

## Chronic pain (primary and secondary) in over 16s: assessment of all chronic pain and management of chronic primary pain

**[B] Evidence review for communication between healthcare professionals and people with chronic pain (chronic primary pain and chronic secondary pain)**

*NICE guideline NG193*

*Qualitative evidence review underpinning recommendations 1.1.1 to 1.1.23 in the NICE guideline*

*April 2021*

*This evidence review was developed by the National Guideline Centre based at the Royal College of Physicians*



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# 1 Communication between healthcare professionals and people with chronic pain

## 1.1 Review question: What are the best methods of communication between healthcare professionals and people with chronic pain?

## 1.2 Introduction

Over the last two decades the emergence of new technologies has broadened how we communicate with others inside and outside of the healthcare setting. Use of web-based information and social media has become routine for many. Our daily lives have become more complex in the range of methods we use to absorb, process, articulate, and exchange information. However, traditional interpersonal interactions like face-to-face meetings, or telephone encounters remain important.

In recognition of the diversity of potential interactions in a clinical setting, it is important to consider variables such as age, preferences or disabilities; reasons for the interaction, for example diagnostic consultation, information exchange, or need for additional pain resources; and the methods used, for example face-to-face, web-based, and/or written interactions. The hope is that this information will help healthcare professionals to understand the best ways to communicate with people living with chronic pain and put these methods into practice. In addition, it may guide future research to understand this area better.

Other stakeholders have importance here too; wider groups such as carers or resource designers are also likely to benefit from a good understanding of the best form of interaction between healthcare professionals and people living with chronic pain.

This review intends to identify the methods of communication that people with chronic pain themselves and their healthcare professionals report to be the most helpful.

## 1.3 Characteristics table

For full details see the review protocol in appendix A.

**Table 1: Characteristics of review question**

<b>Objective</b>	To identify barriers and facilitators to good communication between people with chronic pain and the healthcare professional during consultation.
<b>Population and setting</b>	People, aged 16 years and over, with chronic pain and their healthcare professionals. Any setting in which NHS care is provided.
<b>Context</b>	Any barriers or facilitators to good communication described by study participants. For example: <ul style="list-style-type: none"><li>• Strategies that people with chronic pain think might improve communication in chronic pain management.</li><li>• Ways that healthcare providers could minimise poor communication in chronic pain consultations.</li></ul>
<b>Review strategy</b>	Thematic synthesis of qualitative findings. Results presented in a narrative format. Quality of the evidence is assessed using the GRADE-CERQual approach for each review finding.

## 1.4 Qualitative evidence

### 1.4.1 Included studies

We searched for qualitative studies exploring people with chronic pain and healthcare professionals' experiences of care for chronic pain, in order to identify barriers and facilitators to good communication between people with chronic pain and the healthcare professional during consultation.

Thirty one qualitative studies, reported in thirty four papers, were included in the review;<sup>16, 22, 32, 37, 42, 47, 61, 70, 74, 76, 78-80, 82-85, 89, 91, 93, 96, 98, 99, 115, 121, 125, 137, 160, 164, 167, 174, 181, 193, 194, 204, 206, 211</sup> these are summarised in Table 2 below. Key findings from these studies are summarised in Section 1.4.4 and 1.4.5 below. See also the study selection flow chart in appendix C, study evidence tables in appendix D, and excluded studies lists in appendix F.

As a large number of papers were identified for this review, extraction of data from relevant studies was halted once data saturation was reached. Data saturation is the point at which no new themes, or data contributing to themes emerged from studies that were found to match the review protocol. Studies that information was not extracted from due to saturation being reached are listed in appendix E.

The aim of all the studies was to explore peoples' experience of receiving or providing chronic pain care. Seven of the included studies were secondary reports, synthesising qualitative research from a range of qualitative studies. The majority of the primary studies were conducted with adults with chronic pain, using interviews or focus groups. Only a minority of studies included healthcare providers.

### 1.4.2 Excluded studies

See the excluded studies list in appendix F.

### 1.4.3 Summary of qualitative studies included in the evidence review

**Table 2: Summary of studies included in the review**

Study	Design	Population	Research aim	Comments
<b>Primary Studies</b>				
Beitel 2017 <sup>22</sup>	Qualitative research, based on semi-structured interviews.	Methadone maintenance treatment drug counsellors with no prior training in pain management who were recruited from three opioid treatment programmes. Mean age 43.9 years (SD 12.7 years)	To examine how drug counsellors with no prior training in pain management respond to their patients' reports of chronic pain.	Moderate limitations noted around participant selection and impact of the researchers on the process. Study conducted in the US. Limited to a very specific but important subgroup of patients.
Breckons 2017 <sup>32</sup>	Longitudinal qualitative research, based on semi-structured interviews at different time points.	Patients with persistent orofacial pain. Age reported in ranges from <40 to >70.	To examine patients' use and experience of health care for persistent orofacial pain over a 12-month period.	No significant methodological limitations noted. Study conducted in the UK.
Buchman 2016 <sup>37</sup>	Qualitative research, based on semi-structured interviews and focus groups.	Adults (aged between 35 and 64) with self-reported chronic pain in the low back region for 2 years or longer, and under the care of a primary care physician for pain management.	To provide an in-depth examination of how adults living with chronic pain negotiate trust and demonstrate trustworthiness with clinicians in therapeutic encounters.	No significant methodological limitations noted. Study conducted in Canada.
Calner 2017 <sup>42</sup>	Qualitative research, based on semi-structured interviews.	Adults with persistent neck, back, or shoulder pain. Aged between 20-74 years.	To explore and describe the expectations people with persistent pain have prior to physiotherapy treatment.	No significant methodological limitations noted. Study conducted in Sweden.
Cheng 2019 <sup>47</sup>	Science Café Approach, including survey and focus groups.	Adults (aged 18 years and older) with chronic pain, providers with chronic pain and providers without chronic pain.	To understand how chronic pain impacts low-income individuals with chronic pain and their communities from multiple perspectives	No significant methodological limitations noted. Study conducted in the US

Study	Design	Population	Research aim	Comments
Donovan 2017 <sup>74</sup>	Qualitative research, based on semi-structured interviews.	Medicaid members living with chronic pain who used the emergency department (ED) more than 3 times in the past year. Age range 21 to 64.	To understand the lived experiences of ED use by patients with chronic pain and a history of frequent ED use.	Moderate limitations noted around the impact of the researchers on the process. Study conducted in the US.
Driscoll 2018 <sup>76</sup>	Qualitative research, using focus groups (6 with men and 4 with women)	Veterans who reported moderate to severe non-cancer pain on at least 2 outpatient visits in the prior year and who had a referral for pain specialty care. Age not reported.	To explore and compare the challenges men and women perceive when using an integrated health system to manage chronic pain.	Moderate limitations noted around the impact of the researchers on the process. Study conducted in the US.
Ernstzen 2016 <sup>78</sup>	Qualitative research, based on in-depth interviews.	Adults with chronic musculoskeletal pain. Age not reported.	To explore patients' experiences and perspectives of their chronic musculoskeletal pain and its management in the private healthcare sector in South Africa.	Moderate limitations noted about recruitment. Study conducted in South Africa.
Evers 2017 <sup>79</sup>	Qualitative research, using focus groups.	Adults (aged 18 years or older, range 25 to 84 years), and had a visit to a primary care physician in the previous week that resulted in a diagnosis code for non-specified back pain.	To identify opportunities to improve key aspects of physicians' communications with patients with chronic low back pain.	Moderate limitations noted around the impact of the researchers on the process. Study conducted in the US.
Franklin 2016 <sup>80</sup>	Qualitative research, based on semi-structured interviews.	Adults with chronic musculoskeletal pain for more than 3 months. Age mean 53.8 years.	To identify the key factors that influence individuals' experiences in the management of chronic pain.	Moderate limitations noted around the impact of the researchers on the process. Study conducted in the UK.
Fu 2016a <sup>82</sup> , Fu 2018a <sup>84</sup> and Fu 2018b <sup>85</sup>	Qualitative research, based on in-depth semi-structured interviews.	Adults with chronic back pain. Age range 27 to 69 years.	To evaluate the nature and the influence of patient-professional partnerships on	Moderate limitations noted around the impact of the researchers on the process. Study conducted in UK.



Study	Design	Population	Research aim	Comments
			the self-management of chronic back pain.	
Gjesdal 2018 <sup>89</sup>	Qualitative approach, based on semi-structured interviews.	Adults (aged 18 to 67 years) with chronic non-malignant pain (>6 months), the pain condition as a primary disorder and living at home (outpatients).	To explore the experiences with healthcare received by people living with chronic non-malignant pain in Norway.	Moderate limitations noted around the impact of the researchers on the process. Study conducted in Norway.
Gordon 2017 <sup>91</sup>	Qualitative study, using focus groups.	Primary care healthcare professionals, people with chronic pain, and their carers. Age not reported.	To examine the opinions of primary care healthcare professionals and people with chronic pain and their carers, in order to identify possible barriers to the facilitation and adoption of self-management.	Moderate limitations noted around the impact of the researchers on the process. Study conducted in the UK.
Grieve 2016 <sup>93</sup>	Qualitative research, based on semi-structured telephone interviews.	Adults with complex regional pain syndrome. Age range 30 to 59 years.	To explore the specific information requirements of patients with CRPS and provides insight into how health professionals can best provide this.	Moderate limitations noted around recruitment. Study conducted in the UK.
Grus 2020 <sup>96</sup>	Mixed methods study with qualitative research based on semi-structured interviews	Adults (aged over 18 years) who had received long-term opioid treatment and had a pain-related diagnosis	To explore the relationship between patients' overall satisfaction with their primary care providers and their satisfaction with their chronic pain treatment, as well as the provider behaviours that contributed to chronic pain patients' satisfaction	Serious limitations noted around the impact of the researchers on the process, the rigorousness of the analysis and the collection of data.  Study conducted in the US. Additional themes were reported, but not extracted due to data saturation.
Hadi 2016 <sup>98</sup> and Hadi 2017 <sup>99</sup>	Qualitative research, based on semi-structured interviews.	Adult (aged over 18 years) patients with chronic pain discharged from a pain clinic.	To identify barriers to effective pain management	Moderate limitations noted around the impact of the researchers on the process.

Study	Design	Population	Research aim	Comments
			encountered by patients with chronic pain in the NHS.	Study conducted in the UK.
Janke 2016 <sup>121</sup>	Qualitative research, based on semi-structured interviews.	Adults who were obese and in chronic pain. Age 50 or older 56.6%	To examine perceptions of those with comorbid chronic pain and obesity regarding their experience of comorbidity management in primary care.	Moderate limitations noted around the impact of the researchers on the process. Study conducted in the US.
Kanter 2017 <sup>125</sup>	Qualitative study, using focus groups.	Women (aged over 18) with a known diagnosis of interstitial cystitis/bladder pain syndrome (IC/BPS).	To seek information regarding patient experience with IC/BPS symptoms and with their medical care to elicit suggestions to improve patient satisfaction.	Moderate limitations noted around the impact of the researchers on the process and ethics. Study conducted in the US.
Nafradi 2018 <sup>164</sup>	Qualitative research, based on semi-structured interviews.	Older adults (aged 35 to 80 years) with chronic pain, in treatment for a minimum of 3 months.	To study patients' perspectives about the role of the doctor–patient relationship in promoting the resilience process.	Moderate limitations noted around how participants were selected . Study conducted in Switzerland.
Outlaw 2018 <sup>174</sup>	Qualitative research, based on video-recorded patient interviews.	Adults (aged 18 and over) attending the chronic pain clinic.	To improve the overall experience for patients using chronic pain services at a large teaching hospital in England.	Moderate limitations noted around how participants were selected and the limited reporting of methods. Study conducted in the UK.
Reibel 2017 <sup>181</sup>	Qualitative research, based on phenomenological interviews.	Women with fibromyalgia. Age not reported.	To gain an understanding of the lived experiences of women with fibromyalgia.	Moderate limitations noted around recruitment and ethics. Study conducted in the US.
Sternke 2016 <sup>193</sup>	Qualitative research, using focus groups.	Adults with chronic pain and depression. Age range 27 to 84 years old.	To analyse patients' perspectives on the emergent theme of empathy and describe how patients construct their experiences and expectations surrounding empathic interactions.	Moderate limitations noted around the impact of the researchers on the process. Study conducted in the US.

Study	Design	Population	Research aim	Comments
Sullivan 2019 <sup>194</sup>	Qualitative research, based on semi-structured interviews.	Physiotherapists with at least one year's post-graduate experience in musculoskeletal practice and who had lived through situations of communicating the diagnosis of chronic non-specific lower back pain to their patients	To explore clinicians' experiences of communicating their understanding of chronic low back pain to their patients	No significant methodological limitations noted. Study conducted in the UK.
Valenzuela-Pascual 2019 <sup>211</sup>	Qualitative research, based on semi-structured interviews and one discussion group.	Adults with chronic low back pain. Age range 20 to 65 years. Primary care physicians and nursing staff working in any primary healthcare center in the city of Lleida, Spain were also recruited.	To explore and compare the perceptions of patients and primary healthcare professionals regarding the management of chronic low back pain	Moderate limitations noted around the impact of the researchers on the process. Study conducted in Spain. Additional themes were reported, but not extracted due to data saturation.
<b>Secondary Studies</b>				
Baker 2018 <sup>16</sup>	Documentary analysis of grey literature, patient blogs and interviews with pain care providers	Adults and children with chronic pain (ages not reported). Clinicians and postgraduate trainees from local pain clinics.	To explore what happens when the discourses of compassionate care and evidence based practice interact.	A mixed methods approach using a range of documentary sources. No significant methodological limitations noted. Focused on Canadian reports and information. Evidence from adults only was extracted.
Crowe 2017 <sup>61</sup>	Systematic review of qualitative studies.	Older people (aged 65 and older) with chronic non-malignant pain.	To examine how older people cope with non-malignant chronic pain.	No significant methodological limitations noted. Limited to older people.
Devan 2018 <sup>70</sup>	Systematic review of qualitative studies, with meta-synthesis.	Adults (16 years old and older) with chronic pain.	To synthesize enablers (what works) and barriers (what does not) of incorporating self-management strategies for	Well- conducted and reported systematic review and meta-synthesis. Limited to people participating in self-management interventions.

Study	Design	Population	Research aim	Comments
			people in everyday life after completion of a pain self-management intervention.	
Fu 2016b <sup>83</sup>	Systematic review of qualitative studies.	Adults with chronic back pain. Age not reported.	To explore the influence of patient–professional partnerships on patients’ ability to self-manage chronic back pain, and to identify key factors within these partnerships that may influence self-management.	No significant methodological limitations noted. Limited to people participating in self-management interventions.
Moore 2019 <sup>160</sup>	Supra (or secondary) analysis of 2 qualitative studies.	Older adults (aged 45 and older) with chronic musculoskeletal pain.	To explore how the use of medical images and models by healthcare professionals can inform patients’ understanding of chronic musculoskeletal illness and pain.	Moderate limitations noted around how participants were selected for case analysis. Both primary studies were conducted in the UK.
Toye 2018 <sup>204</sup>	Systematic review of qualitative studies, based on a range of qualitative approaches.	Professionals providing healthcare to adults with chronic non-malignant pain. Age not reported.	To undertake a qualitative evidence synthesis of qualitative research using meta-ethnography to increase the understanding of what it is like for healthcare professionals to provide healthcare to people with chronic non-malignant pain and thus inform improvements in the experience and quality of healthcare.	No significant methodological limitations noted.
Toye 2017 <sup>206</sup>	Systematic review of qualitative studies, based on a range of qualitative approaches.	People living with chronic pain. Age not reported.	To bring together qualitative evidence syntheses that explore patients’ experience of living with chronic non-malignant pain and develop	No significant methodological limitations noted.

Study	Design	Population	Research aim	Comments
			conceptual understanding of what it is like to live with chronic non-malignant pain for improved healthcare.	

See appendix D for full evidence tables.

## 1.4.4 Qualitative evidence synthesis

Seventeen themes were identified from the twenty-eight included studies (see Table 3). Main findings are grouped into five overarching categories.

**Table 3: Review findings**

Main findings	Statement of findings
<b>Style of communication</b>	
Validation and belief <sup>16, 37, 42, 78, 79, 82, 84, 85, 89, 98, 99, 164, 204</sup>	Effective interaction and communication requires mutual contribution and a shared responsibility to generate mutual understanding and trust. A key component of effective interaction is the patient feeling believed and having their experience validated.
Listening and empathy <sup>22, 37, 47, 70, 79, 80, 83, 89, 91, 98, 99, 125, 174, 193, 206</sup>	Listening is a key skill to achieve good communication. Effective communication includes being listened to and encouraged, feeling understood and understanding the cause of the pain.
Open and non-judgmental <sup>47, 70, 74, 76, 78</sup>	Open and non-judgmental communication is necessary to support a strong, therapeutic alliance.
Supportive and collaborative <sup>61, 76, 78, 82, 84, 85, 89, 91</sup>	A supportive and collaborative relationship between patients and healthcare providers can help patients to feel more able to cope with their condition and be more engaged and confident in self-care.
Optimistic and hopeful <sup>82, 84, 85, 125</sup>	Patients want to be optimistic about the outcomes of treatment and value the healthcare professional being hopeful about the impact of care.
Empowering <sup>82, 84, 85, 164</sup>	Empowering patients to pay attention to their physical sensation can support cooperation and engagement in care.
Language <sup>80, 82, 84, 85, 174, 211</sup>	The use of lay language and understandable terminology is helpful when communicating with patients with chronic pain.
Patient-centredness <sup>194</sup>	A patient-centred approach may include tailoring communication specific to what the individual patient may find meaningful, in order to build good rapport may help to get the patient on board with the healthcare providers' perspective.
<b>Content of communication</b>	
Negative test results <sup>32, 194</sup>	Negative test results can be communicated in a way that is perceived by patients as being dismissive of their pain and can lead to patients feeling their treatment options are being limited because of the test results.
Diagnosis and explanation of symptoms <sup>42, 79, 93, 98, 99, 164, 181, 206</sup>	A specific diagnosis and an explanation of the acute cause of their pain is valued by patients. Patients understand the difficulty of treating chronic pain, and they appreciate it when physicians acknowledge their lack of certainty of how best to help a patient.
Treatment options <sup>61, 76, 79, 80, 98, 99, 121, 125, 164, 174</sup>	Adults with chronic pain want to know more about their condition and the range of options available to manage their pain, including nonpharmacological options.
<b>Timing of communication</b>	
Self-management <sup>91</sup>	Discussions about self-management often happen late in the care pathway, or not at all.
Prior to attendance <sup>174</sup>	Patients are often poorly informed of what to expect from the pain service before they attend for treatment.
<b>Approach to communication</b>	
Use of visual aids and demonstration <sup>80, 82, 84, 85, 160</sup>	The use of visual aids as part of the consultation can help patients to better understand their pain and the impact of their behaviours and activities.

