reported it!' ... And then nobody checks on it! ... Yes ... And that information's just sitting there! So there is a danger that where they would have picked up a phone and spoke [*sic*] to someone, they've just put it on, they've just put it ... put the information in! Em ... So it's what do you do then? Mm ... (HP19 CNS)

Health professionals were unsure about how to interpret the reports and what response would be expected from them. Health professionals found it difficult to interpret reports without prior knowledge of the patient, more detailed pain information and a full clinical history. Much of this information would be available to health professionals if they knew the patient and had access to their medical records. Knowledge of the patient was particularly important, as the scores are subjective and may not mean the same for one patient as they do for another. Knowledge of the patient helped them to make a judgement about the severity of the patients' scores. Health professionals would try to prioritise reports in order of severity. Severity was usually defined by patient scores:

I, that's a really difficult, I don't know erm you just have to make a judgement whoever, whoever is, is responding and they have to prioritise their, who they respond to first ... I erm done [*sic*] on reported severity I suppose. (HP6 palliative care doctor)

2. Appraisal of current practice

Health professionals felt that collectively they provide a comprehensive pain assessment and management package tailored to meet the needs of individual patients. Health professionals' faith and belief in their current pain management approach was at the root of their apprehension about the implementation of PainCheck as they felt it was an unnecessary addition to current practice:

I think 'cos for us we keep such a tight control over people's pain I think so you know if I change something then I'm making a plan for like two days later I'm going to be on the phone to them. (HP1 CNS)

The types of pain management offered and the type and frequency of visits were all dependent on the individual patient and factors such as their diagnosis, how quickly their disease was progressing and the type of pain they were experiencing:

So we see a lot of patients for just kind of a supportive role, but then as things progress obviously we see them more. (HP15 district/community nurse)

The pain management approach was heavily focused on medication. If a patient was in pain, the first step would usually be to review their medication and the patients' medication adherence and make changes if required. Health professionals would provide pain management advice which again often focused on medication and the importance of taking regular medication and taking the prescribed amount. Non-pharmacological approaches to pain management were only mentioned by a small number of health professionals:

Erm it takes a, it takes erm a conscious effort to think of non-pharmaceutical measures such as position and warmth. (HP22 GP)

Despite their confidence in their current pain management approach, health professionals discussed the challenges and limitations of recording patient data within a multidisciplinary team using a range of EHR. Health professionals were confident in their own system of recording patient data but recognised that the multiple methods used may make it difficult when coordinating multidisciplinary care. Methods used to record patient data varied across disciplines. The district nurses relied heavily on paper records, and there was widespread variation in the electronic systems used between and within health professional groups:

Erm so that's it that's where it will be a problem but that's an ongoing IT problem where people, you know, different systems don't speak to each another. Cos it's the same, you know, in hospital our system doesn't speak to the hospital. (HP16 CNS)

3. Pain management is everybody's responsibility

Health professionals described pain management as a joint responsibility between the individual health professional, their colleagues, the wider healthcare team and the patient. Effective pain management relied heavily on all parties playing their part. Patients were seen to hold back information due to perceived fears about pain and medication. These fears impeded patients taking an active role in pain management.

Health professionals rarely spoke purely as an individual. Instead, they used 'we' as they spoke to identify themselves

as part of a team. They felt that they were part of a wider team of allied health professionals who worked together to provide a comprehensive care package for patients. Health professionals had their own individual and complimentary roles. Health professionals' opinions differed over who should take the lead in the care of palliative cancer patients and who should be responsible for managing PainCheck. Some health professionals believed that the GPs were the key care providers as they were the only constant in the patients care. Others felt that when the palliative care team was involved, the GP often took a less active role. Opinions varied between individuals and health professional groups and across geographical areas:

In reality (*laughs*) I think a lot of the GPs, once we're involved, do relinquish quite a lot of responsibility to us! And whether we, we kind of maybe end up condoning that because ... we're quite often are making a lot of clinical decisions around the pain relief and we're doing quite in-depth assessments and more frequent than GPs would! Em so I think it's partly our responsibility to, if we're making a clinical decision, discuss it with the GP, no matter how ... time consuming that might be just to upskill the GPs. I think that's ongoing long standing problem. Em but we could maybe help upskill GPs by, you know discussing pain management more. Em ... but I think where a GP is quite upfront about their knowledge and skills and feel that they have ... done or they don't have the necessary skills to manage a patient then, to a point, we can manage them for a few weeks on end without a GP involved because ... em ... the GP isn't going to add anything at that point. (HP8 CNS)

And unfortunately it just, it comes back to the GP really. Is that the GP is the ... is the co-ordinator of care even though they may not play much of a role in delivering the care to that person with advanced cancer, they are the person that's overseeing it! (HP11 GP)

Health professionals expected patients to have a role in pain management. They often let patients determine the visiting schedule and relied on the patient to contact them to report changes. This approach worked if the patient took the initiative to report their pain, but not all patients would choose to do this, some need prompting:

I think that we need to encourage patients to report and manage their own pain better than they do. (HP10 palliative care doctor)

Patients' fears and beliefs about pain and medication affected their ability to take an active role in pain management. Patients had concerns about taking too much medication which meant they may not take the dose prescribed by the health professional. These beliefs may influence the likelihood of them reporting their pain to health professionals. Patients may hold back medication, as they prefer to experience a low level of pain or they may feel that they 'should' experience some pain. Some patients may also feel that reporting pain may affect their treatment choices:

but some people want to have, to be in a certain amount of pain, they don't want to be pain free 'cos if they've got pain they want to monitor it, they don't want to hide it or they don't want to cover it all up 'cos then they won't know how they are. (HP1 CNS)

Because sometime they deny, deny any pain on questioning. But erm the family will say 'oh he's been up all night, you know, he's been walking the floor and won't tell you he doesn't want any pain killers' and that kind of thing. (HP9 district/community nurse)

Discussion

We found that while health professionals can see potential benefits of PainCheck, they were sceptical about implementation. These findings are important in terms of designing an implementation strategy once formal evaluation has taken place. To understand the impact of these findings, we have interpreted them within the collective action construct¹⁹ of Normalisation Process Theory.²⁰ The construct includes four components which explore levels of interaction between different groups when implementing a new technology. The four components are Interactional Workability, Relational Integration, Skill Set Workability and Contextual Integration.

