

Research

People with low back pain want clear, consistent and personalised information on prognosis, treatment options and self-management strategies: a systematic review

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KEY WORDS

Health information
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Need
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A B S T R A C T

Question: What health information needs are perceived by people with low back pain? **Design:** Systematic review of publications examining perceived health information needs related to low back pain identified through Medline, EMBASE, CINAHL and PsycINFO (1990 to 2018). **Participants:** Adults with low back pain of any duration. **Data extraction and analysis:** Two reviewers independently extracted descriptive data regarding study design and methodology, and assessed risk of bias. Aggregated findings of the perceived needs of people with low back pain regarding health information were meta-synthesised. **Results:** Forty-one studies (34 qualitative, four quantitative and three mixed-methods) were identified. Two major areas of perceived health information needs for low back pain emerged. The first major area was needs related to information content: general information related to low back pain, its cause and underlying pathology; strong desire for diagnosis and imaging; prognosis, future disability and effect on work capacity; precipitants and management of flares; general management approaches; self-management strategies; prevention; and support services. The second major area of needs related to how the information was delivered. People with low back pain wanted clear, consistent information delivered in suitable tone and understandable language. **Conclusion:** Available data suggest that the information needs of people with low back pain are centred around their desire for a diagnosis, potentially contributing to expectations for and overuse of imaging. People with low back pain expressed a strong desire for clear, consistent and personalised information on prognosis, treatment options and self-management strategies, related to healthcare and occupational issues. To correct unhelpful beliefs and optimise delivery of evidence-based therapy, patient and healthcare professional education (potentially by an integrated public health approach) may be warranted. [Lim YZ, Chou L, Au RTM, Seneviwickrama KLMD, Cicuttini FM, Briggs AM, Sullivan K, Urquhart DM, Wluka AE (2019) People with low back pain want clear, consistent and personalised information on prognosis, treatment options and self-management strategies: a systematic review. *Journal of Physiotherapy* 65:124–135]

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Introduction

In the Global Burden of Disease study, low back pain (LBP) is ranked highest in terms of years lived with disability, with one in ten people experiencing LBP at any point in time worldwide.¹ Approximately 90% of LBP cases have no identifiable pathoanatomical cause, and are called 'non-specific LBP'.² Despite the high prevalence of LBP globally, recommended treatments have only modest effects.^{2,3} A large range of diagnostic and therapeutic interventions are frequently applied, despite evidence that they are of low value.^{2,3} Although many people with LBP do not seek medical care, LBP is still one of the most common reasons for general practice or physician visits worldwide, with a pooled prevalence of care-seeking of 58%.^{4–7} In the United States, LBP is the third most common reason for visiting a

doctor.⁸ In Australia, the proportion of people seeking medical care for LBP has surged by 20% over 10 years.⁵

There are a number of published national and international clinical guidelines to support the management of LBP.⁹ Although many groups have developed these clinical practice guidelines for LBP management, they tend to contain relatively uniform recommendations incorporating best available evidence, clinician expertise and patients' preferences.⁹ However, these guidelines, as in other areas, have not resulted in change to clinical practice.^{10–12} The uptake of guidelines is determined by a complex interplay between clinicians, patients and available resources within the healthcare system. First, clinicians must decide to follow the guidelines in daily clinical practice. Various clinician-related factors have been identified to explain clinicians' suboptimal use of guideline recommendations in practice:

inadequate education and awareness of current guidelines; insufficient time and resources to appropriately engage patients; pressure to maintain patient-clinician relationships; concern for liability; previous clinical experience; and financial disincentives.^{11,13,14} Second, whether patients follow their healthcare providers' advice is influenced by their engagement in their own care and their relationship with the healthcare provider.^{15,16} Dissatisfied patients tend to use more healthcare resources, seek care from multiple providers, have less favourable LBP rehabilitation outcomes, and are less likely to return to work than satisfied patients.^{15–18} As such, better understanding of patients' goals, preferences and expectations related to the management of LBP may improve patient satisfaction, better facilitate delivery of patient-centred care, and potentially improve LBP outcomes.^{18–20}

Although education is recommended in most guidelines, the focus has been on management strategies, especially on minimising imaging use in LBP, rather than how to maximise function and live well with LBP.^{21–23} Most guidelines do not specify what content should be included in patient education, leaving this open to interpretation and marked heterogeneity in the clinical approach.^{21,23} In particular, strategies to link LBP education (knowledge) with positive behaviour change and effective pain-coping behaviours (skills) are lacking in guidelines. Guidelines usually suggest that patients should be reassured and advised to remain active. Additionally, previous studies have recognised gaps between patients' and clinicians' beliefs in LBP management, which could negatively impact on the practitioner-patient therapeutic relationship.^{24–26} Hence, it is important to: explicitly seek and understand patients' perspectives; understand and address patients' attitudes, concerns and beliefs, especially in the domains of diagnostic uncertainty; and encourage resuming normal activity that is meaningful to patients. Increased clinician awareness of patients' perspectives and expectations has the potential to improve outcomes in LBP.

Therefore, the research question for this systematic review was:

What health information needs are perceived by people with low back pain?

Methods

This systematic review was performed within a larger project examining patients' perceived needs relating to musculoskeletal health,²⁷ based on the framework proposed by Arksey and O'Malley for scoping reviews.²⁸

Identification and selection of studies

Electronic searches of Medline, EMBASE, CINAHL and PsycINFO were performed from 1990 to July 2018. A comprehensive search strategy combining both MeSH terms and text words was used to capture information about patients' perceived health information needs related to LBP (see Appendix 1 on the eAddenda). It was developed by a multidisciplinary team involving an academic librarian (KS), and input from one patient representative and three clinician researchers (rheumatologists, FC and AW, and physiotherapist, AB). The review's focus on patients' perceived health information needs was interpreted to encompass a broad concept involving patients' needs, expectations and requirements related to health information. LBP was defined as non-specific LBP, with or without leg pain, excluding back pain related to fractures, malignancy, infection and inflammatory back conditions. In order that the review would capture the breadth of patients' perspectives on health information needs and back pain, studies were not excluded based on study methods. The reference lists of published articles were examined to identify additional sources. All review papers, conference papers, reports or literature reviews were excluded. Studies were limited to English-language reports of studies of humans.

Two investigators (RA and YL) independently assessed the eligibility of available studies using a three-stage determination method: title screening, abstract screening, followed by full text. Studies were included if inclusion criteria were met: studies had to concern patients aged > 18 years; studies had to report on patients' perspectives regarding their needs, expectations and requirements related to health information; and studies had to concern patients with LBP.