Main findings	Statement of findings
	Patients also find it helpful when the healthcare professional demonstrated activities or self-management skills in the consultation.
Mode of communication <sup>82-85</sup>	Face-to-face and written communication of information is useful.
Location of information <sup>174</sup>	Information is sometimes provided in locations that are not easily accessible for people with chronic pain.
Continuity of care <sup>76, 80, 93, 96</sup>	Care that lacks continuity can negatively impact on the follow-up and longer term care. A lack of continuity in care can also increase the risk of patients being given different and, potentially, conflicting information.
<b>Other</b>	
Time <sup>80, 82, 84, 85, 98, 9996</sup>	Longer consultation times can help patients and healthcare professionals to develop a relationship, and allow patients to discuss other issues which impact on their pain.

### 1.4.4.1 Narrative summary of review findings

#### 1.4.4.1.1 Style of communication

##### Review Finding 1: Validation and belief

Participants reported that effective interaction and communication required mutual contribution and shared responsibility to generate mutual understanding and trust. A key component of effective interaction was the person feeling believed and having their experience validated. People also expected a good interaction, respect and affirmation as individuals with specific needs.

Some adults with chronic pain reported a negative experience of care, with the healthcare professional not understanding the pain, not believing that the person's pain was real, and making statements that the pain was in their head. Participants felt disbelieved and judged by healthcare professionals. People sometimes found it difficult to convince their healthcare professional of the level of their pain. When interactions with healthcare professionals made the participants feel insignificant, they found it difficult to express their needs, which seemed to reinforce practical difficulties and unfulfilled expectations and make them lose hope in their recovery.

The level of trust and belief was particularly challenging when people were requesting opioids for their pain. People experienced doubts that their clinicians believed they were being honest about their motives for seeking treatment (for example, drug misuse or drug diversion). Participants also felt that stigmatised identities, such as being a person with chronic pain and a person with an addiction, influenced the participants' perceived trustworthiness. This was reflected by the physicians, who were concerned that people may not be telling the truth about their motivations to obtain opioid medications.

Participants also reported their positive experiences of care. Adults with chronic pain described interactions with a supportive healthcare professional, where being believed in and mutual trust existing were emphasized. Receiving psychological support and validation from healthcare providers was seen as an important factor to consider concerning patient resilience. When seeking opioid treatment, not all participants reported that clinicians found them untrustworthy or dismissed their treatment-seeking motives or testimony.

Adults with chronic pain wanted:

- Physicians to validate a person's pain experience by imparting an understanding that the way each individual experiences and relates to pain is unique.
- Healthcare professionals to believe people's experiences.

Explanation of quality assessment: This review finding was based on both secondary and primary research, including people with different types of chronic pain and from different countries. Most studies were based in primary or community care settings. Some of the studies had minor methodological limitations relating to the impact of the researchers on the process and 1 with concerns about participant selection, but overall, this is unlikely to lower our confidence in the results. There was a judgement of high confidence in this review finding.

### **Review Finding 2: Listening and empathy**

Participants' views of effective communication included being listened to and encouraged, feeling understood and understanding why they had the pain. People wanted to know that all their providers were truly listening to them. They stated that effective treatment required providers to understand that their disease experiences were real and that their needs were valid.

Participants had experienced encounters where they felt there was a lack of interest shown by their healthcare professionals in listening to their problems and managing their pain. A perceived lack of empathic listening as well as empathic action was also associated with feelings of frustration and a sense of being uncared for. People also perceived that their clinicians demonstrated a lack of respect for them.

In more positive experiences, people described good encounters with a supportive healthcare professional where being listened to was emphasized. One provider also described it as their 'primary responsibility' being to listen. Those who felt heard by the providers appeared to be most satisfied, even if improved pain was not the outcome. People were also more trusting and more likely to adhere to self-management suggestions if they felt the clinician was interested in them and listened to what they had to say. Participants commonly cited 'improved listening' as the key thing they desired from healthcare professionals.

Participants also wished for an empathic encounter with their physician, with careful listening used to get to know the patient, and discover what is important to them in their care and recovery. Participants wanted their physician to try to know them and understand how pain uniquely affects their lives. Attempting to understand people's lived experiences of chronic pain facilitated both patient and counsellor engagement in treatment. Examples included empathizing with people who did not understand why they had chronic pain or were attempting to manage pain while having an opioid use disorder.

Explanation of quality assessment: This review finding was based on both secondary and primary research, including people with different types of chronic pain, from different countries, and in a range of healthcare settings. Some of the studies had minor methodological limitations relating to the impact of the researchers on the process and 2 with concerns about participant selection, but overall, this is unlikely to lower our confidence in the results. There was a judgement of high confidence in this review finding.

### **Review Finding 3: Open and non-judgmental**

Patients and practitioners considered that open and non-judgmental communication was necessary to support a strong, therapeutic alliance. In practice, some people felt stigmatized for their condition, particularly around their use of opioids and during the monitoring of opioid use, such as urine drug testing. People also experienced stigma related to other socioeconomic factors, such as homelessness and race, where they considered that provider assumptions had impacted negatively on their quality of care.

Explanation of quality assessment: This review finding was based on both secondary and primary research, including people with different types of chronic pain and in a range of healthcare settings. The majority of the studies were conducted in the US, and the



experience of care and the concern around opioid prescribing may be less applicable to the UK population. Some of the studies had minor methodological limitations relating to the impact of the researchers on the process, but overall, this is unlikely to lower our confidence in the results. There was a judgement of moderate confidence in this review finding.

#### **Review Finding 4: Supportive and collaborative**

Participants valued a supportive and collaborative relationship with their healthcare provider. A supportive and collaborative relationship was seen as being necessary to establish a good partnership with health professionals. It helps people to be supported to self-manage their condition and agree realistic goals, and enabled them to feel comfortable to discuss about their difficulties and ask for help. Participants reported good experiences of care where they had discussions in collaboration with their healthcare provider and were able to explore the risks and benefits of treatment. A supportive and collaborative relationship also fostered other positive behaviours, including people with chronic pain feeling more able to cope and being more resilient. People who had a supportive and collaborative relationship also felt more confident in practising and maintaining self-management strategies. However, the emotional impact of pain was difficult for many people and they often felt unsupported by healthcare professionals in this aspect of their condition.

Explanation of quality assessment: This review finding was based on secondary and primary research, including people with different types of chronic pain and from different countries. Most studies were based in primary or community care settings. Some of the studies had minor methodological limitations relating to the impact of the researchers on the process,, but overall, this is unlikely to lower our confidence in the results. There was a judgement of high confidence in this review finding.

#### **Review Finding 5: Optimistic and hopeful**

Participants expressed their need to be optimistic and to hold positive beliefs about their treatment and outcome. Encouragement from providers that they were willing to explore other potential avenues for improvement and that they were optimistic that symptoms would improve was very important to people with chronic pain.

Explanation of quality assessment: This review finding was based on primary research, including people with chronic back pain and interstitial cystitis/bladder pain syndrome, from the UK and the US in community and specialist settings. Each of the studies had minor methodological limitations, but overall, this is unlikely to lower our confidence in the results. There was a judgement of low confidence in this review finding, because of the adequacy of the data and the limited relevance to other people with chronic pain rather than methodological limitations.

#### **Review Finding 6: Empowering**

People valued the healthcare professional empowering them to pay attention to their physical sensations, which supported cooperation. Allowing people with chronic pain to acknowledge and accept their pain enabled them to engage with their healthcare professional in exploring treatment options and solutions.

Explanation of quality assessment: This review finding was based on primary research, including people with different types of chronic pain, from the UK and Switzerland in community settings. Each of the studies had minor methodological limitations regarding the impact of the researchers on the process and participant selection, but overall, this is unlikely to lower our confidence in the results. There was a judgement of moderate confidence in this review finding, because of the adequacy of the data.

**Review Finding 7: Language**

Participants wanted their healthcare professionals to be knowledgeable but they also highlighted the importance of healthcare providers using lay language and understandable terminology. This helped to support engagement. When this does not occur, it can lead to misunderstandings. For example, people were often told the clinical name of their condition, but not what it actually meant or its implications on their care. Not all participants found this problematic and whilst some criticised the use of medical terms, others did not find this to be a problem as they would ask healthcare professionals to clarify as needed. Some healthcare professionals felt that it is not always possible to translate medical language to patients.

Explanation of quality assessment: This review finding was based on primary research, including people with different types of chronic pain as well as healthcare professionals, from the UK and Spain in a range of healthcare settings. Some of the studies had minor methodological limitations regarding the impact of the researchers on the process and participant selection, but overall, this is unlikely to lower our confidence in the results. There was a judgement of moderate confidence in this review finding, because of some incoherence in the findings.

**Review Finding 8: Patient-centredness**

Healthcare professionals described the importance of understanding their patients and agreed that a patient-centred approach, using active listening and questions helped to build a good rapport and for the patient to feel believed. Understanding what approaches are most meaningful for the individual patient may help the diagnosis be accepted. This can be a tentative process using both verbal and nonverbal communication.

Tailoring of communication using a patient-centred approach may also help healthcare professionals to tap into the things that would motivate patients to get on board with the clinician's perspectives. This may be also helpful when the pain diagnosis clashes with patients' existing beliefs.

Explanation of quality assessment: This review finding was based on primary research, including healthcare professionals working with people with chronic non-specific low back pain in the UK. There was a judgement of moderate confidence in this review finding, because of the adequacy of the data.

**1.4.4.1.2 Content of communication****Review Finding 1: Negative test results**

Some participants described communication of negative or inconclusive test results as evidence of a failure to acknowledge their condition on the part of healthcare professionals and a failure to progress. For some people, a negative test result appeared to mark an end point in healthcare professionals' efforts to diagnose and treat their pain; therefore, it seemed to those individuals that a diagnosis was necessary to qualify for further medical care. Some healthcare professionals reported feelings of anxiety and uncertainty, and a desire to avoid failures in communication when dealing with negative test results. Healthcare professionals also reported seeking colleagues for support due to doubts and uncertainty regarding their diagnosis.

For people where a negative diagnostic test was communicated to them as "good news," there was a clear discord between how a negative test was perceived by the person with chronic pain and the healthcare professional.

Explanation of quality assessment: This review finding was based on primary research, including both healthcare professionals caring for people with chronic non-specific low back pain and people with persistent orofacial pain, from the UK and in primary and secondary care. There was a judgement of low confidence in this review finding, because of the

moderate concerns about relevance to all people with chronic pain and because of the adequacy of the data.

### **Review Finding 2: Diagnosis and explanation of symptoms**

Participants wanted a medical diagnosis and an explanation of the acute cause of their pain. People wanted this to be specific and individualised, and not information that was more general. People often understood the difficulty of treating back pain, however they were frustrated if they could not get answers to their questions. In contrast, people appreciated when physicians acknowledged the lack of certainty of how best to help.

People also wanted a clear and specific diagnosis along with information about what can be done to minimise future damage. In some cases, people were given verbal information at the diagnosis, although this often comprised the name of the condition only, without further elaboration. This left people feeling uncertain of the implications for their prognosis. People did not only want information at diagnosis. For example, women with fibromyalgia felt they were not given clear answers on the cause of their pain at multiple contacts with healthcare professionals and this contributed to ongoing uncertainty about their illness and their ability to manage their condition.

Explanation of quality assessment: This review finding was based on secondary and primary research, including people with different types of chronic pain, from different countries, and in different settings. Some of the studies had minor methodological limitations relating to the impact of the researchers on the process and 2 with concerns about participant selection, but overall, this is unlikely to lower our confidence in the results. There was a judgement of high confidence in this review finding.

### **Review Finding 3: Treatment options**

Adults with chronic pain wanted to know more about their condition and the range of options to manage their pain, including nonpharmacological options. They valued an outline of the care process, information on why a particular option was chosen, and how it was going to impact on them. Most participants thought that healthcare professionals were very clear when they explained things and they appreciated the extra time that was spent discussing treatments and concepts.

Participants reported positive experiences with primary care physicians who reviewed and inquired about previous treatments before offering other options. Exploring other treatments was preferable to being given the impression that there were no further options. People with chronic pain who were also obese expressed frustration that there was limited support, beyond general information, to help them to understand and manage their weight and pain in their everyday lives. Physicians were also seen as fostering the patients' knowledge and understanding of the condition and treatment by providing explanations and arguments, thus enhancing their health literacy.

Explanation of quality assessment: This review finding was based on both secondary and primary research, including people with different types of chronic pain from the UK, the US, and Switzerland in a range of healthcare settings. Some of the studies had minor methodological limitations relating to the impact of the researchers on the process and 2 with concerns about participant selection, but overall, this is unlikely to lower our confidence in the results. There was a judgement of high confidence in this review finding.

#### **1.4.4.1.3 *Timing of communication***

### **Review Finding 1: Self-management**

Participants felt a discussion about self-management came too late or not at all.

Explanation of quality assessment: This review finding was based on primary research, including people with chronic pain, from the UK, in primary care. There was a judgement of low confidence in this review finding, because coherence was not assessable and because of the adequacy of the data.

### **Review Finding 2: Prior to attendance**

People with chronic pain were poorly informed of what to expect from the pain service. Letters of invitation to clinic or procedures failed to give enough information.

Explanation of quality assessment: This review finding was based on primary research, including people with chronic pain, in the UK and in secondary care. There was a judgement of low confidence in this review finding, because coherence was not assessable and because of the adequacy of the data.

#### **1.4.4.1.4 Approach to communication**

### **Review Finding 1: Use of visual aids and demonstrations**

Participants valued the use of visual aids as part of the consultation for a number of reasons. People reported that the use of anatomical models and images helped them to understand their pain better and also reassured them their pain was being taken seriously and their pain was real. Visual aids also helped people to understand the impact of their behaviours and activities.

Participants also found it helpful when the healthcare professional demonstrated activities or self-management skills and they said they were more willing to practice self-management skills, especially when the demonstration was tailored to the individual.

Explanation of quality assessment: This review finding was based on secondary and primary research, including people with musculoskeletal or joint pain, all from the UK in a range of healthcare settings. Some of the studies had minor methodological limitations, but overall, this is unlikely to lower our confidence in the results. There was a judgement of low confidence in this review finding, because of the adequacy of the data and the limited relevance to people with other types of chronic pain.

### **Review Finding 2: Mode of communication**

Participants felt most positively about face-to-face communication, as the language and non-verbal communication that health professionals used made them feel at the centre of care and involved in the process. People also liked written material on the experience of others and alternative options as this helped them to choose a tailored programme that was relevant to them.

Explanation of quality assessment: This review finding was based on secondary and primary research, including people with chronic back pain and people using self-management strategies, in a range of healthcare settings. One of the studies had minor methodological limitations, but overall, this is unlikely to lower our confidence in the results. There was a judgement of moderate confidence in this review finding, because of some incoherence.

### **Review Finding 3: Location of information**

In one pain service, patient information leaflets were presented in a poorly designed stand which prevented the titles from being easily readable without individually picking each leaflet out of the stand. The location was seen as being off-putting for people who found it painful to move around.

Explanation of quality assessment: This review finding was based on primary research, including people with chronic pain, in the UK and in secondary care. There was a judgement of low confidence in this review finding, because coherence was not assessable and because of the adequacy of the data.

#### **Review Finding 4: Continuity of care**

Participants reported being seen by different providers, meaning they had to 'retell their story' which they perceived as leading to a lack of provider responsibility for follow-up care and a failure to progress treatment. Participants sometimes did not feel comfortable seeking care elsewhere if their primary healthcare professional was unavailable. Another implication of seeing multiple healthcare professionals was that people were given different levels of detail of information and information that was conflicting, which reduced their trust in the healthcare professionals. Participants were also concerned that breakdowns in communication continuity could leave them without medication.

Explanation of quality assessment: This review finding was based on primary research, including people with different types of chronic pain, all from the UK or the US, in a range of healthcare settings. Some of the studies had minor methodological limitations relating to impact of the researchers on the process, but overall, this is unlikely to lower our confidence in the results. There was a judgement of high confidence in this review finding.

#### **1.4.4.1.5 Other**

##### **Review Finding 1: Time**

Participants reported that time pressures could make it difficult to build partnerships with their healthcare professionals, and it limited their ability to discuss other issues which impacted on their pain. People valued consultations with healthcare professionals who were able to take more time and did not limit them to just one topic. This avoided having to return repeatedly for visits within a short time frame which imposed an additional financial burden. People also felt they had to be more assertive in shorter consultations in order to get answers to their questions.

Explanation of quality assessment: This review finding was based on primary research, including people with different types of chronic pain, all from the UK or the US, in a range of healthcare settings. Some of the studies had minor methodological limitations relating to impact of the researchers on the process, but overall, this is unlikely to lower our confidence in the results. There was a judgement of high confidence in this review finding. There was some concern regarding the applicability of findings from one study, however this did not lower confidence in the results overall.