Interactional workability explores interactions between patients and health professionals. Health professionals felt that they had a strong relationship with patients at present and were concerned that implementation of PainCheck would jeopardise this. Health professionals were not able to identify with PainCheck as a way of enhancing existing care provision, but instead, saw it as a means of replacing face-to-face contact, and in that respect, they felt existing practices were threatened. As other research has found,²¹ discussing the possibility of implementing a new technology made participants reflect on current working practices. Health professionals felt that they provided individually tailored and effective pain management.

Providing patient-centred care focusing on the individual and giving them some autonomy has been shown to have a positive effect on patient satisfaction.²² Health professionals stressed the importance of the patients' role in pain reporting and management. Many health professionals did not consider that some patients hold back information²³ and therefore found it difficult to see the purpose of PainCheck. Implementing PainCheck may encourage patients to report their pain routinely and make it easier for health professionals to identify problems. Health professionals' focus on medication is a potential deterrent to implementing PainCheck as they may not consider the benefits of patients' self-monitoring and trying to employ self-help measures. It has been recognised that non-pharmacological pain management strategies form part of a holistic approach and should be integrated into pain management guidelines.²⁴ Initially, health professionals were defensive about their current practice; however, as they

explored the capabilities of PainCheck, they discussed the positive impact it could have on interactional workability and highlighted barriers to effective pain management in their current practice.

Relational integration focuses on the impact technology has on interactions between professional groups. This concept reflects the health professionals' concerns about process issues such as who would have access to PainCheck reports and who would be responsible for responding. These issues are crucial and should be addressed before implementation. Health professionals used the term 'we' when talking about pain management, but it was not always clear who would take on the responsibility of engaging with PainCheck. This responsibility may change over time depending on the situation of the individual patient and the level of palliative care team involvement.

Skill set workability focuses on how the new technology fits with the existing skills of the users. Health professionals felt that whoever was reviewing the reports needed to have the knowledge and skills to interpret the report and to also know what action was required. If non-palliative care specialists were responding to PainCheck reports, they may need additional training. Research suggests GPs and community nurses have a good level of knowledge of palliative care issues, but areas were identified where training was required, lack of knowledge in some areas may be due to inexperience as they do not deal with cancer patients routinely.²⁵ Pain management is often better in palliative care, but not all patients access this service.²⁶

Contextual integration outlines how the technology fits within the organisation where it will be implemented. Health professionals' apprehensions about the integration of PainCheck within current practice are reflected within this component. Health professionals could see the potential benefits of routine monitoring but were sceptical about integration into practice. Similar feelings of uncertainty have been echoed in other research, and the reason for this uncertainty was often ambiguity about the role of the system.²⁷ These uncertainties were evident in the interviews with health professionals.

Much of the uncertainty about the system stemmed from the health professionals only being given the PainCheck report; therefore, the information they had was limited. Health professionals want enough information to allow them to take action but not so much information that it detracts from direct patient contact.²⁸ When implemented into practice, health professionals would know the patient and/or they would have access to patient records to aid interpretation. Embedding PainCheck within existing EHR would enable immediate access to the patient's background and clinical information. Linking to existing EHR ensures that a wide range of health professionals could easily access PainCheck reports, an issue which has been recognised as crucial to ensuring patients and healthcare professionals engage effectively.²⁹ Studies using a system

accessed through a separate web interface have found contextual integration difficult.^{30,31}

At present, there are no formal cancer pain assessment guidelines available in the United Kingdom. Therefore, we took an explorative approach to the interviews to ascertain how health professionals currently assess and manage cancer pain and to explore their views on the use of electronic pain monitoring tools and what such tools should contain. There was considerable variability in the pain management approach adopted by the health professionals interviewed, and very few of the health professionals interviewed used a formal assessment tool. Those health professionals who did tended to ask patients to provide a verbal score of their current pain.

This study has shown that even the most sceptical of health professionals can see the potential benefits of implementing an electronic patient-reported pain monitoring system. For successful implementation, the purpose of PainCheck should be made clear to professionals (that it is designed to enhance their relationship with patients, not replace it), and a clear pathway of responsibility and actions needs to be established. For optimal use, the system should be embedded into existing EHR. For patients receiving palliative care, the community nurse specialist may be the best person to monitor and respond to PainCheck, but for those patients not receiving palliative care, then this responsibility is likely to fall to the GP.

The main limitation to this study is the sample. The sample was taken from a small number of health professionals from the West Yorkshire region; therefore, the results may not be generalisable. The sample, however, did contain a mix of different health professionals with a range of different responses to the scenario questions.

The user-centred design approach is a valuable method and has ensured that PainCheck contains information relevant to the palliative care context. This approach will ease the process of integration into clinical practice in the future. Lack of coordination between care providers has been identified as a barrier to effective pain management.³² Electronic pain monitoring systems have the potential to enhance patient-professional relationships, but only once barriers to implementation have been identified and fully addressed.

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