Data extraction and synthesis

Two authors (YL and RA) independently extracted characteristics of the included studies using a standardised data extraction form developed for this review. Data were extracted on: year of publication; country; study design; study population, including baseline characteristics of the participants (number of participants, gender, age); primary study aim; and study results. Data extraction syntheses were performed according to principles of meta-ethnography to synthesise qualitative data.²⁹ A framework of concepts and underlying themes was developed, initially based on primary data in the studies and any pertinent points raised by the authors, which was further independently refined by another author (YL), and then independently reviewed by two experienced rheumatologists (FC and AW) and a physiotherapist (AB) to ensure clinical meaningfulness and construct validity.

Assessment of methodological quality

Two reviewers (YL and LC) independently assessed the quality of the studies. The Critical Appraisal Skills Programme tool was used for qualitative studies.³⁰ External and internal validity of quantitative studies were assessed through the 11 criteria in Hoy's risk of bias tool, where overall quality of studies was scored as low risk if scoring ≥ 8 'yes' answers, moderate risk of bias if scoring 6 to 7 'yes' answers, and high risk of bias if scoring ≤ 5 'yes' answers.³¹

Results

Flow of studies through the review

A total of 3733 studies were identified by the initial search. After removal of duplicates, 2794 studies were screened and 2694 studies were excluded on screening of the title and abstract, leaving 100 studies for full-text review. Of the 100 full-text articles that were assessed, 59 studies were excluded. Thus, 41 studies were included in this systematic review. Details of the study selection and reasons for exclusion are shown in the flow diagram (Figure 1). The PRISMA extension for scoping reviews checklist³² is presented in Appendix 2 on the eAddenda.

Characteristics of included studies

Table 1 provides an overview of the characteristics of the included studies. Most of the included studies were from the United Kingdom or Europe,^{24,25,33–60} six were from the United States of America,^{61–66} two from Australia,^{67,68} and one each from Iran,⁶⁹ Israel⁷⁰ and New Zealand.⁷¹

Twelve studies recruited participants from primary care practice,^{24,25,35,44,49–51,59,61,66,68,70} eight from tertiary pain clinics,^{33,38,52–55,63,64} nine from hospital or rehabilitation clinics,^{34,36,37,41,45,48,57,60,62} three from specialist spine or osteopathy clinics,^{39,40,42} four from the general community,^{43,46,56,71} two from research centres,^{47,69} one from the intervention arm of a trial,⁵⁸ one from an education forum,⁶⁷ and one from an occupational health clinic.⁶⁵

The duration of LBP was either undefined or mixed in 15 studies,^{24,25,40,41,46,47,49–51,56–58,66,70,71} subacute (≥ 6 weeks) in one study,⁵⁹ chronic (> 3 months) in 22 studies,^{33–39,42–45,48,52–55,60,61,63,64,67,69} and acute in three studies.^{62,65,68}

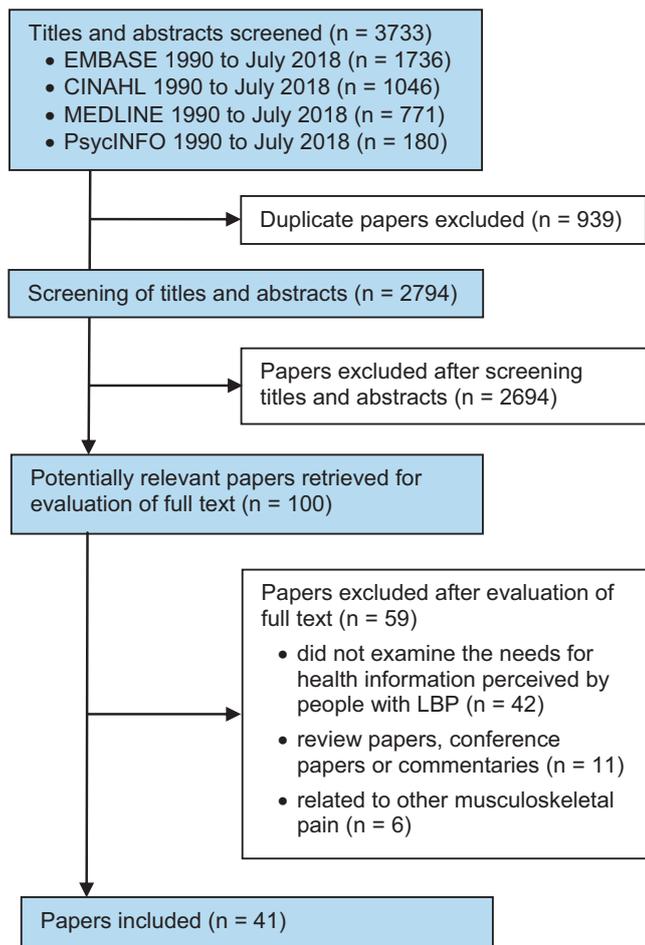


Figure 1. Flow of studies through the review. LBP = low back pain.

Of the included studies, 33 were qualitative studies,^{25,33–35,38,40,42–61,63,64,67–71} five were quantitative studies,^{24,36,37,62,65} and three used mixed methods.^{39,41,66} Of the qualitative studies, 30 used interviews or semi-structured interviews,^{25,33–35,38–40,42,44–55,57,58,60,61,63,66–68,70,71} eight used focus groups,^{25,41,43,56,57,59,69,70} and two used narrative methods. Of the quantitative studies, all five used questionnaires.^{24,36,37,62,65}

Eight of the included studies had over 100 participants.^{24,36,37,41,46,62,64,65} The age of the participants in the included studies ranged from 18 to 86 years, but was not reported for two studies.^{41,63} The included studies had a female predominance: 28 studies had $\geq 50\%$ female participants,^{24,34–37,40–43,45–47,50–54,57–60,62,64,66–69,71} while two studies did not specify the gender distribution.^{25,33}

Quality assessment

Tables 2 and 3 provide details of the risk of bias and quality assessment of the included studies. The initial agreement between the two reviewers was 94% for qualitative assessment criteria and 97% for quantitative risk of bias criteria. Differences in scoring between reviewers were evaluated and resolved by discussion. Where the two reviewers could not achieve consensus, a third reviewer (AW) adjudicated. The overall quality of the qualitative studies was poor, especially for the Critical Appraisal Skills Programme criteria relating to recruitment strategy, data collection and recognition of any impact of the relationship between researcher and participants. The quality of quantitative studies was low to moderate. Overall, the low to moderate quality scores of both qualitative and quantitative studies related to possible biases in recruitment and data collection.