## 1.4.5 Qualitative evidence summary

**Table 4: Summary of evidence**

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
<b>Style of communication – validation and belief</b>					
11 studies, reported in 14 publications	Combination of interviews (6 studies), focus groups (2 studies), systematic review (1 study), documentary analysis and interviews (1 study) and a mixed approach of interviews and focus groups (1 study).	A key component of effective interaction is the patient feeling believed and having their experience validated.	Limitations	No or very minor concerns about methodological limitations	HIGH
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	
			Adequacy	No concerns about adequacy	
<b>Style of communication – listening and empathy</b>					
14 studies, reported in 15 publications	Combination of interviews (5 studies), focus groups (5 studies), systematic review (2 studies), survey and a focus group (1 study) and a mixed approach of	Effective communication includes being listened to and encouraged, feeling understood and understanding the cause of the pain.	Limitations	No or very minor concerns about methodological limitations	HIGH
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
	interviews and focus groups (1 study).		Adequacy	No concerns about adequacy	
<b>Style of communication – open and non-judgmental</b>					
5 studies	Combination of interviews (2 studies), focus groups (1 study), systematic review (1 study), and a survey and a focus group (1 study).	Open and non-judgmental communication is necessary to support a strong, therapeutic alliance.	Limitations	No or very minor concerns about methodological limitations	MODERATE
			Coherence	No or very minor concerns about coherence	
			Relevance	Moderate concerns about relevance <sup>a</sup>	
			Adequacy	No concerns about adequacy	
<b>Style of communication – supportive and collaborative</b>					
6 studies, reported in 8 publications	Combination of interviews (3 studies), focus groups (2 studies), and systematic review (1 study).	A supportive and collaborative relationship between patients and healthcare providers can help patients to feel more able to cope with their condition and be more engaged and confident in self-care.	Limitations	No or very minor concerns about methodological limitations	HIGH
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	
			Adequacy	No concerns about adequacy	
<b>Style of communication – optimistic and hopeful</b>					

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
2 studies, reported in 4 publications	Combination of interviews (1 study), and focus groups (1 study).	Patients want to be optimistic about the outcomes of treatment and value the healthcare professional being hopeful about the impact of care.	Limitations	No or very minor concerns about methodological limitations	LOW
			Coherence	No or very minor concerns about coherence	
			Relevance	Moderate concerns about relevance <sup>a</sup>	
			Adequacy	Moderate concerns about adequacy <sup>a</sup>	
<b>Style of communication – empowering</b>					
2 studies, reported in 4 publications	Interviews.	Empowering patients to pay attention to their physical sensation can support cooperation and engagement in care.	Limitations	No or very minor concerns about methodological limitations	MODERATE
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	
			Adequacy	Moderate concerns about adequacy <sup>a</sup>	
<b>Style of communication – language</b>					
	Combination of interviews (4		Limitations	No or very minor concerns about	MODERATE



Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
4 studies, reported in 6 publications	studies), and discussion groups (1 study).	The use of lay language and understandable terminology is helpful when communicating with patients with chronic pain.		methodological limitations	
			Coherence	Moderate concerns about coherence <sup>a</sup>	
			Relevance	No or very minor concerns about relevance	
			Adequacy	No concerns about adequacy	
Style of communication – patient-centredness					
1 study	Interviews	Using a patient-centred approach may help to build a good rapport and may also help to get the patient on board with the healthcare providers' perspective	Limitations	No or very minor concerns about methodological limitations	MODERATE
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	
			Adequacy	Moderate concerns about adequacy <sup>a</sup>	
Content of communication – negative test results					
2 studies	Interviews.	Negative test results can be communicated in a way that is perceived by patients as being dismissive of their pain and can lead to patients feeling their treatment options are being limited because of the test results. Healthcare	Limitations	No or very minor concerns about methodological limitations	LOW

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
		professionals are also concerned that communicating negative test results may lead to interpersonal conflict which may damage the relationship and can lead to uncertainty in their own diagnosis.	Coherence	No or very minor concerns about coherence	
			Relevance	Moderate concerns about relevance <sup>a</sup>	
			Adequacy	Moderate concerns about adequacy <sup>a</sup>	
Content of communication – diagnosis and explanation of symptoms					
7 studies, reported in 8 publications	Combination of interviews (5 studies), focus groups (1 study), and systematic review (1 study).	A specific diagnosis and an explanation of the acute cause of their pain is valued by patients.	Limitations	No or very minor concerns about methodological limitations	HIGH
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	
			Adequacy	No concerns about adequacy	
Content of communication – treatment options					
9 studies, reported in 10 publications	Combination of interviews (5 studies), focus groups (3 studies), and systematic review (1 study).	Adults with chronic pain want to know more about their condition and the range of options available to manage their pain, including non-pharmacological options.	Limitations	No or very minor concerns about methodological limitations	HIGH
			Coherence	No or very minor concerns about coherence	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
			Relevance	No or very minor concerns about relevance	
			Adequacy	No concerns about adequacy	
<b>Timing of communication – self-management</b>					
1 study	Focus groups.	Discussions about self-management often happen late in the care pathway, or not at all.	Limitations	No or very minor concerns about methodological limitations	LOW
			Coherence	Moderate concerns about coherence <sup>a</sup>	
			Relevance	No or very minor concerns about relevance	
			Adequacy	Moderate concerns about adequacy <sup>a</sup>	
<b>Timing of communication – prior to attendance</b>					
1 study	Interviews.	Patients are often poorly informed of what to expect from the pain service before they attend for treatment.	Limitations	No or very minor concerns about methodological limitations	LOW
			Coherence	Moderate concerns about coherence <sup>a</sup>	
			Relevance	No or very minor concerns about relevance	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
			Adequacy	Moderate concerns about adequacy <sup>a</sup>	
<b>Approach to communication – use of visual aids and demonstration</b>					
3 studies, reported in 5 publications	Interviews.	The use of visual aids and demonstration can help patients to better understand their pain and the impact of their behaviours and activities.	Limitations	No or very minor concerns about methodological limitations	LOW
			Coherence	No or very minor concerns about coherence	
			Relevance	Moderate concerns about relevance <sup>a</sup>	
			Adequacy	Moderate concerns about adequacy <sup>a</sup>	
<b>Approach to communication – mode of communication</b>					
2 studies, reported in 4 publications	Combination of interviews (1 study), and systematic review (1 study).	Face-to-face and written communication of information is useful.	Limitations	No or very minor concerns about methodological limitations	MODERATE
			Coherence	Moderate concerns about coherence <sup>a</sup>	
			Relevance	No or very minor concerns about relevance	
			Adequacy	No concerns about adequacy	
<b>Approach to communication – location of information</b>					

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
1 study	Interviews	Information is sometimes provided in locations that are not easily accessible for people with chronic pain.	Limitations	No or very minor concerns about methodological limitations	LOW
			Coherence	Moderate concerns about coherence <sup>a</sup>	
			Relevance	No or very minor concerns about relevance	
			Adequacy	Moderate concerns about adequacy <sup>a</sup>	
<b>Approach to communication – continuity of care</b>					
4 studies	Combination of interviews (2 studies), and focus groups (2 studies).	Care that lacks continuity can negatively impact on follow-up and longer term care, and on the consistency of information offered to patients.	Limitations	No or very minor concerns about methodological limitations	HIGH
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	
			Adequacy	No concerns about adequacy	
<b>Other - time</b>					
	Interviews.	Longer consultation times can help patients and healthcare professionals to develop a relationship, and	Limitations	No or very minor concerns about	HIGH

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
4 studies, reported in 7 publications		allow patients to discuss other issues which impact on their pain.		methodological limitations	
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	
			Adequacy	No concerns about adequacy	

<sup>a</sup> Please see narrative summary of review findings for explanation of quality assessment.

## 1.5 Economic evidence

The committee agreed that health economic studies would not be relevant to this review question, and so were not sought.

## 1.6 Evidence statements

### 1.6.1 Qualitative evidence statements

#### Theme: Style of communication

- High quality evidence from eleven studies highlighted the importance of validation and belief for effective communication between healthcare professionals and people with chronic pain.
- High quality evidence from fourteen studies highlighted the importance of listening and empathy for effective communication between healthcare professionals and people with chronic pain.
- Moderate quality evidence from five studies suggested that an open and non-judgmental communication style facilitated effective communication between healthcare professionals and people with chronic pain.
- High quality evidence from six studies suggested that a supportive and collaborative communication style facilitated effective communication between healthcare professionals and people with chronic pain.
- Low quality evidence from two studies suggested that an optimistic and hopeful communication style facilitated effective communication between healthcare professionals and people with chronic pain.
- Moderate quality evidence from two studies suggested that empowering patients to pay attention to their physical sensation can support cooperation and engagement in care.
- Moderate quality evidence from four studies suggested that the use of lay language and understandable terminology is helpful when communicating with people with chronic pain.
- Moderate quality evidence from one study suggested that a patient-centred approach may help build good rapport may help to get the patient on board with the healthcare providers' perspective.

#### Theme: Content of communication

- Low quality evidence from two studies showed that negative test results can be communicated in a way that is perceived by patients as being dismissive of their pain and can lead to patients feeling their treatment options are being limited because of the test results.
- High quality evidence from seven studies showed that a specific diagnosis and an explanation of the acute cause of their pain is valued by people with chronic pain; they understand the difficulty of treating chronic pain and appreciate when physicians acknowledge their lack of certainty of how best to help.
- High quality evidence from nine studies suggested that people with chronic pain want to know more about their condition and the range of options available to manage their pain, including nonpharmacological options.

#### Theme: Timing of communication

- Low quality evidence from one study suggested that discussions about self-management often happen late in the care pathway, or not at all.
- Low quality evidence from one study suggested that people with chronic pain are often poorly informed of what to expect from the pain service before they attend for treatment.

**Theme: Approach to communication**

- Low quality evidence from three studies showed that the use of visual aids and demonstrations as part of the consultation can help people with chronic pain to better understand their pain and the impact of their behaviours and activities.
- Moderate quality evidence from two studies suggested that face-to-face and written communication of information is useful.
- Low quality evidence from one study suggested that location of information is sometimes provided in locations that are not easily accessible for people with chronic pain.
- High quality evidence from four studies showed that care that lacks continuity can negatively impact on the follow-up and longer term care.

**Theme: Other**

- High quality evidence from four studies suggested that longer consultation times can help patients and healthcare professionals to develop a relationship, and allow patients to discuss other issues which impact on their pain.

## 1.7 The committee's discussion of the evidence

### 1.7.1 Interpreting the evidence

#### 1.7.1.1 The quality of the evidence

Thirty-one qualitative studies were included in the review. Seven of the studies were secondary reports, synthesising qualitative research from a range of qualitative studies. Five of these included interviews with patients alone, two with healthcare professionals alone and three with both patients and healthcare professionals. Twenty-four of the studies were primary (original) qualitative studies. Eighteen of these included interviews with patients alone, two with healthcare professionals alone, two with both patients and healthcare professionals, and one with carers as well as patients and healthcare professionals.

Confidence in the review findings ranged from high to low. The main reasons for downgrading were coherence, relevance and adequacy. Some studies were based on people with specific types of chronic pain, so findings were not necessarily applicable to the wider review population. Some findings were based on evidence from a small number of studies, which meant that there was variable coherence and concerns about the adequacy of data (i.e. the richness and quantity of the data), despite data saturation being reached (i.e. no new information or themes were observed in the qualitative analyses).

The committee also noted that several of the studies were set in specialist pain clinics or services, so findings from these studies may be less applicable to primary care settings.

The committee placed greater weight on high and moderate confidence findings than low confidence findings during discussion of the evidence.

#### 1.7.1.2 Findings identified in the evidence synthesis

##### **Style of communication**

The *style* of communication emerged as an important theme from the evidence review about communication between healthcare professionals and people with chronic pain. High quality evidence suggested that feeling believed, being listened to, and the validation of a person's experience were important features of effective communication. The reviews promoted empathy and a supportive and collaborative communication style. The committee considered the recommendations in the NICE patient experience guideline (CG138) alongside the review findings. The committee found that this existing guideline partially supported these



findings. However, the evidence in this review suggested that the features of communication style were of vital importance in the context of consultations with people with chronic pain. Therefore, specific recommendations were made to address the requirements of people with chronic pain, including recognition that chronic pain can cause distress and fostering a collaborative supportive relationship and to develop a care plan with the person. The committee agreed that it was important for healthcare professionals to seek feedback about whether a shared understanding of the factors contributing to the experience of pain had been achieved. It was also agreed that asking the person about their understanding of their condition, and the understanding of those close to them should be included in the consultation.

There was moderate confidence in the evidence that healthcare professionals found a patient-centred approach helped build good rapport and helped people with chronic pain to get on board with their perspective. The committee discussed the importance of patient centredness when communicating with people with chronic pain. In particular, understanding a person's strengths, interests and abilities, as well as how pain impacts on their life, can help inform the shared care plan. Therefore, the committee decided to make recommendations to ask the person to describe how pain affects their life and to explore the person's priorities, strengths, preferences, interests and abilities.

Another facilitator of effective communication was found to be an *open and non-judgemental* approach. This evidence was based mainly on US populations, with a focus around opioid prescribing. The committee considered that this type of communication style was in line with best practice for all people with chronic pain and is reflected in the NICE guideline for patient experience in adult NHS services (CG138).

There was low confidence in the evidence finding that people with chronic pain want to be *optimistic* about the outcomes of treatment, and value the healthcare professional being hopeful about the impact of care. The committee expressed concerns because optimism can be difficult to generate in a situation where pain may be persistent, particularly if the focus of treatment is on pain reduction. The committee considered the relative quality of the evidence, as well as evidence from reviews of pain management interventions in this guideline and the problems that can arise from encouraging unrealistic expectations from treatments. It was agreed that the recommendations should highlight the importance of being honest about uncertainties around the diagnosis, prognosis and effectiveness of treatment in the recommendations.

Some evidence suggested that allowing people to acknowledge and accept their pain enabled them to engage with their healthcare professional in exploring treatment options and solutions. The committee therefore decided to recommend that acceptance is included as part of the assessment of the person's understanding of their condition.

The evidence also suggested that empowering people to pay attention to their physical sensations can support cooperation and engagement in care. It was noted that constant scanning of body symptoms can increase anxiety and awareness of pain and the committee debated the difference between pain experience and physical sensation. The committee noted that this evidence highlighted the importance of people with chronic pain actively reflecting on their self-management skills and the effectiveness of treatment. The committee reflected this in the recommendations about developing a shared understanding and care plan with people with chronic pain.

There was moderate confidence in the evidence finding that the use of lay language and understandable terminology is helpful due to concerns about coherence of the qualitative data. However, this is an area which is specifically addressed by the NICE patient experience guideline (CG138). Therefore no additional recommendations were made.

## **Content of communication**

Evidence suggested that normal and negative test results can be communicated in a way that is perceived by people with chronic pain as being dismissive of their pain, and can also result in them feeling their treatment options are being limited. The committee deliberated on the wording of investigation reports, for example “negative”. There was low confidence in this finding due to concerns about relevance as the evidence was based on people with orofacial pain and healthcare professionals caring for people with chronic low back pain and therefore might not be generalizable to all people with chronic pain and due to the adequacy of the data. However, the committee agreed that this barrier to good communication was also applicable to other types of chronic pain and to all test results including negative, normal and abnormal results. The committee considered that chronic pain can arise independently of a specific tissue diagnosis or biological contributor, and that communication between healthcare professionals and people with chronic pain should reflect this. Therefore, the committee made a recommendation to communicate test results in a manner that does not invalidate the lived experience of pain.

There was high confidence in the evidence finding that people with chronic pain valued a specific diagnosis and an explanation of the cause of their pain. This fed in to the discussion about chronic pain arising where no biological cause or contributor can be identified and supported the recommendations for a communication style that fosters a supportive and collaborative relationship and communication of test results in a manner that does not invalidate the lived experience of pain.

There was also high confidence in the finding that adults with chronic pain want to know more about their condition and the range of options available to manage their pain, including non-pharmacological options. The committee considered that there are a range of treatment options and management strategies available, yet many healthcare professionals and people with chronic pain prioritise pharmacological options. Although provision of information about available treatment options is already recommended in the patient experience guideline, the committee acknowledged the particular importance for the chronic pain population and wanted to highlight the importance of self-management and non-pharmacological alternatives. The committee agreed it was important to recognise that self-management of pain can involve strategies that clinically appear unusual. This should be viewed with respect and constructive curiosity. Therefore, the committee made recommendations to discuss all relevant management options, including non-pharmacological/non-invasive treatments.

### **Timing of communication**

The committee decided to specify that consideration of all relevant management options, including advice to support self-management, should take place at all stages of care, including the first contact. This was in response to the review finding that discussions about self-management often happen late in the care pathway, or not at all. Despite concerns regarding data adequacy, the committee decided that this was particularly important to highlight as initiating this type of discussion early on and at subsequent consultations can make a difference to how people are able to manage their pain.

The committee discussed the finding that people are often poorly informed about what to expect from a pain service before they attend for treatment, which came from evidence of low confidence. Concerns around coherence and adequacy meant that the finding was difficult to interpret, although the committee recognised that this was a common issue in clinical practice. The committee discussed whether this issue was related to another finding in the evidence about people with chronic pain wanting to be optimistic and hopeful and also for their healthcare professionals to be hopeful about the impact of care. The evidence for these findings came from treatments taking place in pain and physiotherapy clinics. Providing information on treatment options, clarifying the person’s expectations from treatment and discussing the aims of the proposed treatments to support a shared decision-making discussion are specifically addressed by the NICE patient experience guideline (CG138). Therefore no additional recommendations were made.

## Approach to communication

The use of visual aids, face-to-face and written communication and continuity of care were found to be facilitators of good communication. The committee discussed the different modes of communication, including digital formats. It was agreed that the appropriateness of different modes is based on individual preferences and circumstances and that this should be included in shared decision making. The committee reviewed recommendations from the NICE guideline on patient experience (CG138) and concluded that the findings were captured and that there were no specific nuances within the chronic pain population that required additional recommendations.

One finding suggested that information is sometimes provided in locations that are not easily accessible for people with chronic pain. However, this was rated as having low confidence and was in relation to the location of information leaflets at a particular pain service and was not regarded by the committee as having wide applicability. Ensuring equality in accessibility of services is also considered in the NICE patient experience guideline (CG138). Therefore no recommendation was made.

## Other

Three studies highlighted that insufficient length of consultations was a barrier to building partnerships or discussing other issues which impacted on pain. These findings came from evidence of high confidence. The committee discussed ways to address this, including double or triple appointment slots, or scheduling a series of appointments to consider different issues. The lay members expressed the views that quality of consultation was more important than length, but also that for patients with very complex medical situations, more time may be useful in discussing all the issues affecting and affected by pain. The committee decided not to make a specific recommendation on this topic as making extra time and best use of the available time were considered to be a normal part of good clinical practice. The NICE guideline on patient experience (CG138) specifically addresses these issues and the committee chose not to make any further recommendations specific to the chronic pain population.

### 1.7.2 Cost effectiveness and resource use

Economic evidence was not applicable to this review as it was a qualitative review.

The committee agreed that this review was key for management of chronic pain because successful communication with the person with chronic pain is both therapeutic in itself and is crucial to building a trusting relationship, validating their pain experience and discussing how to manage their pain.

The committee agreed that many of the themes that were identified reflect best practice and should be undertaken already although the evidence highlighted that people's experiences vary substantially. The committee therefore made recommendations about communication style, content, timing and approach specific to people with chronic pain that were not covered in the NICE guideline on patient experience (CG138).

A particular theme reported to be an enabler of good communication that could impact resource use, was the length of consultations. Discussions with a person experiencing chronic pain can take time and it may not always be possible to validate the person's pain experience, discuss the management options and the person's goals, provide advice to support self-management, check the person feels understood and has had a chance to reflect on the effectiveness of treatments; all within one consultation. Ways of addressing this include double appointments in primary care, or agreeing with the person that they should make a future appointment to continue discussions. The NICE guideline on patient experience (CG138) specifically addresses these issues and the committee chose not to make any further recommendations specific to the chronic pain population.

Nevertheless, where more consultation time is needed than currently provided, the implications for resource use may be significant, for example in training costs or clinicians' time. As the quality of practice nationwide across different settings of care is unknown, it is impossible to quantify any national implication for resource use.

### **1.7.3 Other factors the committee took into account**

The committee were cognisant of the principles embodied in the NICE guideline on patient experience (CG138), particularly in optimising communication in different patient groups and ensuring that services are equally accessible to, and supportive of, all people using adult NHS services. The committee chose not to make any further recommendations specific to the chronic pain population.

The committee noted that there was no evidence available for people aged under 18 years. They agreed by consensus that there are some particular considerations that should be taken into account in the assessment of young people (aged 16 to 25) such as age-related differences in presentation of symptoms, the impact of the pain on family interactions and dynamics and the impact of the pain on education and social and emotional development. Consensus recommendations were included. The committee noted that some of these factors may also apply to older people (for example, older people may also be attending further education) but these were of particular importance to this younger age group.

The committee noted that the equality issues identified in the equality impact assessment form were particularly important to consider in these recommendations, in particular giving consideration to people with cognitive impairment, learning difficulties and those whose first language is not English. It was agreed that the recommendations as worded reflected the need for tailoring communication according to people's abilities and needs and therefore separate recommendations were not required for these groups, but their needs should be taken into account.

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# Appendices

## Appendix A: Review protocols

Review protocol for communication between healthcare professionals and people with chronic pain

ID	Field	Content
0.	PROSPERO registration number	NA
1.	Review title	What are the best methods of communication between healthcare professionals and people with chronic pain?
2.	Review question	What are the best methods of communication between healthcare professionals and people with chronic pain?
3.	Objective	To identify barriers and facilitators to good communication between people with chronic pain and the healthcare professional during consultation.
4.	Searches	<p>The following databases will be searched:</p> <ul style="list-style-type: none"> <li>• Embase</li> <li>• MEDLINE</li> <li>• CINAHL, Current Nursing and Allied Health Literature</li> <li>• PsycINFO</li> <li>• ASSIA</li> </ul> <p>Searches will be restricted by:</p> <ul style="list-style-type: none"> <li>• English language</li> </ul>

		<ul style="list-style-type: none"> <li>• Human studies</li> <li>• Letters and comments are excluded.</li> </ul> <p>Other searches:</p> <ul style="list-style-type: none"> <li>• Inclusion lists of relevant systematic reviews will be checked by the reviewer.</li> </ul> <p>The searches may be re-run 6 weeks before final committee meeting and further studies retrieved for inclusion if relevant.</p> <p>The full search strategies will be published in the final review.</p>
5.	Condition or domain being studied	Chronic pain (pain that persists or recurs for longer than three months).
6.	Population	Inclusion: People, aged 16 years and over, with chronic pain and healthcare professionals.
7.	Intervention/Exposure/Test	NA
8.	Comparator/Reference standard/Confounding factors	NA
9.	Types of study to be included	Qualitative interview and focus group studies (including studies using grounded theory, phenomenology or other appropriate qualitative approaches); quantitative data from questionnaires will only be considered if insufficient qualitative evidence is identified.
10.	Other exclusion criteria	Conference abstracts will be excluded as it is expected there will be sufficient full text published studies available.
11.	Context	-

12.	Primary outcomes (critical outcomes)	Themes will be derived from the evidence identified for this review, and not pre-specified by the guideline committee in advance.
13.	Secondary outcomes (important outcomes)	NA
14.	Data extraction (selection and coding)	<p>EndNote will be used for reference management, sifting, citations and bibliographies. All references identified by the searches and from other sources will be screened for inclusion. 10% of the abstracts will be reviewed by two reviewers, with any disagreements resolved by discussion or, if necessary, a third independent reviewer. The full text of potentially eligible studies will be retrieved and will be assessed in line with the criteria outlined above. No duplicate screening was deemed necessary for this question, for more information please see the separate Methods report for this guideline.</p> <p>A standardised form will be used to extract data from studies (see <a href="#">Developing NICE guidelines: the manual</a> section 6.4).</p>
15.	Risk of bias (quality) assessment	<p>Risk of bias will be assessed using the Critical Appraisal Skills Programme (CASP) qualitative checklist.</p> <p>10% of all evidence reviews are quality assured by a senior research fellow. This includes checking:</p> <ul style="list-style-type: none"> <li>• papers were included /excluded appropriately</li> <li>• a sample of the data extractions</li> <li>• correct methods are used to synthesise data</li> <li>• a sample of the risk of bias assessments</li> </ul> <p>Disagreements between the review authors over the risk of bias in particular studies will be resolved by discussion, with involvement of a third review author where necessary.</p>
16.	Strategy for data synthesis	<p>Evidence will be analysed using thematic analysis; findings will be presented narratively and diagrammatically where appropriate. Findings will be reported according to GRADE CERQual standards.</p> <p>Additional qualitative studies will be added to the review until themes within the analysis become saturated; i.e. studies will only be included if they contribute towards the development of existing themes or to the development of new themes.</p>

17.	Analysis of sub-groups	NA	
18.	Type and method of review	<input type="checkbox"/>	Intervention
		<input type="checkbox"/>	Diagnostic
		<input type="checkbox"/>	Prognostic
		<input checked="" type="checkbox"/>	Qualitative
		<input type="checkbox"/>	Epidemiologic
		<input type="checkbox"/>	Service Delivery
		<input type="checkbox"/>	Other (please specify)
19.	Language	English	
20.	Country	England	
21.	Anticipated or actual start date	21/11/2018	
22.	Anticipated completion date	19/08/2020	
24.	Named contact	<p>5a. Named contact National Guideline Centre</p> <p>5b Named contact e-mail Chronicpain@nice.org.uk</p> <p>5e Organisational affiliation of the review National Institute for Health and Care Excellence (NICE) and the National Guideline Centre</p>	

25.	Review team members	<p>From the National Guideline Centre:</p> <p>Serena Carville, Guideline Lead</p> <p>Beth Shaw, Systematic Reviewer</p> <p>Maria Smyth, Senior Systematic Reviewer</p> <p>Rebecca Boffa, Senior Systematic Reviewer</p> <p>Margaret Constanti, Senior Health Economist</p> <p>Joseph Runicles, Information Specialist</p> <p>Katie Broomfield, Project Manager</p>
26.	Funding sources/sponsor	This systematic review is being completed by the National Guideline Centre which receives funding from NICE.
27.	Conflicts of interest	All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must declare any potential conflicts of interest in line with NICE's code of practice for declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a member's declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.
28.	Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of <a href="#">Developing NICE guidelines: the manual</a> . Members of the guideline committee are available on the NICE website: <a href="https://www.nice.org.uk/guidance/indevelopment/gid-ng10069">https://www.nice.org.uk/guidance/indevelopment/gid-ng10069</a>
29.	Other registration details	NA
30.	Reference/URL for published protocol	NA
31.	Dissemination plans	NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as:



		<ul style="list-style-type: none"> <li>• notifying registered stakeholders of publication</li> <li>• publicising the guideline through NICE's newsletter and alerts</li> <li>• issuing a press release or briefing as appropriate, posting news articles on the NICE website, using social media channels, and publicising the guideline within NICE.</li> </ul>
32.	Keywords	-
33.	Details of existing review of same topic by same authors	NA
35.	Additional information	-
36.	Details of final publication	<a href="http://www.nice.org.uk">www.nice.org.uk</a>

**Table 5: Health economic review protocol**

The committee agreed that health economic studies would not be relevant to this review question, and so were not sought.

## Appendix B: Literature search strategies

The literature searches for this review are detailed below and complied with the methodology outlined in Developing NICE guidelines: the manual<sup>165</sup>

For more information, please see the Methods Report published as part of the accompanying documents for this guideline.

### B.1 Clinical search literature search strategy

Searches for patient views were run in Medline (OVID), Embase (OVID), CINAHL, Current Nursing and Allied Health Literature (EBSCO) and PsycINFO (ProQuest). Search filters were applied to the search where appropriate.

**Table 6: Database date parameters and filters used**

Database	Dates searched	Search filter used
Medline (OVID)	1946 – 20 May 2020	Exclusions Qualitative studies
Embase (OVID)	1946 – 20 May 2020	Exclusions Qualitative studies
CINAHL, Current Nursing and Allied Health Literature (EBSCO)	Inception – 20 May 2020	Exclusions Qualitative studies
PsycINFO (ProQuest)	Inception – 20 May 2020	Qualitative studies

#### Medline (Ovid) search terms

1.	chronic pain/ or pain, intractable/
2.	((persist* or intract* or chronic or longstanding or long standing or longterm or long term or refractory or prolong* or long last* or sustain* or linger* or syndrome*) adj3 pain*).ti,ab.
3.	or/1-2
4.	letter/
5.	editorial/
6.	news/
7.	exp historical article/
8.	Anecdotes as Topic/
9.	comment/
10.	case report/
11.	(letter or comment*).ti.
12.	or/4-11
13.	randomized controlled trial/ or random*.ti,ab.
14.	12 not 13
15.	animals/ not humans/
16.	exp Animals, Laboratory/
17.	exp Animal Experimentation/
18.	exp Models, Animal/
19.	exp Rodentia/
20.	(rat or rats or mouse or mice).ti.
21.	or/14-20

22.	3 not 21
23.	limit 22 to English language
24.	"patient acceptance of health care"/ or exp patient satisfaction/
25.	Patient Education as Topic/
26.	patient participation/
27.	((information* or advice or advising or advised or support*) adj3 (patient* or need* or requirement* or assess* or seek* or access* or disseminat*)).ti,ab.
28.	(information* adj2 (patient* or need* or requirement* or support* or seek* or access* or disseminat* or barrier* or facilitat*)).ti,ab.
29.	((client* or patient* or user* or carer* or consumer* or customer*) adj2 (attitud* or priorit* or perception* or preferen* or expectation* or choice* or perspective* or view* or satisfact* or inform* or experience or experiences or opinion* or educat* or learn* or train* or program* or advi?e* or instruct* or teach* or knowledge or understanding or misunderstanding or communicat* or involvement or support)).ti,ab.
30.	physician-patient relations/
31.	*decision making/
32.	((share* or sharing or making or made or agree* or participat* or support* or collaborat* or joint) adj2 decision*).ti,ab.
33.	shared decision making.ti,ab.
34.	((consult* or communicat* or learning) adj2 (style* or technique* or method* or approach*)).ti,ab.
35.	Professional-Patient Relations/
36.	Motivational Interviewing/
37.	(collaborative working or motivation* interview* or therapeutic alliance or nondirective therap* or non directive therap* or reflective listening or decision balancing or interview* style* or intrinsic motivation*).ti,ab.
38.	or/24-37
39.	Qualitative research/ or Narration/ or exp Interviews as Topic/ or exp "Surveys and Questionnaires"/ or Health care surveys/
40.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
41.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* adj3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).ti,ab.
42.	or/39-41
43.	23 and 38 and 42

**Embase (Ovid) search terms**

1.	chronic pain/ or intractable pain/
2.	((persist* or intract* or chronic or longstanding or long standing or longterm or long term or refractory or prolong* or long last* or sustain* or linger* or syndrome*) adj3 pain*).ti,ab.
3.	or/1-2
4.	letter.pt. or letter/
5.	note.pt.
6.	editorial.pt.
7.	case report/ or case study/
8.	(letter or comment*).ti.
9.	or/4-8

10.	randomized controlled trial/ or random*.ti,ab.
11.	9 not 10
12.	animal/ not human/
13.	nonhuman/
14.	exp Animal Experiment/
15.	exp Experimental Animal/
16.	animal model/
17.	exp Rodent/
18.	(rat or rats or mouse or mice).ti.
19.	or/11-18
20.	3 not 19
21.	limit 20 to English language
22.	patient attitude/ or patient preference/ or patient satisfaction/ or consumer attitude/
23.	patient information/ or consumer health information/
24.	patient education/
25.	patient participation/
26.	((information* or advice or advising or advised or support*) adj3 (patient* or need* or requirement* or assess* or seek* or access* or disseminat*)).ti,ab.
27.	(information* adj2 (patient* or need* or requirement* or support* or seek* or access* or disseminat* or barrier* or facilitat*)).ti,ab.
28.	((client* or patient* or user* or carer* or consumer* or customer*) adj2 (attitud* or priorit* or perception* or preferen* or expectation* or choice* or perspective* or view* or satisfact* or inform* or experience or experiences or opinion* or educat* or learn* or train* or program* or advi?e* or instruct* or teach* or knowledge or understanding or misunderstanding or communicat* or involvement or support)).ti,ab.
29.	doctor patient relation/
30.	*decision making/
31.	((share* or sharing or making or made or agree* or participat* or support* or collaborat* or joint) adj2 decision*).ti,ab.
32.	((consult* or communicat* or learning) adj2 (style* or technique* or method* or approach*)).ti,ab.
33.	professional-patient relationship/
34.	motivational interviewing/
35.	client centered therapy/
36.	(collaborative working or motivation* interview* or therapeutic alliance or nondirective therap* or non directive therap* or reflective listening or decision balancing or interview* style* or intrinsic motivation*).ti,ab.
37.	or/22-36
38.	health survey/ or exp questionnaire/ or exp interview/ or qualitative research/ or narrative/
39.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
40.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* adj3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).ti,ab.
41.	or/38-40
42.	21 and 37 and 41

**CINAHL (EBSCO) search terms**

S1.	(MH "Chronic Pain")
S2.	((persist* or intract* or chronic or longstanding or long standing or longterm or long term or refractory or prolong* or long last* or sustain* or linger* or syndrome*) n3 pain*)
S3.	S1 OR S2
S4.	(MH "Consumer Satisfaction+") OR (MH "Patient Education") OR (MH "Health Education")
S5.	(MH "Consumer Participation")
S6.	((information* or advice or advising or advised or support*) n3 (patient* or need* or requirement* or assess* or seek* or access* or disseminat*))
S7.	(information* n2 (patient* or need* or requirement* or support* or seek* or access* or disseminat* or barrier* or facilitat*))
S8.	((client* or patient* or user* or carer* or consumer* or customer*) n2 (attitud* or priorit* or perception* or preferen* or expectation* or choice* or perspective* or view* or satisfact* or inform* or experience or experiences or opinion* or educat* or learn* or train* or program* or advi?e* or instruct* or teach* or knowledge or understanding or misunderstanding or communicat* or involvement or support))
S9.	(MH "Physician-Patient Relations") OR (MH "Professional-Patient Relations+")
S10.	(MH "Decision Making, Patient+")
S11.	((share* or sharing or making or made or agree* or participat* or support* or collaborat* or joint) n2 decision*)
S12.	((consult* or communicat* or learning) n2 (style* or technique* or method* or approach*))
S13.	(MH "Motivational Interviewing")
S14.	(collaborative working or motivation* interview* or therapeutic alliance or nondirective therap* or non directive therap* or reflective listening or decision balancing or interview* style* or intrinsic motivation*)
S15.	S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14
S16.	(MH "Qualitative Studies+")
S17.	(MH "Qualitative Validity+")
S18.	(MH "Interviews+") OR (MH "Focus Groups") OR (MH "Surveys") OR (MH "Questionnaires+")
S19.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*)
S20.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* n3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or riceour* or spiegelberg* or merleau*)
S21.	S16 OR S17 OR S18 OR S19 OR S20
S22.	S3 AND S15 AND S21
S23.	PT anecdote or PT audiovisual or PT bibliography or PT biography or PT book or PT book review or PT brief item or PT cartoon or PT commentary or PT computer program or PT editorial or PT games or PT glossary or PT historical material or PT interview or PT letter or PT listservs or PT masters thesis or PT obituary or PT pamphlet or PT pamphlet chapter or PT pictorial or PT poetry or PT proceedings or PT "questions and answers" or PT response or PT software or PT teaching materials or PT website
S24.	S22 not S23