Results of review

Two major areas of patients' perceived health information needs for LBP emerged from the review: information content and information delivery. Selected results from individual studies relating to each of these themes are presented in Boxes 1 and 2, respectively. For a complete list of results supporting these themes, see Appendices 3 and 4 on the eAddenda.

Patients' perceived needs regarding health information content related to low back pain

General information content related to low back pain: Nine studies identified patients' needs for general information about LBP.^{35,41,42,57,60,65,69–71} Participants were keen to learn about simple and basic information regarding LBP. Specifically, they wanted a clear and detailed explanation of the nature of LBP, largely related to its unpredictable, intermittent and fluctuating course to further improve their understanding of LBP.^{35,41,42,57,60,65,69–71}

Diagnosis and cause or aetiology for low back pain: Twenty-seven studies identified patients' needs for a diagnosis for LBP and/or an explainable cause of LBP.^{25,33–35,38–41,43–50,52–55,57–59,61,68–70} Findings included participants' needs for an 'exact' diagnosis of LBP for a variety of reasons, including the validation and legitimisation of patients' symptoms.^{34,43,52,54,59,61} The lack of a diagnosis was associated with frustration.³⁸ Some participants believed that their pain could not be substantiated without a specific diagnosis.⁴⁵ Additionally, patients felt that a lack of a diagnosis indicated that health professionals did not know what they were doing, resulting in a perceived lack of a therapeutic relationship with the health practitioner.^{46,47} Participants in Ong's study required a diagnosis as the starting point for therapy.⁴⁷ Invariably, most participants wanted to know the cause of symptoms.^{25,33–35,38–41,43–50,52–55,57–59,61,68,70} Many were dissatisfied with being told that the pain was 'age related' or 'wear and tear'.^{33,38} Some participants demanded and were insistent on having a biomechanical or physical explanation.^{38,48,54,57} In a single study by Toye, participants identified that both a physical and psychological explanation were relevant.⁵⁴

Perceived needs for imaging: Eight papers found that participants believed imaging to be an essential component of the assessment of LBP.^{24,46,49,52,59,61,68,70} This was thought to be required and necessary to confirm the diagnosis and identify structural damage and the cause of LBP. Two studies identified the relief that participants felt when a structural cause to LBP was identified.^{40,52}

Prognosis, including future disability and effect on work capacity: The importance of information regarding the natural history of LBP was identified in 15 studies.^{34,39,41–43,47,49,50,54,57,58,64,65,68,71} Participants in these studies wanted information about the prognosis of LBP, in particular its favourable prognosis and benign nature. LBP was commonly associated with significant fears,^{34,43,50,58,64} with some participants being concerned about future disability.^{34,43,50,64} Coole found that participants were interested in information about work capacity, particularly knowing their ability to work with LBP.³⁴

Information about precipitation of flares: Four studies identified participants' needs to learn about potential precipitants of flares for LBP.^{34,35,54,69} Participants attributed this need to the unpredictable nature of LBP flares,^{34,35} whereby knowledge in this area would help them to deconstruct fear of specific movements perceived to be associated with LBP⁵⁴ and, hence, gained self-control with flare-up management.³⁴

General information about low back pain management: Twenty-one studies found that that participants wanted information about management of LBP.^{24,25,33,35,39,40,42,43,48–50,52,53,56–58,60,64,66,69,71} Many participants wanted information on general treatment options, including pharmacological and non-pharmacological strategies.^{24,25,35,39,43,48,50,53,56–58,60,64} Participants wanted to be provided with information about the available options.

With regards to pharmacological strategies, participants wanted information about different analgesia options for the management of LBP, prior to taking the medicine.^{34,49,64,66} In the study by Liddle, participants wanted to know the role and efficacy of analgesia in

Table 1
Characteristics of the included studies.

Author (Year) Country	Diagnosis of LBP	Participants			Aim stated in study publication	Study methodology
		N	Source	Age (yr) ^a Gender		
Allegretti (2010) ⁶¹ US	Chronic (>6 months)	23	Primary care practice	45 (28 to 72) 12M:11F	Explore paired interviews of shared experiences among chronic LBP patients and their physicians	Qualitative: Interview
Ali (2015) ⁵⁷ UK	Any duration	18	Hospital and private physio clinics	(19 to 81) 9M:9F	Explore patients' expectations and satisfaction with physiotherapy management of LBP	Qualitative: Focus group and interview
Amonkar (2011) ²⁴ UK	NS	427 (206 LBP)	General practices	>18 158M:269F	Investigate perceptions and expectations of general practitioners and patients concerning management of simple LBP	Quantitative: Questionnaire
Bishop (2011) ⁶² US	Acute (≤89 days)	112	Hospital clinics	40 54M:58F	Examine patients' expectations related to common interventions for LBP and the influence that specific expectations about spinal manipulation might have had on disability	Quantitative: Questionnaire
Borkan (1995) ⁷⁰ Israel	Anyone with ≥ 1 episode of LBP (duration NS)	66	Primary care practices	40 (18 to 67) 43M:23F	Increase understanding of LBP from patients' perceptions and experiences	Qualitative: Focus groups, interviews, participant observation
Bowman (1994) ⁶³ US	Chronic (duration NS)	15	Pain clinic	Age NS 9M:6F	Examine the reactions of individuals to chronic LBP	Qualitative: Interview
Briggs (2012) ⁵⁷ Australia	Chronic (≥3 months)	14	Pain self-management education forums	57 (35 to 77) 5M:9F	Explore barriers experienced by consumers in rural Western Australia to access information, services and implementing effective self-management behaviours for CLBP	Qualitative: Semi structured telephone interview
Buus (2015) ⁵⁸ Denmark	NS	25	Participants from intervention arm of a trial who had completed follow-up (n=110)	47 (9) 11M:14F	Explore LBP patients' perceptions of long-term effects of participating in a counselling intervention to change work routine and to exercise	Qualitative: Semi-structured interviews
Campbell (2007) ³³ UK	Chronic (≥1 year)	16	Hospital (patients from pain management programme)	(34 to 78) Gender NS	Examine treatment expectations, whether they influence health service consumption in people with chronic LBP	Qualitative: Interviews
Coole (2010) ³⁴ UK	Chronic (3 months to 35 years)	25	LBP pain rehabilitation	45 (22 to 58) 12M:13F	Explore individual experiences and perceptions of patients awaiting rehabilitation who were concerned about their ability to work due to persistent, or recurrent LBP	Qualitative: Semi-structured interview
Corbett (2007) ³⁵ UK	Chronic (duration NS)	37	General practitioner clinic	(19 to 59) 15M:22F	Illustrate the struggle between hope and despair through the narrative of people with chronic LBP	Qualitative: Narrative and interview
Darlow (2013) ⁷¹ New Zealand	Acute (<6 weeks) and chronic (>3 months)	23	General public	(18 to 67) 9M:14F	Explore the formation and impact of attitudes and beliefs among people experiencing acute and chronic LBP	Qualitative: Semi-structured interview
Dima (2013) ⁵⁹ UK	Chronic (≥ 6 weeks)	75	General practitioner or complementary and alternative medicine clinics	Median 62 (29 to 85) 27M:48F	Explore patient preferences and beliefs about LBP treatments	Qualitative: Focus groups
Farin (2013) ³⁷ Germany	Chronic (≥ 6 months)	701	Rehabilitation centre	51 (11) 300M:401F	Identify predictors of communication preferences in patients with chronic LBP	Quantitative: Questionnaire
Farin (2012) ³⁶ Germany	Chronic (duration NS)	703	Rehabilitation centre	51 (11) 301M:402F	Develop an instrument that measures the extent of matching between patient communication preferences and physician communication behaviour	Quantitative: Questionnaire