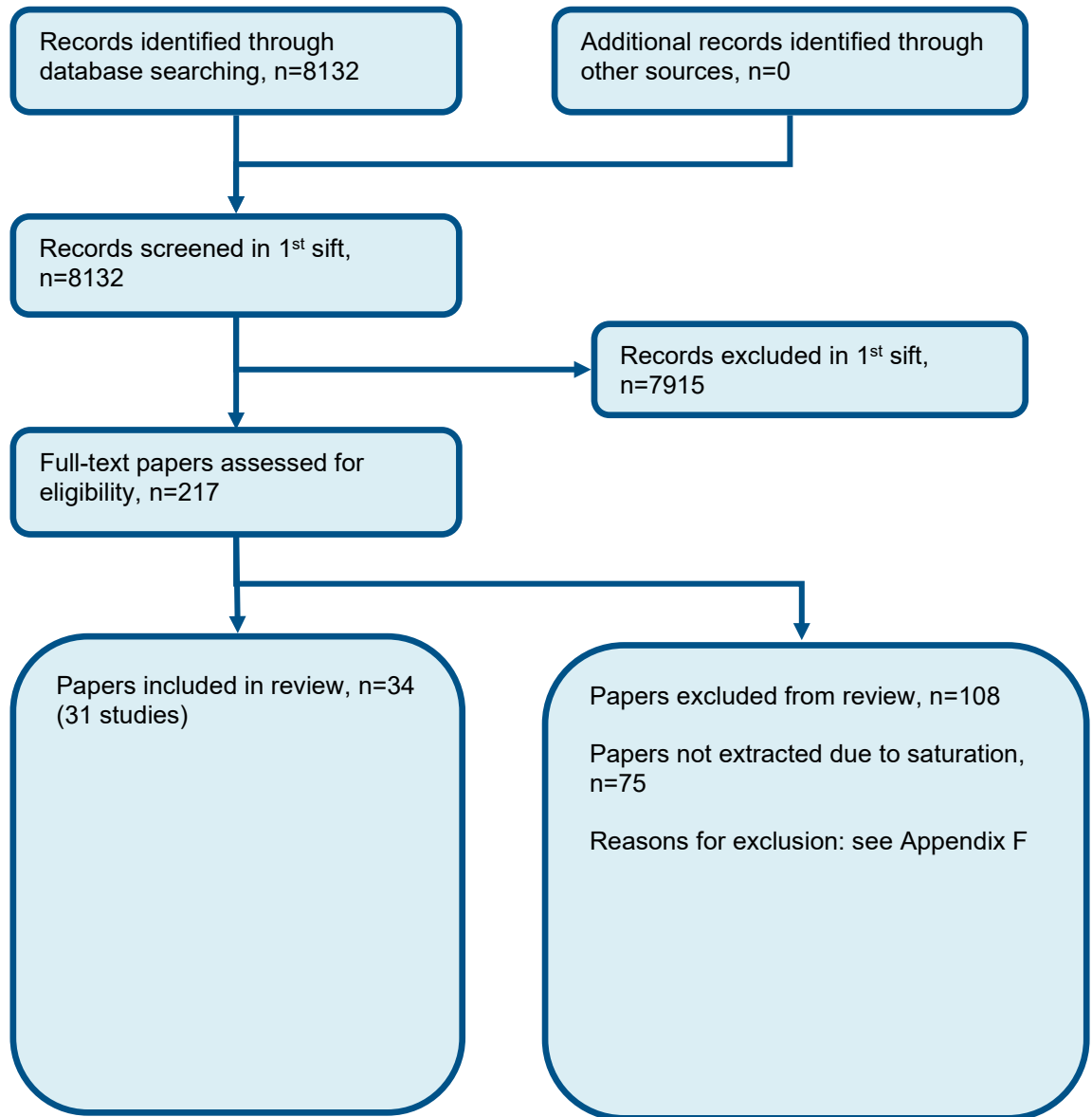
**PsycINFO (ProQuest) search terms**

1.	MAINSUBJECT.EXACT.EXPLODE("Chronic Pain") OR TI,AB((persist* OR intract* OR chronic OR longstanding OR "long standing" OR longterm OR "long term" OR refractory OR prolong* OR "long last*" OR sustain* OR linger* OR syndrome*) NEAR/3 pain*)
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2.	(MAINSUBJECT.EXACT("Therapeutic Processes") OR TI,AB((share* OR sharing OR making OR made OR agree* OR participat* OR support* OR collaborat* OR joint) NEAR/2 decision*)) OR (TI,AB((consult* OR communicat* OR learning) NEAR/2 (style* OR technique* OR method* OR approach*)) OR MAINSUBJECT.EXACT("Decision Making"))
3.	MAINSUBJECT.EXACT("Motivational Interviewing") OR TI,AB("collaborative working" OR "motivation* interview*" OR "therapeutic alliance" OR "nondirective therap*" OR "non directive therap*" OR "reflective listening" OR "decision balancing" OR "interview* style*" OR "intrinsic motivation*")
4.	SU.EXACT("Client Education") OR SU.EXACT.EXPLODE("Client Attitudes") OR TI,AB((information* or advice or advising or advised or support*) N/3 (patient* or need* or requirement* or assess* or seek* or access* or disseminat*)) OR TI,AB(information* N/2 support*) OR TI,AB((client* or patient* or user* or carer* or consumer* or customer*) N/2 (attitud* or priorit* or perception* or preferen* or expectation* or choice* or perspective* or view* or satisfact* or inform* or experience or experiences or opinion*))
5.	((su.exact.explode("qualitative research") or su.exact("narratives") or su.exact.explode("questionnaires") or su.exact.explode("interviews") or su.exact.explode("health care services") or ti,ab(qualitative or interview* or focus group* or theme* or questionnaire* or survey*) or ti,ab(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* near/3 analys*) or theoretical-sampl* or purposive-sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*))
6.	2 or 3 or 4
7.	1 and 5 and 6

## Appendix C: Qualitative evidence selection

Figure 1: Flow chart of qualitative study selection for the review of communication between healthcare professionals and people with chronic pain





## Appendix D: Qualitative evidence tables

Study	Baker 2018 <sup>16</sup>
Aim	To explore what happens when the discourses of compassionate care and evidence based practice interact
Population	Adults and children with chronic pain; numbers by age were not reported, but it is assumed that the majority of texts related to adults, rather than children  n=458 text reports, comprising 204 grey literature reports (non-peer-reviewed sources, e.g., guidelines), 247 patient blogs, and 9 interviews with clinicians and postgraduate trainees from local pain clinics
Setting	Any setting included
Study design	Qualitative approach, based on document analysis
Methods and analysis	<p>Interpretive qualitative approach, using principles of Foucauldian critical discourse analysis Grey literature and patient blog texts were gathered concurrently and purposively, and the interviews were informed by ongoing analyses. Texts were collected and analysed until saturation was reached.</p> <p>Phase 1 focused on the grey literature. Researchers coded meaning units (segments of text that represent one idea or concept) and wrote memos in response to guiding questions. Coded meaning units were then synthesized into main themes. Meetings with the principal investigators and monthly meetings with the full team guided the analytic process.</p> <p>Phase 2 involved analysis of the interview transcripts abductively, informed by the guiding analytic questions and the analysis from phase 1.</p> <p>Phase 3 involved synthesising the analyses from phases 1 and 2, at the systems level (e.g., policy documents and practice guidelines) the institutional level (e.g., chronic pain centre documents) and the individual level (patient blog posts). The study aimed to develop representative stories.</p>
Findings	<p><b>Style of communication – validation</b></p> <p>Clinicians, as witnesses, can either validate or invalidate the patient experience. A lack of validation results in a non-compassionate experience of care. When patients perform their pain effectively, clinicians validate the pain experience by acknowledging the meaning of the experience from the patient’s perspective, thus performing belief in the patient. However, when patients do not perform their pain effectively, clinicians are often sceptical, rendering patient experiences of pain invisible and/or invalid.</p> <p>Other themes were identified in the study but were not directly related to communication, and so are not reported further here.</p>

<b>Study</b>	<b>Baker 2018</b> <sup>16</sup>
Limitations and applicability of evidence	No significant methodological limitations noted Study conducted in Canada, and focused on local data and text reports

<b>Study</b>	<b>Beitel 2017</b> <sup>22</sup>
Aim	To examine how drug counsellors with no prior training in pain management respond to their patients' reports of chronic pain
Population	Methadone maintenance treatment drug counsellors with no prior training in pain management who were recruited from three opioid treatment programmes  n=30; Female 20, male 10; Ethnicity white 77%, African-American 13%, Hispanic 7%, other 3%; Mean age 43.9 years (SD 12.7 years); Mean years of counselling experience 5.8 (SD 5.2 years). Qualifications Master's 53%, doctoral degree 3%, 17% had a 4-year degree, 13% had a 2-year degree, and the remainder (14%) had a high school diploma or general educational development
Setting	Opioid treatment programme
Study design	Qualitative research, based on semi-structured interviews
Methods and analysis	Face-to-face interviews  Data analysis followed the principles of grounded theory, using the constant comparative method for systematic inductive analysis. Data coding involved reviewing a subset of the transcripts independently and then initial themes recorded using the open-coding technique by 2 researchers. Themes were not identified in advance and were instead derived from the data. Upon reaching consensus of broad themes and their working definitions, the team then revisited the data using this preliminary coding scheme to develop a set of axial codes that involved conceptually grouping open codes into domains and identifying the subthemes in each domain. Each transcript was coded independently with review and reconciliation of coding schemes. The relevance of themes and subthemes were tested by repeated comparative assessment of succeeding data and continued until thematic saturation was reached.
Findings	<b>Style of communication – empathy</b> Respondents reported that attempting to understand patients' lived experiences of chronic pain facilitated patient and counsellor engagement in treatment. Examples included empathizing with patients who did not understand why they had chronic pain or were attempting to manage pain while having an opioid use disorder.  Other themes were identified in the study but were not directly related to communication, and so are not reported further here.

<b>Study</b>	<b>Beitel 2017</b> <sup>22</sup>
Limitations and applicability of evidence	Moderate limitations noted around participant selection and impact of the researchers on the process Study conducted in the US Limited to a very specific but important subgroup of patients
<b>Study</b>	<b>Breckons 2017</b> <sup>32</sup>
Aim	To examine patients' use and experience of health care for persistent orofacial pain over a 12-month period
Population	Patients with persistent orofacial pain  n=22; Age 40 and under 4/22, 41 to 49 6/22, 50 to 59 4/22, 60 to 69 6/22, 70 and older 2/22; Time since pain started 12 months or less 3/22, 12 months to 5 years 9/22, 5 to 10 years 2/22, 10 years or more 8/22; Healthcare professionals seen 1 to 4 11/22, 5 to 8 7/22, 9 to 12 4/22  Purposive maximum variation sample of those participating in the DEEP study was taken according to sex, care environments experienced, time in care, and origin of persistent orofacial pain
Setting	Primary and secondary care
Study design	Longitudinal qualitative research, based on semi-structured interviews at different time points
Methods and analysis	Iterative thematic analysis  Interviews were digitally recorded and transcribed verbatim. Immersion in the data began with an initial reading of the transcripts while researchers listened to the recording to familiarize themselves with the data and identify transcription errors or missing data. The 2 interviewers carried out coding of data, and regular discussion of emerging themes took place at project team meetings. Data from baseline and 12 months were treated identically with respect to coding and identification of themes, and pairs of interviews were also examined together to examine experiences in the period between the 2 interviews. Care pathways for each patient were assembled.
Findings	<b>Content of communication – negative test results</b> Some patients described communication of negative or inconclusive test results as evidence of a failure to acknowledge their condition on the part of healthcare professionals and a failure to progress. For patients where a negative diagnostic test was communicated to them as “good news,” there was a clear discord between how a negative test was perceived by the patient and the healthcare professional.  For some patients, a negative test result appeared to mark an end point in healthcare professionals' efforts to diagnose and treat their pain; therefore, it seemed to those individuals that a diagnosis was necessary to qualify for further medical care.  Other themes were identified in the study but were not directly related to communication, and so are not reported further here.
Limitations and applicability of evidence	No significant methodological limitations noted Study conducted in the UK Focus on a specific type of chronic pain (orofacial pain) in a small number of participants.

<b>Study</b>	<b>Buchman 2016</b> <sup>37</sup>
<b>Aim</b>	To provide an in-depth examination of how adults living with chronic pain negotiate trust and demonstrate trustworthiness with clinicians in therapeutic encounters
<b>Population</b>	<p>Adults (aged between 35 and 64) with self-reported chronic pain in the low back region for 2 years or longer, and under the care of a primary care physician for pain management</p> <p>n=27; Age mean 54.3 years (SD 7.3); Female 63%; Ethnicity 56% multiple or other, Canadian, European or white 32%, Aboriginal 12%; Duration of pain 14.4 years (SD 11.3); With current primary care physician mean 6.1 years (SD 5.34)</p> <p>Also a provider feedback group consisting of 6 physicians (5 men), representing the specialties of family medicine (n=1), internal medicine (n=2), and psychiatry (n=3)</p>
<b>Setting</b>	Primary care
<b>Study design</b>	Qualitative research, based on semi-structured interviews and focus groups
<b>Methods and analysis</b>	<p>Semi-structured interviews, triangulated with 2 groups of patient participants in the interviews and physicians Feedback groups feedback groups were conducted to refine the analytic categories and minimize researcher misinterpretation</p> <p>Grounded theory analysis was used.</p> <ol style="list-style-type: none"> <li>1. Organizing raw data into broad thematic categories</li> <li>2. Identifying key codes and organizing into larger themes</li> <li>3. Relating categories to subcategories and to bring segmented data back together to describe the studied experience in full depth</li> </ol> <p>Rigor was addressed using a second coder for data analysis, including a process for member checking, and triangulating the data with the physician feedback group</p>
<b>Findings</b>	<p><b>Style of communication – empathy</b> Patients perceived that their clinicians have demonstrated a lack of care, empathy, and respect.</p> <p><b>Style of communication – belief</b> Participants experienced doubts that their clinicians believed that they were being honest about their motives for seeking treatment (e.g., drug misuse or drug diversion). Not all patient participants reported that clinicians found them untrustworthy or dismissed their treatment seeking motives or testimony. Patients also felt that stigmatized identities, such as being a person with chronic pain and a person with an addiction, can influence the participants’ perceived trustworthiness. Physicians were concerned that patients may not be telling the truth about their motivations to obtain opioid medications.</p> <p>Other themes were identified in the study but were not directly related to communication, and so are not reported further here.</p>

<b>Study</b>	<b>Buchman 2016</b> <sup>37</sup>
Limitations and applicability of evidence	No significant methodological limitations noted Study conducted in Canada

<b>Study</b>	<b>Calner 2017</b> <sup>42</sup>
Aim	To explore and describe the expectations people with persistent pain have prior to physiotherapy treatment
Population	Adults with persistent neck, back, or shoulder pain  n=10; Female 40%; Age range 20 to 74 years; Duration of pain range 7 to 192 months; Naïve to physiotherapy 30%
Setting	Physiotherapy services in primary care
Study design	Qualitative research, based on semi-structured interviews
Methods and analysis	Audio recorded semi-structured interviews analysed using an iterative method to develop meaning units. Meaning units were then condensed and formulated into codes, which in turn were developed into categories.
Findings	<b>Style of communication – validation</b> Patients expected good interaction, respect and affirmation as individuals with specific needs.  <b>Content of communication – explanation of symptoms</b> Patients emphasized the importance of getting an explanation of the acute cause of their pain. Some patients wanted this to be specific and individualised, and not general information.  Other themes were identified in the study but were not directly related to communication, and so are not reported further here.
Limitations and applicability of evidence	No significant methodological limitations noted Study conducted in Sweden

<b>Study</b>	<b>Cheng 2019</b> <sup>47</sup>
Aim	To understand how chronic pain impacts low-income individuals with chronic pain and their communities from multiple perspectives
Population	Adults (aged 18 years and older) who could participate in English.  <u>Patients with chronic pain</u>

Study	Cheng 2019 <sup>47</sup>
	<p>n=12; Female 75%; Age mean 46.4 (SD 11.4) years; Race Black/African American 50%, Caucasian/White 0%, Other 33%, Not answered 17%; Ethnicity Hispanic 25%, Non-Hispanic 67%, Not answered 8%</p> <p><u>Providers with chronic pain</u> n=9; Female 89%; Age mean 55.0 (SD 14.2 years; Race Black/African American 56%, Caucasian/White 0%, Other 11%, Not answered 33%; Ethnicity Hispanic 11%, Non-Hispanic 78%, Not answered 11%; All worked for organizations with some role in chronic pain care</p> <p><u>Providers without chronic pain</u> n=5; Female 60%; Age mean 29.2 (SD 3.5) years; Race Black/African American 0%, Caucasian/White 80%, Other 20%, Not answered 0%; Ethnicity Hispanic 20%, Non-Hispanic 80%, Not answered 0%; All worked for organizations with some role in chronic pain care</p>
Setting	Community
Study design	Science Café Approach, including survey and focus groups
Methods and analysis	Data were collected through self-reported questionnaires and audio or video recordings of two focus groups. Quantitative and qualitative data were analysed with SAS 9.3 and NVivo 10. Initial codes were derived from the moderator guide. A modified grounded theory approach was used to generate new codes. Video recording was analysed to observe body language and non-verbal responses.
Findings	<p><b>Style of communication – listening</b> Patients wanted to be listened to and one provider described it as their ‘primary responsibility’ is to listen.</p>
	<p><b>Style of communication – non-judgmental</b> Patients experienced a range of stigma related to opioid use, homelessness, and race where they considered that provider assumptions had impacted on their quality of care.</p>
	<p>Other themes were identified in the study but were not directly related to communication, and so are not reported further here.</p>
Limitations and applicability of evidence	<p>No significant methodological limitations noted Study conducted in the US</p>

Study	Crowe 2017 <sup>61</sup>
Aim	To examine how older people cope with non-malignant chronic pain
Population	<p>Older people (aged 65 and older) with chronic non-malignant pain</p> <p>n=17 qualitative studies, published between 1996 and 2015</p>

<b>Study</b>	<b>Crowe 2017</b> <sup>61</sup>
Setting	Any setting included
Study design	Systematic review of qualitative studies
Methods and analysis	Searched 3 databases. Used thematic analysis to analyse themes from the included studies. CERQual was used to assess confidence in each meta-theme and individual study quality was assessed using the CASP checklist.
Findings	<b>Style of communication – support</b> While most patients did not want medical interventions, some did want support from health services.
	<b>Content of communication – treatment options</b> Patients wanted support through the provision of information on which to base decisions about how to best manage the pain.
	Other themes were identified in the study but were not directly related to communication, and so are not reported further here.
Limitations and applicability of evidence	No significant methodological limitations noted Limited to older people

<b>Study</b>	<b>Devan 2018</b> <sup>70</sup>
Aim	To synthesize enablers (what works) and barriers (what does not) of incorporating self-management strategies for people in everyday life after completion of a pain self-management intervention
Population	Adults (16 years old and older) with chronic pain  n=33 studies, with 512 participants with a variety of chronic pain conditions (e.g., primary pain, musculoskeletal pain, orofacial pain, provoked vestibulodynia, migraine). Studies were predominantly conducted in high-income countries such as the UK (n=12), Europe (n=9), US (n=4), Australia (n=4),26, and Canada (n=3). 4 studies used mixed-method design, with the remaining being qualitative only. 2 studies used focus groups and 31 used individual interviews for data collection.
Setting	Any setting included
Study design	Systematic review of qualitative studies exploring the perceptions of individuals with chronic pain participating in a self-management intervention using qualitative data collection methods
Methods and analysis	Thematic synthesis taking a 3-step approach using NVivo <ol style="list-style-type: none"> <li>1. Line-by-line coding of text segments specific to review objectives was made from results and discussion sections of the included articles</li> <li>2. Raw codes labelled to form “descriptive themes”</li> <li>3. “Analytical themes” generated from “descriptive themes” that went beyond the synthesis of included articles</li> </ol>

<b>Study</b>	<b>Devan 2018</b> <sup>70</sup>
	When coding was completed, the whole research team discussed the synthesis of findings and examined the analytical themes from the analysis. An iterative approach was undertaken by moving between the raw data and themes. Final analytical themes were derived by consensus among the research team. GRADE CERQual was used to assess the level of confidence for main and sub- themes.
Findings	<b>Style of communication – open and non-judgmental</b> Continued and effective self-management of chronic pain was supported by a collaborative partnership with clinicians. A strong therapeutic alliance was achieved via open and non-judgmental communication, being believed and listened to, valuing the person and person centeredness by means of shared decision making and guided problem solving. Other themes were identified in the study but were not directly related to communication, and so are not reported further here.
Limitations and applicability of evidence	No significant methodological limitations noted Limited to people participating in self-management interventions

<b>Study</b>	<b>Donovan 2017</b> <sup>74</sup>
Aim	To understand the lived experiences of emergency department (ED) use by patients with chronic pain and a history of frequent ED use
Population	Medicaid members living with chronic pain who used the ED more than 3 times in the past year  n=24; Age range 21 to 64; Female 62%; 64% White, 26% Latino/ Hispanic and other All patients reported musculoskeletal pain; 8 also reported concomitant pain-related systemic illnesses (e.g., cancer, diabetic neuropathy). All patients were eligible to participate in the Pain Management program and 19 patients identified as currently participating
Setting	ED
Study design	Qualitative research, based on semi-structured interviews
Methods and analysis	The coding scheme was created by the research team. Deductive thematic analysis was used. The research team created a coding structure based on the interview guide, which was refined as interviews were completed. Coding was completed in duplicate by 5 research team members trained in qualitative analysis; each transcript’s coding was discussed by the larger research team and discrepancies resolved with discussion
Findings	<b>Style of communication – non-judgmental</b> Patients felt defensive in the ED and believed they were suspected of diverting or misusing pain medication; yet patients also reported that medication was being “pushed” on them at the expense of finding an underlying problem. Other themes were identified in the study but were not directly related to communication, and so are not reported further here.



<b>Study</b>	<b>Donovan 2017</b> <sup>74</sup>
Limitations and applicability of evidence	Moderate limitations noted around the impact of the researchers on the process Study conducted in the US

<b>Study</b>	<b>Driscoll 2018</b> <sup>76</sup>
Aim	To explore and compare the challenges men and women perceive when using an integrated health system to manage chronic pain
Population	Purposive sample of veterans who reported moderate to severe non-cancer pain on at least 2 outpatient visits in the prior year and who had a referral for pain specialty care  n=48; Female 46%, 64% white with mean pain intensity score of 7.0 (SD 2.09) and mean duration of 16.20 (SD 12.25) years; Male 54%, 77% white with mean pain intensity score of 6.15 (SD 1.73) and mean duration of 14.24 (SD 12.19) years. Pain was reported in many locations (mean 5.17 in women and 4.28 in men)
Setting	Veterans Affairs integrated health care system
Study design	Qualitative research, using focus groups (6 with men and 4 with women)
Methods and analysis	A constant comparative approach with sequential analysis was used to reach thematic consensus.  The focus group was moderated by a moderated with a semi-structured interview guide. Codes were not pre-specified but emerged from the data, and these were developed into themes.
Findings	<p><b>Approach to communication – continuity of care</b> Patients were seen by different providers, leading them to have to ‘retell their story’ which they perceived as leading to a lack of provider responsibility for follow-up care.</p> <p><b>Style of communication – supportive and collaborative</b> Patients perceived that providers were more focused on the computer with limited eye contact. This was led to the perception that providers lacked respect and compassion for the patients. Some patients experienced good care, where they had collaborative discussions and were able to explore the risks and benefits of treatment.</p> <p><b>Style of communication – non-judgmental</b> Providers appeared reluctant to prescribe opioids and some processes, such as urine drug testing, made patients feel confused and angry. People with a history of substance abuse felt this as being particularly prominent.</p> <p><b>Style of communication – listening</b> Patients who felt heard by the providers appeared to be most satisfied, even if improved pain was not the outcome.</p> <p><b>Content of communication – treatment options</b></p>

<b>Study</b>	<b>Driscoll 2018</b> <sup>76</sup>
	Patient wanted to discuss a range of options, including nonpharmacological options. In particular, some women found this hard and this related to their experience in the military.
	Other themes were identified in the study but were not directly related to communication, and so are not reported further here.
Limitations and applicability of evidence	Moderate limitations noted around the impact of the researchers on the process Study conducted in the US

<b>Study</b>	<b>Ernstzen 2016</b> <sup>78</sup>
Aim	To explore patients' experiences and perspectives of their chronic musculoskeletal pain and its management in the private healthcare sector in South Africa
Population	Adults with chronic musculoskeletal pain  n=3; Female 100%; Duration of pain, range 15 to 24 months; Severity of pain, range 4 to 8 on the Visual Analog Scale
Setting	Private health care
Study design	Qualitative research, based on in-depth interviews
Methods and analysis	Interviews were transcribed verbatim. Inductive, thematic content analysis of the interview transcripts was conducted, through an iterative process of immersion in the data and interpretation and validation.  The lead researcher independently assigned initial codes, then revisited the data to check accuracy as part of validity checking. 2 external auditors evaluated the data coding of 2 transcripts as part of validation. Co-researchers approved the final themes. A summary of the findings was communicated to the participants to aid validation.
Findings	<b>Style of communication – open</b> The participants valued a collaborative relationship between the patient and the HCP and expressed a desire to be part of the solution. The collaborative relationship was described as open communication between the patient and the HCP and approachability of the HCP.  <b>Style of communication – supportive</b> The participants mentioned several attributes of the HCP that fostered patient-centred care and positively influenced the participants' coping mechanisms. These attributes included approachability, good communication skills, a caring nature, genuineness, trustworthiness and guidance.  <b>Style of communication –belief</b>

<b>Study</b>	<b>Ernstzen 2016</b> <sup>78</sup>
	Participants reported a lack of understanding of the pain, the HCPs not believing that the patient's pain was real, and statements that the pain was in the patient's head
	Other themes were identified in the study but were not directly related to communication, and so are not reported further here.
Limitations and applicability of evidence	Moderate limitations noted about recruitment Study conducted in South Africa

<b>Study</b>	<b>Evers 2017</b> <sup>79</sup>
Aim	To identify opportunities to improve key aspects of physicians' communications with patients with chronic low back pain (CLBP)
Population	Adults (aged 18 years or older), and had a visit to a primary care physician in the previous week that resulted in a diagnosis code for non-specified back pain. Patients had chronic pain, although no definition was reported.  n=28; Age range 25 to 84 years; Male 61%; White 64%, African-American 24%, Asian 11%, other 4%;
Setting	Primary care
Study design	Qualitative research, using focus groups
Methods and analysis	3 groups, 1 for each risk group, with a maximum of 12 participants each  Using an iterative process based on a thematic analysis approach, the primary coder developed a code list on the basis of emergent themes. The code list was reviewed and revised by the secondary coder. Both analysts then coded one transcript using a draft code list and compared their coding. Codes were added and revised, and definitions were clarified on the basis of differences.  The analysis team discussed key themes of interest with other project members, prioritizing codes related to communication between physicians and patients about their CLBP. Prioritization was based on the overall frequency of the codes and issues of most importance to the field from the perspective of our research team.
Findings	<b>Style of communication – listening and empathy</b> Patients wished for an empathic encounter with their physician, a visit that emphasized careful listening, getting to know the patient, and discovering what is important to them in their care and recovery. Patients described wanting their physician to try to know them and understand how pain uniquely affects their lives.  <b>Style of communication – validation and belief</b> Patients shared a desire for physicians to validate their pain experience by imparting an understanding that the way each patient experiences and relates to pain was unique.  <b>Content of communication – specificity of diagnosis</b>

<b>Study</b>	<b>Evers 2017</b> <sup>79</sup>
	<p>Patients wanted physicians to give clear and specific diagnoses with information about what can be done to minimize future damage. Patients had an awareness and frustration with the difficulty of treating back pain. They recognized that physicians do not have all the answers and realized the difficulty of treating back pain; some appreciated when physicians acknowledged that lack of certainty of how best to help a patient.</p> <p><b>Content of communication – treatment options</b>                  Patients reported positive experiences with primary care physicians who reviewed and inquired about previous treatments before offering other options.</p> <p>Other themes were identified in the study but were not directly related to communication, and so are not reported further here.</p>
Limitations and applicability of evidence	<p>Moderate limitations noted around the impact of the researchers on the process</p> <p>Study conducted in the US</p>

<b>Study</b>	<b>Franklin 2016</b> <sup>80</sup>
Aim	To identify the key factors that influence individuals' experiences in the management of chronic pain
Population	<p>Adults with chronic musculoskeletal pain for more than 3 months</p> <p>n=8; Female 75%; Age mean 53.8 years; Duration of pain mean 17.3 years.</p>
Setting	Secondary care
Study design	Qualitative research, based on semi-structured interviews, conducted in the clinic or at home
Methods and analysis	Qualitative content analysis was iterative, and codes were identified and refined into themes. A constant comparative method was used.
Findings	<p><b>Style of communication – listening</b>                  Patients were more trusting and more likely to adhere to the self-management suggestions if they felt the clinician was interested in them and listened to what they had to say.</p> <p><b>Approach to communication – continuity of care</b>                  Patients were 'passed around' different HCPs and they felt this led to a failure to progress treatment.</p> <p><b>Other – time</b>                  Patients found the clinic sessions were too short and they had to be more assertive to get answers from the clinician.</p> <p><b>Style of communication – medical jargon and explanation</b>                  Patients were often told the clinical name of their condition, but not what it actually meant or its implications on their care.</p>

<b>Study</b>	<b>Franklin 2016</b> <sup>80</sup>
	<p><b>Content of communication – specificity of response</b> Patients felt frustrated if they could not get answers to their questions.</p> <p><b>Approach to communication – use of visual aids</b> Patients reported that the use of anatomical models and images helped them to understand better their pain and also reassured them their pain was being taken seriously and their pain was real.</p> <p><b>Content of communication – treatment options</b> Patients liked to given an outline of their care process, why an option was chosen, and how it was going to influence them. Other themes were identified in the study but were not directly related to communication, and so are not reported further here.</p>
Limitations and applicability of evidence	Moderate limitations noted around the impact of the researchers on the process Study conducted in the UK

<b>Study</b>	<b>Fu 2016a</b> <sup>82</sup> , <b>Fu 2018a</b> <sup>84</sup> and <b>Fu 2018b</b> <sup>85</sup>
Aim	To evaluate the nature and the influence of patient-professional partnerships on the self-management of chronic back pain
Population	Adults with chronic back pain  n=26; Age range 27 to 69 years; Female 81%; Duration of pain was a minimum of 12 months
Setting	Community-based pain management service
Study design	Qualitative research, based on in-depth semi-structured interviews
Methods and analysis	An iterative process of analysing the transcripts was undertaken, involving initial line-by-line coding, focused coding and theoretical coding. Theoretical saturation was achieved when no new categories or themes appeared during data interpretation. Rigour was established using the criteria of an audit trail, dependability and conformability.
Findings	<p><b>Style of communication – collaborative</b> All the patients highlighted that it was necessary to establish a good partnership with health professionals. It was a basis for them to be supported to self-manage their condition and agree realistic goals enabling them to feel comfortable to discuss about their difficulties and ask for help.</p> <p><b>Style of communication – supportive</b> Patients reported that self-management support was underpinned by a partnership, in which health professionals provided knowledge and skills and patients were willing to accept the support and practise skills. Support motivated patients to practise self-management.</p>

Study	Fu 2016a <sup>82</sup> , Fu 2018a <sup>84</sup> and Fu 2018b <sup>85</sup>
	<p><b>Style of communication – validation and belief</b> Patients reported that effective interaction and communication required mutual contribution and shared responsibility to generate mutual understanding and trust</p> <p><b>Style of communication – empowerment</b> Allowing patients to acknowledge and accept their pain enabled them to engage with their HCP in exploring treatment options and solutions.</p> <p><b>Style of communication – optimism</b> Most patients expressed their need to be optimistic and hold positive beliefs about treatment and their outcome.</p> <p><b>Style of communication – medical jargon</b> Patients wanted their HCP to be knowledgeable but also that it was important to use lay language and understandable terminology to support patient engagement.</p> <p><b>Approach to communication – demonstration</b> Patients were more willing to practice self-management skills when HCP demonstrated the skills and tailored the level to the patient.</p> <p><b>Approach to communication – mode</b> Patients liked written material on the experience of others and alternative options as this helped them to choose a tailored programme that was relevant to them.</p> <p><b>Other – time</b> Patients reported that time pressures could make it difficult to build partnerships and to discuss other issues impacting on their pain. Patients valued HCPs who took more time and did not limit them to just one topic. Other themes were identified in the study but were not directly related to communication, and so are not reported further here.</p>
Limitations and applicability of evidence	Moderate limitations noted around the impact of the researchers on the process Study conducted in UK

Study	Fu 2016b <sup>83</sup>
Aim	To explore the influence of patient–professional partnerships on patients’ ability to self-manage chronic back pain, and to identify key factors within these partnerships that may influence self-management
Population	Adults with chronic back pain  n=10 qualitative studies, using either focus groups or individual interviews, with 223 patients and 11 health professionals,

<b>Study</b>	<b>Fu 2016b</b> <sup>83</sup>
Setting	Any setting included
Study design	Systematic review of qualitative studies
Methods and analysis	Simple thematic synthesis. The 10 retrieved studies were read and re-read in-depth with participants' (patients and health professionals) experiences, perceptions and the original authors' findings and conclusions being identified and recorded. Findings and themes were linked and further grouped to broader descriptive codes. Codes were then compared and contrasted across studies to generate new themes.
Findings	<b>Style of communication – listening</b> Patients' views of effective communication included being listened to and encouraged, feeling understood and understanding why they had the pain. The experience of communication by both patients and health professionals highlighted the role of effective listening.
	<b>Method of communication - mode</b> Patients felt most positively about face-to-face communication, as the language and non-verbal communication that health professionals used made them feel at the centre of care and involved in the process
	Other themes were identified in the study but were not directly related to communication, and so are not reported further here.
Limitations and applicability of evidence	No significant methodological limitations noted Limited to people participating in self-management interventions

<b>Study</b>	<b>Gjesdal 2018</b> <sup>89</sup>
Aim	To explore the experiences with healthcare received by people living with chronic non-malignant pain in Norway
Population	Adults (aged 18 to 67 years) with chronic non-malignant pain (>6 months), the pain condition as a primary disorder and living at home (outpatients)
	n=18; Female 16 and male 2; Age range 18 to 67 years, mean 43 years; Sources of pain were back pain (5), neck and shoulders (4), muscular (5), migraine (2), pelvis (1) and knee and calf (1).
Setting	Outpatient
Study design	Qualitative approach with a descriptive and explorative design, based on semi-structured interviews
Methods and analysis	Face-to-face interviews. The researcher provided some structure based on the interview guide but allowed rooms for participants to offer more spontaneous descriptions and narratives. Stages of analysis were: 1 Open reading 2 Identifying meaning units

<b>Study</b>	<b>Gjesdal 2018</b> <sup>89</sup>
	3 Condensed meaning unit 4 Creating codes 5 Sorted codes and abstracted into subthemes, as a team 6 Formulating into a latent theme, as a team
Findings	<b>Style of communication – listening and validation</b> Participants described interactions with a supportive healthcare professional where being listened to, believed in and experiencing mutual trust were emphasized. When interactions with healthcare professionals made the participants feel insignificant, they found it difficult to express their needs, which seemed to reinforce practical difficulties and unfulfilled expectations and make them lose hope in their recovery.
Limitations and applicability of evidence	Moderate limitations noted around the impact of the researchers on the process Study conducted in Norway

<b>Study</b>	<b>Gordon 2017</b> <sup>91</sup>
Aim	To examine the opinions of primary care healthcare professionals (HCPs) and people with chronic pain and their carers, in order to identify possible barriers to the facilitation and adoption of self-management
Population	Primary care HCPs, people with chronic pain, and their carers  n=38 HCPs; Professions GP 16, physiotherapy 15, practice nursing 2, occupational therapy 4, community pharmacy 1; Female 23/28 n=63 patients and carers, 54 patients and 9 carers; Female 43/63
Setting	Primary care
Study design	Qualitative research, using focus groups
Methods and analysis	Thematic analysis  All transcripts were reviewed and initial coding framework with key themes and subthemes was drafted. The framework was discussed. Omissions and misunderstandings were identified. Initial coding framework was revised accordingly. Members of the research team coded the same 2 transcripts. Differences were resolved through discussion. All individual subthemes were reviewed. Subthemes that were not supported with a large amount of data were removed or merged with similar subthemes. Identified themes were discussed at a final focus group.
Findings	<b>Timing of communication – self-management</b> Some patients felt a discussion about self-management came too late or not at all.