Table 1 (Continued)

Author (Year) Country	Diagnosis of LBP	Participants			Aim stated in study publication	Study methodology
		N	Source	Age (yr) ^a Gender		
Hoffmann (2013) ⁵⁸ Australia	Acute (<3 months)	11	Urban general practice	52 (22 to 72) 1M:10F	Explore care expectations, influences on expectation and congruence with clinical guideline recommendations in patients with acute LBP	Qualitative: Semi-structured interview
Holloway (2007) ³⁸ UK	Chronic (duration 2 to 22 years)	18	Pain clinic	(28 to 62) 12M:6F	Explore and conceptualise the experiences of people with chronic LBP in pain clinics	Qualitative: Interview
Kawi (2014) ⁶⁴ US	Chronic (>3 months)	110	Pain clinics	47 (19 to 86) 45M:65F	Describe perceptions of chronic LBP patients on their self-management, self-management support and functional ability	Qualitative: Qualitative content analysis on open-ended survey questions.
Laerum (2006) ³⁹ Norway	Chronic (>3 months)	35	8 outpatient spine clinics	46 (23 to 65) M18:F17	Identify core elements of what patients perceive to be good clinical communication and interaction with specialist in chronic LBP	Mixed: Observation and semi-structured interview
Larsen (2013) ⁴⁰ Denmark	Patients who are out of work due to LBP (duration NS)	8	Specialist centre (spine centre)	(22 to 57) 3M:5F	Illustrate how LBP is expressed and managed in different contexts: at the clinic, at home and at work	Qualitative: Semi-structured interviews
Layzell (2001) ⁴¹ UK	NS	120	Physiotherapy department at Poole Hospital	Age NS 50M:70F	Assess patient satisfaction with current LBP services, and increase understanding of LBP beliefs from patients' perspective	Mixed: Questionnaire and taped focus group
		12	Volunteers from author's workplace and community	Age NS 6M:6F		
Lee-Treweek (2001) ⁴² UK	Chronic (duration NS)	16	Osteopathic practice	(17 to 72) 8M:8F	Illustrate patients' ideas about responsibility and control over their symptoms	Qualitative: Semi-structured interview
Liddle (2007) ⁴³ UK	Chronic (>3 months)	18	Volunteer	(18 to 65) 4M:14F	Identify chronic LBP patients' perceived most value components of treatment by exploring their experiences, opinions and treatment expectations	Qualitative: Focus groups
Mackichan (2012) ⁴⁴ UK	Chronic (duration NS)	23	GP practices	(38 to 83) 12M:11F	Describe patients' experience and their views on self-care and provision of support for self-care for long term LBP	Qualitative: Interview
May (2000) ⁴⁵ UK	Chronic (\geq 1 year)	12	LBP rehabilitation clinic	(20 to 55) 6M:6F	Explore the ways chronic LBP patients respond to the problem of medical doubt	Qualitative: Semi-structured interview
McIntosh (2003) ²⁵ UK	Anyone who has LBP (duration NS)	37	Patients from primary care practice	(25 to 64) Gender NS	Ascertain patients' and clinicians' experiences and expectation of information in LBP to aid development of "patient-centred" information pack	Qualitative: Semi-structured interview and focus groups
Moffett (2000) ⁴⁶ UK	NS	507	Community	(20 to 60) 253M:254F	Compare public and patient perceptions about LBP and its management with current clinical guidelines	Qualitative: Interview
Ong (2011) ⁴⁷ UK	Sciatic pain, acute and chronic (<1 month to >3 years)	37	Selected patients from The Keele BeBack cohort study	(19 to 59) 15M:22F	Enhance the understanding of patients' perspectives on living with sciatica to improve care and treatment outcomes	Qualitative: Interview
Palazzo (2016) ⁶⁰ France	Chronic (mean duration 4.9 years, SD 3.8)	29	Tertiary care hospital	54 (24 to 85) 12M:17F	Assess chronic LBP patients' views concerning barriers to home-based exercise program adherence and expectations regarding new technologies	Qualitative: Semi-structured interviews
Scheermesser (2012) ⁴⁸ Switzerland	Chronic (>3 months)	13	Rehabilitation centre clinic	(38 to 60) 9M:4F	Understand the experience of patients with LBP and explore barriers to successful rehabilitation	Qualitative: Semi-structured interviews and focus groups
Schers (2001) ⁴⁹ Netherlands	Acute and chronic LBP (<6 weeks to >12 weeks)	20	General practices	43 (25 to 68) 11M:9F	Explore factors that determine non-adherence to the guidelines for LBP	Qualitative: Semi-structured interview

Table 1 (Continued)

Author (Year) Country	Diagnosis of LBP	Participants			Aim stated in study publication	Study methodology
		N	Source	Age (yr) ^a Gender		
Shaw (2005) ⁶⁵ US	Acute (duration NS)	544	Community occupational health clinics	36 (18 to 79) 363M:181F	Evaluate the relationship between perceptions of provider communication and treatment satisfaction for acute, work-related LBP	Quantitative: Questionnaire and telephone follow up
Skelton (1995) ⁵¹ UK	>1 recorded visit (duration NS)	52	General practices	41 (18 to 66) 26M:26F	Compare patient and general practitioner perceptions of patient education for LBP	Qualitative: Semi-structured interviews
Skelton (1996) ⁵⁰ UK	>1 recorded visit (duration NS)	52	General practices	41 (18 to 66) 26M:26F	Elicit patients' views on LBP and its management in general practice	Qualitative: Semi structured interviews
Tavaifan (2008) ⁶⁹ Iran	Chronic (>90 days)	24	Rheumatology research centre at Tehran university of medical sciences.	43 (18 to 70) 0M:24F	Explore Iranian women's beliefs regarding the cause of LBP	Qualitative: Focus groups
Toye (2009) ⁵² UK	Chronic (duration NS)	20	Hospital pain management programme	(29 to 67) 7M:13F	Explore how patients with persistent unexplained pain interpret and utilise the bio-psychosocial model	Qualitative: Interview
Toye (2012) ⁵⁴ UK	Chronic (duration range 3 to 23 years)	20	Hospital (pain management programme)	(29 to 67) 7M:13F	Explore the differences between patients with persistent LBP who benefited from a pain management programme, and those who did not	Qualitative: Interviews
Toye (2012) ⁵³ UK	Chronic (duration NS)	20	Hospital (chronic pain management programme)	(29 to 67) 7M:13F	Analyse patients' experience of general practice in relation to their persistent non-specific LBP	Qualitative: Semi-structured interviews
Turner (1998) ⁶⁶ US	Acute and chronic LBP (1 month to > 1 year)	68	Primary care practices	(18 to 75) 24M:44F	Examine the content of primary care visit for LBP	Mixed: Questionnaire, interview
Walker (1999) ⁵⁵ UK	Chronic (2 to 50 years)	20	Pain clinic	(28 to 80) 12M:8F	Explore the lived experience of chronic LBP	Qualitative: Interview and narrative
Young (2011) ⁵⁶ UK	Anyone with a history of LBP (duration NS)	31	Community volunteers with LBP	(20s to mid 70s) 17M:14F	Understand LBP recurrence and how to measure it by describing experiences of those with LBP	Qualitative: Focus groups

F = female, LBP = low back pain, M = male, NS = not stated.

^a Single number is mean unless specified. Number in parentheses is SD. Number range in parentheses is range.

Table 2
Quality of the qualitative studies according to the Critical Appraisal Skills Programme criteria.³⁰

Study	Clear statement of aim	Qualitative methodology appropriate	Appropriate research design	Appropriate recruitment strategy	Appropriate data collection	Researcher reflexivity	Ethical consideration	Rigorous data analysis	Clear statement of findings	Research value
Allegretti 2010 ⁶¹	Y	Y	Y	N	N	N	Y	Y	Y	Y
Ali 2015 ⁵⁷	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Borkan 1995 ⁷⁰	Y	Y	Y	Y	N	N	N	Y	Y	Y
Bowman 1994 ⁶³	Y	Y	Y	N	N	N	N	N	Y	Y
Briggs 2012 ⁶⁷	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Buus 2015 ⁵⁸	Y	Y	Y	Y	N	Y	Y	N	Y	Y
Campbell 2007 ³³	Y	Y	Y	N	Y	U	Y	N	Y	Y
Coole 2010 ³⁴	Y	Y	Y	Y	N	N	Y	Y	Y	Y
Corbett 2007 ³⁵	N	Y	Y	Y	N	Y	N	Y	Y	Y
Darlow 2013 ⁷¹	Y	Y	Y	Y	Y	Y	Y	N	Y	Y
Dima 2013 ⁵⁹	Y	Y	Y	Y	Y	U	Y	Y	Y	Y
Hoffmann 2013 ⁶⁸	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Holloway 2007 ³⁸	Y	Y	Y	N	N	N	Y	N	Y	N
Kawi 2014 ⁶⁴	Y	Y	N	N	N	U	Y	Y	Y	Y
Laerum 2006 ³⁹	Y	Y	Y	Y	N	Y	Y	N	Y	Y
Larsen 2013 ⁴⁰	Y	Y	Y	Y	N	Y	Y	Y	Y	Y
Layzell 2001 ⁴¹	Y	Y	Y	Y	Y	N	N	Y	N	N
Lee-Treweek 2001 ⁴²	N	Y	Y	N	N	N	N	N	N	N
Liddle 2007 ⁴³	Y	Y	Y	N	N	N	Y	Y	Y	N
Mackichan 2012 ⁴⁴	Y	Y	Y	Y	N	N	Y	N	Y	Y
May 2000 ⁴⁵	Y	Y	Y	N	N	N	Y	N	Y	Y
McIntosh 2003 ²⁵	Y	Y	Y	Y	N	N	Y	Y	Y	Y
Moffett 2000 ⁴⁶	Y	Y	Y	N	N	N	N	N	Y	Y
Ong 2011 ⁴⁷	Y	Y	Y	Y	N	N	N	N	Y	Y
Palazzo 2016 ⁶⁰	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Scheermesser 2012 ⁴⁸	Y	Y	Y	N	Y	N	Y	N	Y	N
Schers 2001 ⁴⁹	Y	Y	Y	Y	N	N	Y	Y	Y	Y
Skelton 1995 ⁵¹	Y	Y	Y	Y	N	N	N	N	N	N
Skelton 1996 ⁵⁰	Y	Y	Y	Y	N	N	N	N	N	N
Tavafian 2008 ⁶⁹	Y	Y	Y	N	N	N	Y	N	Y	N
Toye 2009 ⁵²	Y	Y	Y	N	N	Y	Y	N	Y	N
Toye 2012 ⁵³	Y	Y	Y	N	N	Y	Y	N	Y	N
Toye 2012 ⁵⁴	Y	Y	Y	N	N	Y	Y	N	Y	N
Turner 1998 ⁶⁶	Y	Y	Y	Y	N	N	N	N	Y	N
Walker 1999 ⁵⁵	Y	Y	Y	Y	N	Y	Y	Y	Y	Y
Young 2011 ⁵⁶	Y	Y	Y	N	N	Y	Y	N	Y	Y

N = no, U = unclear, Y = yes.

symptom control.⁴³ Participants in only one study expressed the need for information on complementary therapy.⁵⁰