Study	Gordon 2017 <sup>91</sup>
	<p><b>Style of communication – listening and validation</b> Patients commonly cited ‘improved listening’ as the key thing they desired from HCPs. They sometimes found it difficult to convince HCPs of the level of their pain.</p> <p><b>Style of communication – supportive</b> The emotional impact of pain was difficult and patients often felt unsupported by HCPs.</p> <p>Other themes were identified in the study but were not directly related to communication, and so are not reported further here.</p>
Limitations and applicability of evidence	Moderate limitations noted around the impact of the researchers on the process Study conducted in the UK

Study	Grieve 2016 <sup>93</sup>
Aim	To explore the specific information requirements of patients with CRPS and provides insight into how health professionals can best provide this
Population	Adults with CRPS; although participants were not limited to people with chronic pain, all had long term CRPS  n=8; Female 100%; Age range 30 to 59 years; Duration of pain 2 to 15 years
Setting	Not clear
Study design	Qualitative research, based on semi-structured telephone interviews
Methods and analysis	Codes were identified and developed into themes.
Findings	<p><b>Content of communication – diagnosis and explanation of symptoms</b> Patients were given verbal information at the diagnosis, although this often comprised the name of the condition only, without further elaboration. This left patients feeling uncertain of the implications.</p> <p><b>Approach to communication – continuity of care</b> Patients were given different levels of information and conflicting information, which reduced their trust in the HCPs.</p> <p>Other themes were identified in the study but were not directly related to communication, and so are not reported further here.</p>
Limitations and applicability of evidence	Moderate limitations noted around recruitment Study conducted in the UK

Study	Grus 2020 <sup>96</sup>
Aim	To explore the relationship between patients' overall satisfaction with their primary care providers and their satisfaction with their chronic pain treatment, as well as the provider behaviours that contributed to chronic pain patients' satisfaction with their PCPs.
Population	Adults (aged over 18 years) who had received long-term opioid treatment and had a pain-related diagnosis.  n=97; Female 76, male 21; Age (mean, SD) 61.3 (12.1); Non-malignant chronic pain (NCP) types – back and neck pain 58 (59.8%), fibromyalgia and general pain 56 (57.7%), Limb/extremity pain, joint pain, and arthritic disorders 53 (54.6%), other types of pain 46 (47.4%), two or more types 61 (62.9%)
Setting	Hospital
Study design	Qualitative research, based on semi-structured telephone interviews
Methods and analysis	Transcripts were coded and themes developed using a content analysis approach
Findings	<p><b>Approach to communication – continuity of care</b> Patients valued maintaining active lines of communication. Patients reported having complex histories which were difficult to explain if they have to speak to someone other than their primary physician. They often did not feel comfortable seeking care elsewhere. Further, poor care continuity could leave patients without medication.</p> <p><b>Taking time during individual consultations with patients</b> Patients reported being aware of time restrictions on appointments, and valued physicians who took time to listen to all concerns they wanted to share. Having to return for multiple visits within a short space of time may have financial implications.</p> <p>Additional themes were reported, but not extracted due to data saturation.</p>
Limitations and applicability of evidence	Serious limitations noted around the impact of the researchers on the process, the rigorousness of the analysis and the collection of data Conducted in the USA – moderate concerns regarding applicability of the finding about financial implications of multiple visits.

Study	Hadi 2016 <sup>98</sup> and Hadi 2017 <sup>99</sup>
Aim	To identify barriers to effective pain management encountered by patients with chronic pain in the NHS
Population	Adult ( aged over 18 years) patients with chronic pain discharged from a pain clinic  n=19; Female 11, male 8; Age 26 to 30 2, 31 to 35 0, 36 to 40 4, 41 to 45 1, 46 to 50 3, 51 to 55 5, 56 to 60 1, 61 to 65 2, 66 to 70 0, 71 to 75 1; Duration of chronic pain < 1 year 2, 1 to 3 years 4, 3 to 5 years 3, 5 to 10 years 5, over 10 years 4, unclear 1; Pain intensity at baseline none 1, level 4 1, level 5 6, level 6 2, level 7 5, level 8 1, level 9 1, level 10 2

<b>Study</b>	<b>Hadi 2016 <sup>98</sup>and Hadi 2017 <sup>99</sup></b>
Setting	Nurse-pharmacist-managed pain clinic
Study design	Qualitative research, based on semi-structured interviews
Methods and analysis	<p>Convenience sampling was used to recruit the first 5 patients and the remaining 14 patients were recruited using maximum variation sampling. The framework for maximum variation was based on baseline pain intensity, duration of chronic pain and gender. Data collection continued until achieving saturation.</p> <p>Data were analysed using thematic analysis. Each interview was transcribed verbatim and checked against the original recording for accuracy. Individual transcripts were coded, and the coding framework was checked independently by 2 experienced qualitative researchers. Codes were sorted into potential themes, which could be adapted as new themes emerged.</p> <p>Methods, including peer review/debriefing and providing rich thick description were used to enhance rigour and trustworthiness of study findings.</p>
Findings	<p><b>Style of communication – listening and belief</b> A number of patients expressed concerns over a perceived lack of interest shown by healthcare professionals, especially GPs, in listening to their problems and managing their pain. A number of the patients felt they were disbelieved and judged by healthcare professionals.</p> <p><b>Other – time</b> Patients had 1 hour appointments and they felt this allowed them full freedom to express their views.</p> <p><b>Content communication – explanation of symptoms and treatment options</b> Patients valued the in-depth and specialised knowledge of their HCPs. Patients viewed GPs as having limited therapeutic options, with their approach towards pain management being confined to prescribing a range of analgesics, irrespective of whether the patients were gaining any benefit or not.</p> <p>Other themes were identified in the study but were not directly related to communication, and so are not reported further here.</p>
Limitations and applicability of evidence	<p>Moderate limitations noted around the impact of the researchers on the process</p> <p>Study conducted in the UK</p>

<b>Study</b>	<b>Janke 2016 <sup>121</sup></b>
Aim	To examine perceptions of those with comorbid chronic pain and obesity regarding their experience of comorbidity management in primary care
Population	Adults who were obese and in chronic pain

<b>Study</b>	<b>Janke 2016</b> <sup>121</sup>
	n=30; Age 50 or older 56.6%; Female 20%; White 73.3%; Mean pain intensity 5.6 (SD 1.9); Mean BMI 36.8 (SD 8.9)
Setting	Primary care
Study design	Qualitative research, based on semi-structured interviews
Methods and analysis	Constant comparative method was used to analyse data. Emerging categories and areas of similarities and differences were discussed, with dominant themes identified, discussed and subsequently refined. Themes were revised and refined with sub-headings, and categories distilled from these themes.
Findings	<p><b>Content of communication – treatment options</b></p> <p>Participants expressed frustration that there was limited support, beyond general information, to aid them in understanding and managing their comorbid weight and pain in their everyday lives</p> <p>Other themes were identified in the study but were not directly related to communication, and so are not reported further here.</p>
Limitations and applicability of evidence	Moderate limitations noted around the impact of the researchers on the process Study conducted in the US

<b>Study</b>	<b>Kanter 2017</b> <sup>125</sup>
Aim	To seek information regarding patient experience with interstitial cystitis/bladder pain syndrome (IC/BPS) symptoms and with their medical care to elicit suggestions to improve patient satisfaction
Population	Adult (aged over 18) women with a known diagnosis of IC/BPS as defined by the American Urologic Association  n=15; Education, 67% with a degree; Ethnicity white 40%, Hispanic 27%, native American or Alaskan 13%, other 20%; Mean age of 52.6 ± 9.7 years; Diagnosed for an average of 6.3 years; Symptomatic for an average of 12 years, and were not treatment naive
Setting	University hospital urogynaecology clinic
Study design	Qualitative study, using focus groups
Methods and analysis	4 focus groups, with 2 to 6 participants  Focus groups were recorded, de-identified and transcribed, and “coded” by at least 3 authors per transcript. Coding was based on grounded method theory, ideas from codes were grouped into themes, which were then organized into emergent concepts. Using constant comparative methodology, new ideas were continually compared to what had already been generated in order to combine like ideas. Content reviews were conducted after focus groups to generate a list of conceptual gaps that had not been explored sufficiently or probes that may have been overrepresented. Themes were further organized, refined and agreed upon by investigators, in order to create a conceptual framework.

Study	Kanter 2017 <sup>125</sup>
Findings	<p><b>Style of communication – listening and empathy</b> Patients wanted to know that all their providers were truly listening to them. They stated that effective treatment required providers to understand that their disease experiences were real and that their needs were valid.</p>
	<p><b>Content of communication – treatment options</b> Participants wanted more knowledge about their condition and largely preferred to hear about treatment options. During initial visits patients wished to acquire knowledge about IC/PBS, requested information of potential causes of IC/BPS and alternatives to treating it. When patients had undergone unsuccessful treatments, they wanted to know about the additional options that existed rather than hearing that there was nothing that could be done for them. They stated that willingness to discuss the treatments was preferable to being given the impression that there were no further options and being abandoned by frustrated care-providers.</p>
	<p><b>Style of communication – optimism and hope</b> Encouragement from providers that they were willing to explore other potential avenues for improvement was very important to patients. Provider expression of hope for improvement of symptoms was vital.</p>
	<p>Other themes were identified in the study but were not directly related to communication, and so are not reported further here.</p>
Limitations and applicability of evidence	<p>Moderate limitations noted around the impact of the researchers on the process and ethical approval not reported Study conducted in the US</p>

Study	Moore 2019 <sup>160</sup>
Aim	To explore how the use of medical images and models by healthcare professionals can inform patients' understanding of chronic musculoskeletal illness and pain
Population	<p>7 patients (cases) from 2 qualitative studies</p> <p>Details of the cases were not reported; data drawn from 1 qualitative study of 60 older adults' (aged 55 and over) experiences of different pain states, with the aim of examining how older people can best be helped to age well in the presence of musculoskeletal pain and 1 study of semi-structured qualitative interviews with 30 adults aged 45 and over, participating in a trial of physiotherapy for knee pain</p>
Setting	<p>Not reported for the first study Second study based in primary care</p>
Study design	Supra (or secondary) analysis of 2 qualitative studies

Study	Moore 2019 <sup>160</sup>
Methods and analysis	Data from both studies that pertained to participants' explanations and understanding of their condition were collated and subjected to case-by-case analysis. Each case was discussed between the authors to ensure a consensus was reached upon the interpretation of references.
Findings	<b>Approach to communication – use of visual aids</b> Patients reported that the use of models and images helped them to understand better the pathophysiology of pain and the impact of behaviours or activities.
	Other themes were identified in the study but were not directly related to communication, and so are not reported further here.
Limitations and applicability of evidence	Moderate limitations noted around how participants were selected for case analysis Both primary studies were conducted in the UK

Study	Nafradi 2018 <sup>164</sup>
Aim	To study patients' perspectives about the role of the doctor–patient relationship in promoting the resilience process
Population	Older adults (aged 35 to 80 years) with chronic pain, in treatment for a minimum of 3 months  n=10; Female 18, male 2; Age range from 42 to 75 years, mean age 57 years; Diagnosed for an average of 11.35 years (SD 8.89), with a range of 1–35 years; Diagnosed with rheumatoid arthritis 8, fibromyalgia 7, chronic pain after hernia surgery 3; Ethnicity white 100%; Education elementary school 2, completed high school 6, vocational training 10, and 2 completed university studies. Patients were selected using purposive sampling.
Setting	Not clear
Study design	Qualitative research, based on semi-structured interviews
Methods and analysis	After the first 5 interviews, the data were analysed in order to adapt the interview guide based on the most common topics mentioned by participants.  Data were explored following the principles of thematic analysis. Themes were coded to reflect patients' comments. Identified themes were linked and grouped into larger categories in order to define more abstract concepts around which the various arguments were organized. A cyclical approach was used which enabled a rich description of the overall data, as well as to reduce authors' biases.
Findings	<b>Style of communication – empowerment</b> One of the most common themes was the doctor empowering patients to pay attention to their physical sensations, which facilitated cooperation. Features included motivation, collaboration and respect.

<b>Study</b>	<b>Nafradi 2018</b> <sup>164</sup>
	<p><b>Content of communication – knowledge and understanding</b> The physician role in fostering the patients' knowledge and understanding of the condition and treatment by providing explanations and arguments, thus enhancing their health literacy.</p> <p><b>Style of communication – support and validation</b> Receiving psychological support and validation from healthcare providers was seen as an important factor to consider concerning patient resilience.</p> <p>Other themes were identified in the study but were not directly related to communication, and so are not reported further here.</p>
Limitations and applicability of evidence	Moderate limitations noted around how participants were selected Study conducted in Switzerland

<b>Study</b>	<b>Outlaw 2018</b> <sup>174</sup>
Aim	To improve the overall experience for patients using chronic pain services at a large teaching hospital in England
Population	Adults (aged 18 and over) attending the chronic pain clinic  n=7; Age range 22 to 69 years; Male 3, female 4; Time using the pain service range 8 to 44 months
Setting	Hospital-based chronic pain services
Study design	Qualitative research, based on video-recorded patient interviews
Methods and analysis	<p>Patient interviews were recorded. Video recorded interviews were reviewed to identify 'touchpoints' during which patients experience heightened emotions during their interactions with services or staff. The touchpoints were then illustrated in a short 'trigger' film which was made by editing all the video-recorded interviews.</p> <p>A patient experience event was held in where the patients reviewed the 'trigger film' and discussed the touchpoints. Key priorities for service improvement and recommendations for change were identified.</p> <p>Staff audio recorded interviews were analysed to identify the touchpoints they highlighted about providing care.</p> <p>Each participant's interview was reviewed by both analysts, with subsequent notes on emotional responses to the subject topic compared for concordance. Where concordance between examiners was found, a touchpoint was noted, and reviewed using thematic analysis to identify key themes.</p>
Findings	<p><b>Timing of communication – prior to attendance</b> Patients were poorly informed of what to expect from the pain service. Letters of invitation to clinic or procedures failed to give enough information.</p>

Study	Outlaw 2018 <sup>174</sup>
	<p><b>Style of communication – empathy</b> Patients valued staff empathy and expertise. Patients complemented staff working in the pain department, especially valuing how staff resolved their issues and alleviated anxiety by providing information.</p>
	<p><b>Approach to communication – location of information</b> Patient information leaflets were presented in a poorly designed stand which prevented the titles from being easily readable without individually picking each leaflet out of the stand, which was off putting for patients who found it painful to move around.</p>
	<p><b>Content of communication – treatment options</b> Most patients thought that the staff were very clear when they explained things and they appreciated the extra time that was spent discussing treatments and concepts.</p>
	<p><b>Style of communication – medical jargon</b> Some patients criticised use of medical terms, whereas others did not find this to be a problem as they would ask staff to clarify as needed.</p>
	<p>Other themes were identified in the study but were not directly related to communication, and so are not reported further here.</p>
Limitations and applicability of evidence	<p>Moderate limitations noted around how participants were selected and the limited reporting of methods Study conducted in the UK</p>

Study	Reibel 2017 <sup>181</sup>
Aim	To gain an understanding of the lived experiences of women with fibromyalgia
Population	Women with fibromyalgia; although no duration of pain was specified all had long term pain  n=3; No further details reported
Setting	Not clear
Study design	Qualitative research, based on phenomenological interviews
Methods and analysis	Thematic analysis, based on primary identification of themes clustered into meanings.
Findings	<p><b>Content of communication – specificity of diagnosis</b> Women felt they were not given clear answers on the cause of their pain at multiple contacts with HCPs and this contributed to uncertainty about their illness and ability to manage their condition.</p> <p>Other themes were identified in the study but were not directly related to communication, and so are not reported further here.</p>



<b>Study</b>	<b>Reibel 2017</b> <sup>181</sup>
Limitations and applicability of evidence	Moderate limitations noted around recruitment and ethical approval not reported Study conducted in the US

<b>Study</b>	<b>Sternke 2016</b> <sup>193</sup>
Aim	To analyse patients' perspectives on the emergent theme of empathy and describe how patients construct their experiences and expectations surrounding empathic interactions
Population	Adults with chronic pain and depression  n=18; Age range 27 to 84 years old, mean=54.8; Female 61%, Ethnicity black 22% and white 74%
Setting	VA medical centre and primary care
Study design	Qualitative research, using focus groups
Methods and analysis	Constructivist grounded theory was used as a framework to analyse data from four transcripts from focus groups of patients from a Veterans Affairs Medical Center and primary care clinics who had participated in the randomized clinical trial known as Stepped-Care for Affective Disorders and Musculoskeletal Pain (SCAMP) study.  After the primary analysis of the focus group data was completed regarding patient perceived barriers and facilitators to self-management of pain was completed, emergent themes were found in deep reviews of the focus group transcripts and warranted further analysis
Findings	<b>Style of communication – empathy and listening</b> A perceived lack of empathic listening as well as empathic action was associated with feelings of frustration and a sense of being uncared for—a finding with implications for clinical practice and which supports the dissemination of clinical interventions that employ empathy as a therapeutic tool.  Other themes were identified in the study but were not directly related to communication, and so are not reported further here.
Limitations and applicability of evidence	Moderate limitations noted around the impact of the researchers on the process Study conducted in the US

<b>Study</b>	<b>Sullivan 2019</b> <sup>194</sup>
Aim	To explore clinicians' experiences of communicating their understanding of a diagnosis of chronic nonspecific lower back pain to their patients

Study	Sullivan 2019 <sup>194</sup>
Population	Physiotherapists with at least one year's post-graduate experience in musculoskeletal practice and who had lived through situations of communicating the diagnosis of CNSLBP to their patients were considered for inclusion.  n=5
Setting	Not reported
Study design	A qualitative research design, using semi-structured interviews.
Methods and analysis	Interviews were transcribed verbatim and analysed using interpretative phenomenological analysis. Transcripts were read and re-read for immersion, and then line-by-line analysis was done, which led to the emergence of themes. These themes were then grouped into 'super-ordinate' themes.
Findings	<p><b>Style of communication – patient-centredness</b></p> <p>Participants reported an importance of using patient-centred communication using active listening and questioning in order to understand what approaches would be meaningful to the patient. They report adapting their communication style to the individual participant. This helps the patient feel believed and this was thought to be good for rapport. Participants also report tailoring communication in order to get the patient on board with their perspective, when this may clash with patients' own beliefs. Participants also attempted to 'sow seeds' and 'build layers' using both verbal and non-verbal communication to get participants on board.</p>
	<p><b>Content of communication - Negative test results</b></p> <p>Participants described anxiety and uncertainty and a desire to avoid a breakdown in communication when there is a negative test result meaning no explanation for their patients' pain. They reported a pressure to communicate effectively and provide solutions. Some participants report seeking support and opinions of colleagues, as some question the diagnosis themselves.</p>
Limitations and applicability of evidence	No significant methodological limitations noted Study conducted in the UK

Study	Toye 2018 <sup>204</sup>
Aim	To undertake a qualitative evidence synthesis of qualitative research using meta-ethnography to increase the understanding of what it is like for healthcare professionals to provide healthcare to people with chronic non-malignant pain and thus inform improvements in the experience and quality of healthcare
Population	Professionals providing healthcare to adults with chronic non-malignant pain  n=77 studies reporting the experiences of > 1551 healthcare professionals; Professionals included a range of doctors, nurses and allied health professionals in various contexts and geographical locations; Majority of studies were from the US, the UK, Canada, and Sweden. Sample size range 6 to 103, and mean 22.