Non-pharmacological treatment was highly valued. Participants specifically wanted information about the role of physiotherapy, osteopathy, postural advice and back muscle exercises.^{24,25,39,40,42,48,49,53,57,58,60,71} They also wanted to know about which physical activities would be beneficial and which would not, in order to avoid flares of LBP.^{39,40,42,49,56,57,71} Some participants identified the need for information to help them psychologically deal with LBP and improve their ability to cope.^{33,35,53,56} In the context of coping with LBP, maintaining independence was valued by many participants.^{33–35,39,43,56,64,66}

The need for tailored information about low back pain management: Nine studies identified participants' desires for personalised or tailored treatment for LBP.^{37,43,51,57,59,60,62,64,71} They believed that management should be specific to their own circumstances, taking into account their other health conditions,^{59,62} age,^{37,59} and specific

lifestyle needs.^{37,43,57,59,64} Darlow and colleagues' results illustrated the importance of patient-specific advice, as patients were more likely to reject advice if it conflicted with their lived experience, life goals and beliefs.⁷¹ Some participants were frustrated with the provision of general principles and generic exercises instead of individually tailored and specific exercise advice.^{51,57,59,60}

Information about pain management: Five studies described patient-perceived needs for pain management in LBP.^{34,43,49,64,66} Whilst participants wanted general information about pain management, this included both pharmacologic and non-pharmacologic options.⁶⁴ Participants wanted information about role, efficacy, safety, and side effects of pharmacological therapies.^{34,43,49}

Information about management of flares and preventive measures: Seven studies described patients' perceived needs relating to the management of flares and prevention of LBP.^{33,41,43,51,56,65,71} Three of these found that participants wanted information about how to deal with flares when they occurred.^{41,43,71} They valued information that

Table 3
Quality of the quantitative study according to the Hoy risk of bias tool criteria.³¹

Study	Representative study population	Appropriate sampling frame	Random selection or census	Minimal non-response bias	Data collected directly from participants	Acceptable case definition	Valid and reliable measurements	Consistent mode of data collection	Appropriate data collection period	Numerator and denominator appropriate
Amonkar 2011 ²⁴	N	Y	N	N	Y	N	N	Y	N	N
Bishop 2011 ⁶²	N	N	N	N	Y	Y	N	Y	N	N
Farin 2013 ³⁷	N	N	N	N	Y	Y	Y	Y	N	N
Farin 2012 ³⁶	N	N	N	N	Y	N	Y	Y	N	N
Layzell 2001 ⁴¹	N	N	N	N	Y	N	N	Y	N	N
Shaw 2005 ⁶⁵	N	N	N	Y	Y	Y	N	Y	Y	Y

N = no, Y = yes.

Box 1. Selected examples of participant-perceived needs regarding health information content related to low back pain. For a more extensive list, see Appendix 3 on the eAddenda.

General information content related to LBP

- Ali¹⁷ • Participants were keen to have information and explanation about their LBP.
 Darlow⁷¹ • *I had just no frame of reference to figure out like what it was...with a back. I don't know... I'm just completely in the dark.*

Diagnosis and cause/aetiology for LBP

- Ali⁵⁷ • Biomechanical and 'anatomical' explanation of their back problems: *he must explain the wrong movements and positions...; I wanted to know what are the lumbar, coccygeal vertebrae made of and what is spondylosis.*
 Walker⁵⁵ • Need explanation of pain, cause of pain and why the pain developed: *desperate to know what was causing the pain*

Perceived needs for imaging

- Dima⁵⁹ • Participants believed accurate diagnosis could only be achieved through detailed examination (assessment though physical touch) and/or imaging (X-rays and MRI).
 Hoffmann⁶⁸ • Need imaging tests to provide reassurance and confirmation of diagnosis: *Xray was to establish whether...was just a pulled muscle or whether it was a herniated disc.*
 Toye⁵² • Need tests or imaging to confirm legitimacy of LBP: *I kind of cried with relief when I saw what was wrong... but you don't want this unexplained pain.*

Prognosis, including future disability and effect on work capacity

- Coole³⁴ • Patients need information about their ability to work with LBP due to concern about their ability to retain work and to reduce uncertainty about future working capacity.
 Liddle⁴³ • *It actually really really frightened me... You start to worry about paralysis or whatever.*

Information regarding precipitation of flares

- Coole³⁴ • Participants wanted to gain self-control of the unpredictable nature of LBP, especially with flare-ups: *I'd lost confidence in my back because it can go at any time...; They're getting fed up at work you know, when flare-up happens.*
 Toye⁵⁴ • *If you bent a certain way, and your disc slipped and you are incapacitated.*

General information regarding LBP management

- Ali¹⁷ • Patients wanted to be responsible for their back care and had a desire for explanation and to learn their role in the treatment process. They wanted advice and exercise prescription for LBP: *It is my back, it's my responsibility to always look after it; ...must explain the plan in steps within a timeframe and the benefits of every exercise.*
 Darlow⁷¹ • Patients wanted to be reinforced on the importance of remaining active during acute episodes and be equipped with information on correct postures, specific back muscle strengthening to help 'protect the spine'. They valued reassurance about safety of movement in setting of LBP.
 Turner⁶⁶ • Need advice on how to return to normal activities.

Tailored information regarding LBP management

- Ali⁵⁷ • *I cannot pull my knees to my chest at work can I? I sit for 8 hours to take calls.*
 Bishop⁶² • Need tailored advice regarding range of management options available for LBP, including non-interventional and interventional therapies
 Farin³⁷ • Important to consider personal circumstances in managing chronic LBP, especially for older patients.

Information regarding pain management

- Coole³⁴ • Patients wanted to know the role of simple analgesia in LBP, in relation to the safety profile, side effects, effectiveness and impact on work.

Information regarding management of flares and preventive measures

- Layzell⁴¹ • Need information on how to cope and deal with acute flare of LBP.
 Young⁵⁶ • Patients desired strategies to prevent exacerbation of LBP, to reduce anxiety from the unpredictable nature of LBP.

Self-management strategies

- Laerum³⁹ • Want to know what kind of activity he/she preferably could do and should avoid.
 Walker⁵⁵ • Patients wanted to know about self-management, ie, what they could do about the pain and future treatment plan: *I'm crying out for somebody to take an interest in me for I'm a fighter and I want to improve my health.*

Information regarding support services for LBP

- Bowman⁶³ • Need information regarding social network/support groups available.
 Briggs⁶⁷ • *I don't even know where to look...; Information is just not there; it's not available.*
 Coole³⁴ • Patients wanted information from employer regarding absence management policy and procedures, eg, extent of time off allowed for LBP as they were particularly worried about the effect of company bonus schemes on their decision to take time off.

did not conflict with their previous lived experience, and wanted practical information that could be applied under difficult circumstances, such as at work.^{51,71} Five studies also identified the need for information about how they may prevent LBP.^{33,43,56,65,71}

Self-management strategies: Six studies focused on patients' perceived needs about self-management strategies in LBP management.^{25,39,44,55,67,69} Most participants wanted to learn specific exercises that they could perform to manage their LBP.^{39,44,67,69} Many participants were interested in knowing the limit of exercise in self-managed LBP.^{39,44}

Information about support services for low back pain: Five studies identified patients' needs for information about support services for LBP.^{34,41,58,63,67} Some wanted information about availability of medical and allied health services, with one study focusing specifically on barriers to access as perceived by rural patients.^{41,67} One study described the need for information about non-medical support from social networks and support groups.⁶³ Participants in another study

identified the need for information about work-specific support services, for example information from an employer about the absence management policy.³⁴

Patients' perceived needs relating to the mode of delivery of health information related to low back pain

Eleven studies addressed patients' perceived needs related to the mode of delivery of information relating to LBP.^{25,33,36,37,39,48,50,53,55,59,67} The needs related to the quality of information provided, the language and tone used, and the sources of information.

The need for high-quality information: Three studies described the need for high-quality health information about LBP.^{25,53,67} With regards to the quality of information provided by various healthcare practitioners, participants valued valid, trustworthy and consistent information.^{25,53} They disliked receiving conflicting and discordant advice from different health professionals.^{25,53} In one study,

participants were not satisfied with the quality of information obtained from general practitioners.⁶⁷

The need for health information to be delivered in a suitable tone and understandable language: Eight studies identified that patients wanted health information to be delivered in a suitable tone and understandable language.^{25,36,37,39,48,50,55,56} Patients perceived a need for information to be communicated in an open and clear way,^{36,37,39,48,55} with emotional support,^{36,37,55,56} and using simple language without medical jargon^{39,48,55} and with acceptable tone.²⁵ Patients also preferred information to be delivered in their own language, without using medical jargon.⁴⁸

Source of information: Five studies described the need for information on how to source information about LBP.^{25,33,39,59,67} Participants wanted information about where to obtain credible information.^{39,59,67} They found that information not obtained from the medical practitioner – but from physiotherapists, osteopaths, chiropractors, family, friends or magazines – may have provided unhelpful, conflicting information.^{25,33}

Discussion

This review identified 41 relevant studies that addressed aspects of patients' perceived health information needs related to LBP. Within these studies, two major areas of patient-identified needs emerged: health information content-related needs; and needs related to information delivery. Participants sought information about the cause of LBP, underlying pathology and prognosis, with a consistent desire for a legitimate diagnosis. Participants also wanted personalised information about self-management strategies, including the available support services, related to both healthcare and occupational issues.

Underlying much of patients' needs for health information about LBP was the strong need to obtain a 'definitive diagnosis', which underscored the perceived need for imaging for a diagnosis.^{33,35,41,46,52–54,57,59,61,65,70,71} A definitive diagnosis was perceived by many to justify, reassure and legitimise their LBP symptoms, and many were frustrated with the generic 'age-related wear and tear' explanations.^{33,34,40,43,45,52} However, this is contradictory to current evidence-based LBP management that strongly advises against routine back imaging in the absence of red flags, with imaging considered to be low-value healthcare and a potential driver for unhelpful beliefs.^{2,12,72} This finding highlights the clear mismatch between patients' perceived health information needs and clinicians' knowledge in LBP management. In the United States, the 'Choosing Wisely' campaign was launched in 2012, with the aim of raising awareness and educating patients and clinicians to avoid unnecessary medical tests and treatments across various specialties.⁷³ However, a trial examining the effect of reminders for clinicians committing to not image patients with uncomplicated low back pain following these guidelines failed to show any sustained decrease in clinicians' routine LBP imaging orders. This was interpreted as indicating the significant role of patient factors (eg, needs and preferences) in explaining this mismatch.⁷⁴ Despite patients' strong desire for imaging to reach an accurate diagnosis to relieve anxiety about diagnosis, when performed, imaging was not associated with any psychological benefits.^{52,68,75,76} Effective interventions to correct patients' unhelpful beliefs may require enabling clinicians to communicate the role of imaging more effectively and provide reassurance and a meaningful management plan to patients. However, limited time and financial pressures in clinical practice make this challenging.^{11,77} A variety of strategies, such as customised patient education videos and a consumer-focused pamphlet intervention via community pharmacies, has been used to correct LBP-related beliefs outside the clinical consultation, with promising results.^{78,79} However, these strategies were implemented on a small scale, where the effect may differ when they are more widely implemented. Hence, to effectively target the unhelpful belief about the need for imaging in LBP in the community, a large-scale public mass media campaign is required.⁸⁰ A large-scale mass media campaign in Canada targeting general public attitude to stay active, while experiencing LBP was

shown to have sustained impact on changing public LBP misconception of activity avoidance in LBP.⁸¹

In terms of other health information needs, patients wanted clear, trustworthy, consistent information about the nature of LBP, its benign prognosis, and advice on both pharmacological and non-pharmacological management strategies. However, while information about general strategies for managing LBP was wanted, there was also a clear preference for the health practitioners' advice to be tailored to the individual's age, lifestyle, and occupational status^{37,51,57,59,60,64,71} and be delivered in a suitable tone and understandable language. In addition to the need for customised advice on options, safety and efficacy of pain management in LBP, this review also revealed a consistent preference among patients to explore other non-pharmacological domains, including exercise, self-management and support services available for LBP. However, most LBP clinical guidelines have generic recommendations, for example recommendation to consider group exercise to minimise cost, with little emphasis on how to approach 'patient-tailored' management^{21,82} and how to appropriately integrate physical activity with the other factors contributing to the LBP experience. This further illustrates the mismatch between patients' perceived needs and current recommendations in LBP management.