Study	Toye 2018 <sup>204</sup>
Setting	Any setting included
Study design	Systematic review of qualitative studies, based on a range of qualitative approaches
Methods and analysis	Meta-ethnography, through identifying concepts from the studies included and progressively abstracting concepts into a line of argument, or conceptual model GRADE CERQual was used to assess the level of confidence for themes.
Findings	<p><b>Style of communication – belief</b></p> <p>The authors described this theme as “sceptical cultural lens and siren song of diagnosis”. The findings indicate an underlying scepticism that might contribute to an adversarial relationship between HCP and patient. Believing patients’ experiences may provide a more secure foundation for an effective therapeutic relationship.</p> <p>Other themes were identified in the study but were not directly related to communication, and so are not reported further here.</p>
Limitations and applicability of evidence	No significant methodological limitations noted

Study	Toye 2017 <sup>206</sup>
Aim	To bring together qualitative evidence syntheses that explore patients’ experience of living with chronic non-malignant pain and develop conceptual understanding of what it is like to live with chronic non-malignant pain for improved healthcare
Population	<p>People living with chronic pain</p> <p>n=11 qualitative syntheses reporting the experience of 523 people living with chronic non-malignant pain in 187 published reports of 155 unique qualitative studies</p>
Setting	Any setting included
Study design	Systematic review of qualitative studies, based on a range of qualitative approaches
Methods and analysis	Meta-ethnography, through identifying concepts from the studies included and progressively abstracting concepts into a line of argument, or conceptual model, use conceptual findings from qualitative evidence syntheses as primary data
Findings	<p><b>Content of communication – diagnosis</b></p> <p>Patients’ have a strong desire for a medical diagnosis.</p> <p><b>Style of communication – listening and dignity</b></p> <p>Patients want to be listened to and treated with dignity.</p> <p>Other themes were identified in the study but were not directly related to communication, and so are not reported further here.</p>

<b>Study</b>	<b>Toye 2017</b> <sup>206</sup>
Limitations and applicability of evidence	No significant methodological limitations noted

<b>Study</b>	<b>Valenzuela-Pascual 2019</b> <sup>211</sup>
Aim	To explore and compare the perceptions of patients and primary healthcare professionals regarding the management of chronic low back pain
Population	<p>Patients with a history of chronic low back pain longer than 3 months, between 20 and 65 years of age, and able to read, speak, and understand Spanish or Catalan.</p> <p>Primary care physicians and nursing staff from different primary healthcare centers in Lleida, Spain.</p> <p>Patients: n=16; Age range 32-63; Female 50%; Duration of pain 4-480 months</p> <p>Primary healthcare professionals: n=19; Age range 40-63; Female 58%; Duration of professional experience 14-39 years</p>
Setting	Faculty of Nursing and Physiotherapy
Study design	Qualitative study using semi-structured interviews and discussion groups
Methods and analysis	A qualitative content analysis of the transcripts was conducted. Transcripts were read and open coded. Then the coders shared their codes to identify patterns and create categories.
Findings	<p><b>Style of communication – Language</b></p> <p>Both patients and primary healthcare professionals agreed that PHPs do not always adapt their language to the patient which can lead to misunderstandings, however PHPs do not always think it is possible to adapt medical language.</p> <p>Additional themes were reported, but not extracted due to data saturation.</p>
Limitations and applicability of evidence	<p>Moderate limitations noted around the impact of the researchers on the process</p> <p>Study conducted in Spain</p>

## Appendix E: Data saturation

**Table 7: Studies not extracted due to data saturation**

Reference
Afrell 2010 <sup>3</sup>
Agarwal 2018 <sup>4</sup>
Allcock 2007 <sup>7</sup>
Allegretti 2010 <sup>8</sup>
Bair 2009 <sup>15</sup>
Baker 2011 <sup>17</sup>
Barlow 2014 <sup>18</sup>
Barry 2010 <sup>19</sup>
Beck 2000 <sup>20</sup>
Berglund 2015 <sup>23</sup>
Bergman 2013 <sup>25</sup>
Blomberg 2008 <sup>27</sup>
Bonathan 2014 <sup>28</sup>
Briggs 2012 <sup>34</sup>
Brown 2005 <sup>35</sup>
Budge 2012 <sup>38</sup>
Burton 2015 <sup>40</sup>
Calner 2019 <sup>43</sup>
Chew-Graham 1999 <sup>48</sup>
Clarke 2005 <sup>53</sup>
Clarke 2008 <sup>54</sup>
Clarke 2014 <sup>52</sup>
Cooper 2008 <sup>55</sup>
Davis 2002 <sup>65</sup>
Denny 2008 <sup>69</sup>
Dewar 2003 <sup>71</sup>
Dow 2012 <sup>75</sup>
Froud 2014 <sup>81</sup>
Gammons 2014 <sup>86</sup>
Gjesdal 2019 <sup>90</sup>
Grace 1995 <sup>92</sup>
Hansson 2011 <sup>103</sup>
Harle 2018 <sup>104</sup>
Haugli 2004 <sup>109</sup>
Hazaveh 2018 <sup>110</sup>
Henriksson 1995 <sup>111</sup>
Holloway 2007 <sup>114</sup>
Holtrop 2019 <sup>115</sup>
Howarth 2014 <sup>117</sup>
Kenny 2004 <sup>128</sup>
Laerum 2006 <sup>133</sup>

Reference
Ljungvall 2020 <sup>137</sup>
Macneela 2010 <sup>139</sup>
Matthias 2010 <sup>145</sup>
Matthias 2010 <sup>151</sup>
Matthias 2012 <sup>149</sup>
Matthias 2014 <sup>147</sup>
May 2000 <sup>152</sup>
McCrorie 2015 <sup>153</sup>
McGowan 2007 <sup>156</sup>
Müllersdorf 2011 <sup>162</sup>
Navis 2019 <sup>167</sup>
Nielsen 2013 <sup>169</sup>
Nordin 2014 <sup>170</sup>
Ojala 2015 <sup>172</sup>
Oosterhof 2014 <sup>173</sup>
Parsons 2007 <sup>175</sup>
Parsons 2012 <sup>176</sup>
Patel 2008 <sup>177</sup>
Price 2006 <sup>179</sup>
Savidge 1998 <sup>184</sup>
Slade 2009 <sup>187</sup>
Slade 2009 <sup>188</sup>
Slade 2012 <sup>189</sup>
Sloots 2009 <sup>191</sup>
Sloots 2010 <sup>190</sup>
Teh 2009 <sup>197</sup>
Torresan 2015 <sup>200</sup>
Toye 2013 <sup>201</sup>
Toye 2013 <sup>202</sup>
Toye 2014 <sup>203</sup>
Upshur 2010 <sup>209</sup>
Werner 2003 <sup>213</sup>
Wolf 2006 <sup>215</sup>
Zanini 2014 <sup>217</sup>

## Appendix F: Excluded studies

**Table 8: Studies excluded from the qualitative review**

Reference	Reason for exclusion
Adegbola 2012 <sup>1</sup>	Abstract only (conference abstract, not a full paper)
Adegbola 2012 <sup>2</sup>	Focus does not match protocol (acute pain crises)
Ahlsen 2018 <sup>5</sup>	Focus does not match protocol (not communication between patients and healthcare professionals)
Ahluwalia 2019 <sup>6</sup>	Focus does not match protocol (not communication between patients and healthcare professionals)
Andermo 2017 <sup>9</sup>	Focus does not match protocol (academic exploration of language)
Anderson 2002 <sup>10</sup>	Incorrect study design (quantitative analysis)
Anonymous 2001 <sup>11</sup>	Population does not match protocol (included people with acute pain)
Arora 2017 <sup>12</sup>	Abstract only (conference abstract, not a full paper)
Askew 1998 <sup>13</sup>	Population does not match protocol (not clear if limited to patients with chronic pain)
Bahouq 2013 <sup>14</sup>	Incorrect study design (quantitative analysis)
Becker 2020 <sup>21</sup>	Incorrect study design (survey)
Bergman 2012 <sup>24</sup>	Abstract only (conference abstract, not a full paper)
Bhatia 2012 <sup>26</sup>	Abstract only (conference abstract, not a full paper)
Booker 2016 <sup>29</sup>	Unable to obtain paper (not available from LAMS)
Bouckoms 1986 <sup>30</sup>	Incorrect study design (vignettes)
Breaden 2012 <sup>31</sup>	Focus does not match protocol (palliative care)
Breivik 2017 <sup>33</sup>	Incorrect study design (commentary)
Buchbinder 2015 <sup>36</sup>	Focus does not match protocol (description of clinical encounter, not analysis of barriers or facilitators)
Buijs 2009 <sup>39</sup>	Focus does not match protocol (workplace interactions with healthcare professionals)
Buscemi 2018 <sup>41</sup>	Focus does not match protocol (not communication between patients and healthcare professionals)
Cano 2014 <sup>44</sup>	Population does not match protocol (included people with acute pain)
Carroll 2013 <sup>45</sup>	Focus does not match protocol (not communication between patients and healthcare professionals)
Chang 2017 <sup>46</sup>	Focus does not match protocol (substance abuse disorder treatment)
Chew 1997 <sup>49</sup>	Population does not match protocol (included people with acute pain)
Chibnall 1995 <sup>50</sup>	Incorrect study design (commentary)
Chou 2018 <sup>51</sup>	Population does not match protocol (included people with acute pain)
Cornally 2011 <sup>56</sup>	Abstract only (conference abstract, not a full paper)
Cowell 2016 <sup>57</sup>	Abstract only (conference abstract, not a full paper)
Cowell 2018 <sup>59</sup>	Focus does not match protocol (not communication between patients and healthcare professionals)
Cowell 2019 <sup>58</sup>	Focus does not match protocol (description of physiotherapist consultations with no thematic analysis)
Cranen 2012 <sup>60</sup>	Focus does not match protocol (telehealth)
Danielson 2018 <sup>62</sup>	Abstract only (conference abstract, not a full paper)
Danielson 2019 <sup>63</sup>	Focus does not match protocol (describes the content of the interactions rather than reporting the views of patients/HCPs on barriers/facilitators to effective communication)
Darlow 2013 <sup>64</sup>	Population does not match protocol (included people with acute pain)

Reference	Reason for exclusion
Daykin 2004 <sup>66</sup>	Focus does not match protocol (not communication between patients and healthcare professionals)
Denke 2013 <sup>67</sup>	Focus does not match protocol (not communication between patients and healthcare professionals)
Denneny 2019 <sup>68</sup>	Focus does not match protocol (not communication between patients and healthcare professionals)
Dima 2013 <sup>72</sup>	Population does not match protocol (included people with acute pain)
Donovan 2017 <sup>73</sup>	Focus does not match protocol (not communication between patients and healthcare professionals)
Durif-Bruckert 2015 <sup>77</sup>	Population does not match protocol (included people with acute pain)
Garcia-Martinez 2019 <sup>87</sup>	Protocol
Giannitrapani 2016 <sup>88</sup>	Abstract only (conference abstract, not a full paper)
Gronning 2018 <sup>94</sup>	Focus does not match protocol (not communication between patients and healthcare professionals)
Grossnickle 2019 <sup>95</sup>	Focus does not match protocol (not communication between patients and healthcare professionals)
Gulbrandsen 2010 <sup>97</sup>	Incorrect study design (quantitative analysis)
Hale 2017 <sup>100</sup>	Abstract only (conference abstract, not a full paper)
Hall-Lord 1999 <sup>101</sup>	Incorrect study design (quantitative analysis)
Hani 2018 <sup>102</sup>	Focus does not match protocol (not communication between patients and healthcare professionals)
Harrison 2017 <sup>105</sup>	Population does not match protocol (not clear if limited to patients with chronic pain)
Hasenbring 2015 <sup>106</sup>	Incorrect study design (narrative review)
Hassan 2018 <sup>108</sup>	Incorrect study design (no qualitative analysis)
Hassan 2020 <sup>107</sup>	Focus does not match protocol (specific to a particular intervention being trialled)
Henry 2018 <sup>112</sup>	Focus does not match protocol (tapering)
Henry 2018 <sup>113</sup>	Abstract only (conference abstract, not a full paper)
Hopayian 2014 <sup>116</sup>	Population does not match protocol (included people with acute pain)
Howarth 2012 <sup>118</sup>	Incorrect study design (PhD thesis)
Imran 2014 <sup>119</sup>	Abstract only (conference abstract, not a full paper)
Isenberg 2017 <sup>120</sup>	Population does not match protocol (not patients with chronic pain)
Johnson 2016 <sup>122</sup>	Incorrect study design (editorial)
Johnson 2017 <sup>123</sup>	Abstract only (conference abstract, not a full paper)
Jorge 2011 <sup>124</sup>	Focus does not match protocol (description of clinical encounter, not analysis of barriers or facilitators)
Keller 2019 <sup>126</sup>	Focus does not match protocol (specific to a side effect of opioid use)
Kennedy 2018 <sup>127</sup>	Focus does not match protocol (not communication between patients and healthcare professionals)
Kesten 2020 <sup>129</sup>	Focus does not match protocol (specific to a service being trialled)
Kinsman 2011 <sup>130</sup>	Abstract only (conference abstract, not a full paper)
Krasner 1996 <sup>131</sup>	Population does not match protocol (not clear if limited to patients with chronic pain)
Kristiansson 2011 <sup>132</sup>	Focus does not match protocol (description of clinical encounter, not analysis of barriers or facilitators)
Levine 2012 <sup>134</sup>	Abstract only (conference abstract, not a full paper)
Liebschutz 2018 <sup>135</sup>	Focus does not match protocol (aberrant behaviour associated with opioids)



Reference	Reason for exclusion
Lincoln 2011 <sup>136</sup>	Abstract only (conference abstract, not a full paper)
Lovsund 2020 <sup>138</sup>	Population does not match protocol (describes of a new method of assessment, rather than communication)
Maki 2014 <sup>140</sup>	Abstract only (conference abstract, not a full paper)
Maki 2015 <sup>141</sup>	Abstract only (conference abstract, not a full paper)
Manias 2007 <sup>143</sup>	Population does not match protocol (not clear if limited to patients with chronic pain)
Manias 2008 <sup>144</sup>	Focus does not match protocol (description of clinical encounter, not analysis of barriers or facilitators)
Manias 2012 <sup>142</sup>	Population does not match protocol (included people with acute pain)
Matthias 2012 <sup>150</sup>	Abstract only (conference abstract, not a full paper)
Matthias 2013 <sup>148</sup>	Focus does not match protocol (description of clinical encounter, not analysis of barriers or facilitators)
Matthias 2017 <sup>146</sup>	Focus does not match protocol (tapering)
McCrum 2015 <sup>154</sup>	Abstract only (conference abstract, not a full paper)
McDonald 2013 <sup>155</sup>	Abstract only (conference abstract, not a full paper)
McLeod 2013 <sup>157</sup>	Focus does not match protocol (not communication between patients and healthcare professionals)
Mineiro 2018 <sup>158</sup>	Abstract only (conference abstract, not a full paper)
Mittinty 2017 <sup>159</sup>	Unclear methodology (short report and not enough information on methods to assess)
Mueller 2017 <sup>161</sup>	Focus does not match protocol (naloxone)
Muradia 2017 <sup>163</sup>	Abstract only (conference abstract, not a full paper)
Navis 2018 <sup>166</sup>	Abstract only (conference abstract, not a full paper)
Nichols 2020 <sup>168</sup>	Incorrect study design (qualitative systematic review)
O'Connor 2015 <sup>171</sup>	Population does not match protocol (communication between professionals)
Petrie 2005 <sup>178</sup>	Incorrect study design (quantitative analysis)
Puia 2014 <sup>180</sup>	Focus does not match protocol (description of clinical encounter, not analysis of barriers or facilitators)
Robinson 2011 <sup>182</sup>	Incorrect study design (audit)
Sallinen 2019 <sup>183</sup>	Focus does not match protocol (not communication between patients and healthcare professionals)
Setchell 2015 <sup>185</sup>	Population does not match protocol (not patients with chronic pain)
Shue 2018 <sup>186</sup>	Focus does not match protocol (not communication between patients and healthcare professionals)
Smythe 2017 <sup>192</sup>	Population does not match protocol (not clear if limited to patients with chronic pain)
Swift 2019 <sup>195</sup>	Incorrect study design (literature review)
Tankha 2020 <sup>196</sup>	Focus does not match protocol (communication is between partners, not the HCP and patient)
Thomson 2008 <sup>198</sup>	Focus does not match protocol (description of clinical encounter, not analysis of barriers or facilitators)
Thomson 2017 <sup>199</sup>	Population does not match protocol (students, not practising professionals)
Toye 2017 <sup>205</sup>	Abstract only (conference abstract, not a full paper)
Toye 2017 <sup>207</sup>	Focus does not match protocol (not communication between patients and healthcare professionals)
Uhlig 2002 <sup>208</sup>	Incorrect study design (narrative review)

Reference	Reason for exclusion
Vader 2019 <sup>210</sup>	Focus does not match protocol (related to a specific intervention)
Verbeek 2004 <sup>212</sup>	Population does not match protocol (included people with acute pain)
White 2016 <sup>214</sup>	Focus does not match protocol (exploration of mismatches, not barriers and facilitators to communication)
Wyse 2019 <sup>216</sup>	Secondary analysis of an excluded study; focus does not match protocol
Zheng 2012 <sup>218</sup>	Abstract only (conference abstract, not a full paper)