Approaches such as Cognitive Functional Therapy are likely to help bridge this gap.⁸³ Practising clinicians and physicians have been reported to be inadequately trained and lack confidence in managing long-term musculoskeletal pain conditions and have expressed difficulty in adopting and implementing a biopsychosocial approach to LBP management.^{84–87} This may contribute to patients receiving inconsistent advice from different healthcare professionals, which often results in the provision of low-value care, leading to frustration, which threatens the therapeutic practitioner-patient relationship. Educating practitioners to address patients' underlying unhelpful beliefs and attitudes around LBP may improve long-term LBP outcomes.⁸⁸ Hence, new educational approaches to upskill clinicians in the provision of effective LBP education may be required to ensure that correct, consistent information is delivered. Innovative approaches such as interactive group learning or computer-assisted virtual learning, instead of the traditional guideline dissemination and educational updates, have been used successfully.^{85,89} Furthermore, the use of non-threatening, suitable language could be emphasised in these new educational approaches to ensure better success in delivering effective LBP education.⁹⁰

This review also underscored the impact of LBP on employment and the work environment from patients' perspectives. There is a consistent strong desire for information about prognosis, management and prevention of flares, with a personalised approach to back safety at work, information about workers' rights, uncertainties about future work capacity, leave entitlement and informing the workplace about their condition, to avoid being considered a malingerer.^{34,35,57,65} In line with our findings, despite being a common problem, LBP often elicits scepticism from workplace colleagues, with the problem being viewed as psychogenic or malingering, which further exacerbates patients' distress, delaying participation in LBP rehabilitation.^{91,92} Furthermore, other work-related factors, including negative responses from supervisors, job demands and failure by employers to provide suitable modification to work tasks, were also shown to contribute to unsuccessful return to work,⁹¹ suggesting that education interventions need to target not only patients, employers and clinicians, but also the entire societal attitudes and beliefs towards LBP. The Victorian WorkCover Authority mass media campaign 'Back Pain: Don't Take It Lying Down' successfully altered community beliefs in LBP, resulting in a significant sustained reduction in the number of workers' compensation claims for LBP and healthcare utilisation.⁹³ This campaign had been replicated by three other countries, with reasonably positive results,⁹³ making it a compelling evidence-based example for a similar societal approach to enhance LBP outcomes, incorporating all patients' perceived important health information content about LBP.

This review had several limitations. There were few publications that directly assessed the patients' perceived needs for health

Box 2. Selected examples of participant-perceived needs relating to the mode of delivery of health information regarding low back pain. For a more extensive list, see Appendix 4 on the eAddenda.

Need for high quality information

- Briggs⁶⁷ • Patients wanted reliable information, eg, from specialists as they believed GP is not skilled in pain management and 'not up to date' with LBP management.
- McIntosh²⁵ • Need for updated, evidence-based, valid and trustworthy information as alternative Information received from other professionals, eg, physiotherapists, osteopaths, chiropractors, 'was often conflicting'.
- Toye⁵³ • Patients wanted consistent information, not to be confused by conflicting advices or discordant expert opinion: *We believe you have a trace of spondylolisthesis...and when I went to see the consultant, he said "no, your spine is fine...; I was very upset...well who you believe? Do you believe an orthopaedic surgeon, or do you believe a radiologist...; Is somebody else going to say that is something else entirely different later on?*

Need for health information to be delivered in a suitable tone and understandable language

- Farin³⁷ • Need open and clear communication with focus on personal circumstances to provide more emotional support for patients with LBP.
- Walker⁵⁵ • Clinicians need to show better communication and understanding towards patients and avoid using medical terminology to 'de-medicalise' the whole medical consultation process: *They treat you as if you don't understand what they're talking about...I'd like to be spoken to on my own level...; They fail to recognise the reality of feelings of the sufferer.*

Source of information

- Dima⁵⁹ • Patients desired information from credible and trusted sources, personal or professionals: *If it was recommended by somebody I had confidence in...if it's somebody who's either had it done or it's recommended by a GP.*
- Laerum³⁹ • Need to know where to get help.
- McIntosh²⁵ • Alternative sources of information leading to conflicting advice: *When no information obtained from GP, patients access alternative sources of information from other healthcare professionals such as physiotherapists, osteopaths and chiropractors, and other sources such as family and friends..., which could be conflicting.*

information about LBP, such that the identified needs for health information content have been extrapolated from heterogeneous studies evaluating different primary study aims in different populations. Thus, it is possible that all areas of perceived health information needs for LBP may not have been identified within this review. Most of the studies were performed in the UK where the National Health Service is the main healthcare provider. LBP outcomes are affected by compensation status, which differs in various countries and may affect needs; thus, it is unclear whether these findings are generalisable to those of different ethnicities and economies. Most of the other studies were also performed in Western countries with developed healthcare systems. Only one was performed in Iran,⁶⁹ and there were none from other low-income or middle-income countries. The social and cultural aspects of information needs are unlikely to have been captured outside the UK, Europe or the United States. The Australian study by Briggs et al was centred on rural healthcare.⁶⁷ Whether those with LBP were in receipt of compensation or not was not addressed in most of the identified studies. This may have impacted on health information needs.

The strengths of this review relate to the performance of a comprehensive systematic scoping review in four complementary databases to identify patients' perspective of information needs related to LBP. The results were remarkably consistent across the identified studies from high-income countries, spanning care from the community, primary care, hospital clinics, tertiary pain clinics and rehabilitation centres, suggesting universality of the themes.

This review highlighted that patients' health information needs about LBP remained driven by their need for a diagnosis, in order to validate and legitimise their symptoms. This may contribute to the increasing use of inappropriate imaging for LBP. Additionally, other work-related and employment concerns were identified, suggesting that there is ongoing scepticism associated with LBP, especially in the workplace. Inability to access individualised and consistent advice from multiple trustworthy sources may contribute to a deterioration in the patient's relationship with their healthcare provider, further stigmatising them. Thus, an integrated public health approach in addition to upskilling clinicians to improve their ability to provide health information using simple, understandable language, incorporating patients' personal preferences and needs in LBP are urgently required, to send consistent and accurate information to patients. In order to improve clinical outcomes in LBP, addressing and correcting

unhelpful beliefs may better align patients' expectations with those of healthcare providers.

What was already known on this topic: A large range of diagnostic and therapeutic interventions are frequently applied in low back pain management, despite evidence that many of them are of low value. Although education is recommended in most LBP guidelines, most guidelines do not specify what content should be included in patient education.

What this study adds: People with low back pain expressed a strong desire for clear, consistent and personalised information on diagnosis, prognosis, treatment options and self-management strategies, related to healthcare and occupational issues.

eAddenda: Appendices 1–4 can be found online at <https://doi.org/10.1016/j.jphys.2019.05.010>.

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