National Institute for Health and Care Excellence

Draft for consultation

Osteoarthritis: assessment and management (update)

[B] Evidence reviews for post-diagnostic information on osteoarthritis for people with osteoarthritis, their family and carers

NICE guideline <number>

Evidence reviews underpinning recommendations 1.2.1 to 1.2.3 and research recommendations in the NICE guideline

April 2022

Draft for Consultation

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ISBN:

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1 Patient information

1.1 Review question

What information on osteoarthritis, including the management of flare-ups, do people with osteoarthritis, their family and carers need after diagnosis?

1.1.1 Introduction

NICE has developed guidance on patient experience in adult NHS services that includes recommendations on information for patients (https://www.nice.org.uk/guidance/cg138). It is also important to identify and address the unique needs of people with osteoarthritis. Currently some of this information is available on national websites, such as the Versus Arthritis (https://www.versusarthritis.org/about-arthritis/conditions/osteoarthritis/) however it has not been standardised in any way. Each hospital may have its own locally written information to distribute to patients in clinic. This local information may differ between centres, reflecting local practice, but there is no national standard for this information. The language used in patient information is also contentious for osteoarthritis, with some commonly used terms leading to, or reinforcing misconceptions about the condition and its management. This review seeks to identify the information and support needs of patients with osteoarthritis to inform recommendations for practice.

1.1.2 Summary of the protocol

For full details see the review protocol in Appendix A.

Table 1: PICO characteristics of review question

Objective	To determine the information that people with osteoarthritis, their family and careers need during and after diagnosis to effectively understand and manage their condition.
Population and setting	Inclusion: • Adults (age ≥16 years) with osteoarthritis affecting any joint • Family members of adults with osteoarthritis affecting any joint • Carers of adults with osteoarthritis affecting any joint • Healthcare professionals or experts with an interest in osteoarthritis Exclusion: • Children (age <16 years) • People with conditions that may make them susceptible to osteoarthritis or often occur alongside osteoarthritis (including crystal arthritis, inflammatory arthritis, septic arthritis, diseases of childhood that may predispose to osteoarthritis, medical conditions presenting with joint inflammation and malignancy).
Context	Themes will be gathered from the evidence identified for this review and not stated prior to this. Topics may include (but will not be limited to): • Self-management strategies • Management of osteoarthritic flares • Medication use (including rescue medication) • Future management options (e.g., surgery) • Delivery of support • Psychological support

	• Information sources other than healthcare professionals (e.g., support groups, online resources) • Addressing misconceptions related to osteoarthritis • Information about the natural history of osteoarthritis • Information and explanation of osteoarthritis diagnosis • Pragmatic ways of applying management plans to daily living
Review strategy	Synthesis of qualitative research. Results presented in narrative format. Quality of the evidence will be assessed by a GRADE CerQual approach for each review finding.

1.1.3 Methods and process

This evidence review was developed using the methods and process described in Developing NICE guidelines: the manual. Methods specific to this review question are described in the review protocol in Appendix A and the methods document.

Themes were derived mainly from those identified in the protocol and in some instances further themes were identified within these, which were included as subthemes.

Declarations of interest were recorded according to NICE's conflicts of interest policy.

1.1.4 Qualitative evidence

1.1.4.1 Included studies

Forty-five qualitative studies were included in the review;[3-5, 8, 11, 12, 20, 22, 23, 27, 32, 33, 37, 38, 42, 43, 49, 53, 56, 57, 60, 62, 66, 69, 70, 83, 87-91, 93, 101, 105, 107, 112, 114, 117-120, 126, 127, 131] these are summarised in Table 2 below. Key findings from these studies are summarised in the summary of the qualitative evidence below (Table 3). See also the study selection flow chart in Appendix C, study evidence tables in Appendix D, and excluded studies lists in Appendix E.

A lot of studies were conducted in countries that may not be relevant to a UK population. This has been considered in the grading of the relevance of findings, depending on the theme and whether it is thought likely to differ by population or if it is transferable to the UK. The countries included Australia,[42, 57, 62, 88, 91, 107] Belgium,[118] Canada,[5, 18, 49, 53, 60, 66, 85, 93, 119] France,[4, 12, 66] Germany,[112] Kuwait,[3] Hong Kong,[27] Norway,[20, 101] Spain,[23] Sweden,[127] Switzerland,[37] Taiwan[69] and the USA.[8, 38, 70, 120]

Ten studies were in a UK population.[11, 22, 33, 43, 56, 87, 89, 105, 114, 126]

It should be noted that four studies[3, 8, 88, 112] were in a female only population. The rest of the studies were mixed.

Most of the studies included participants in aged around 60 years old, typically ranging from 40 to 80 years old. Some studies included a younger age range. Goldsmith 2017[49] included participants who were as young as 19 years, Erwin 2018[43] had participants from 28 years old and Egerton 2017[42] had participants aged 34 years old. Kao 2014[69] had a low mean age and range at 49.6 (43-55) years old.

There were no studies looking at people with learning disabilities or specific ethnic groups except for McGruer 2019,[88] who investigated the opinions of Māori adults, which was not relevant to the UK setting.

The majority of the studies included patients.[3-5, 8, 11, 12, 18, 20, 22, 23, 27, 33, 37, 38, 43, 49, 53, 56, 60, 62, 66, 69, 70, 85, 88, 89, 93, 101, 105, 114, 118-120, 126, 127] Whereas Egerton 2017[42] and Pitt 2008[107] included GPs only; Rosemann 2006[112] included GPs and patients. Mann 2011[87] and Mikhail 2007[91] included patients and health care practitioners. Hinman 2016[57] included physical therapists, telephone coaches and patients.

One systematic review[117] included information as one theme amongst many others, therefore the studies were ordered for inclusion in the review.

1.1.4.2 Excluded studies

Please see excluded studies in Appendix E.

Three studies were excluded because the theme that they were discussing (where people gained information for deciding on surgery) had reached saturation point.

Please see excluded studies due to saturation in Appendix E.

1.1.5 Summary of studies included in the qualitative evidence

Table 2: Summary of studies included in the evidence review

Study	Design	Population	Research aim	Comments
Alami 2011[4]	Semi-structured face-to-face interview	81 patients with knee osteoarthritis and 29 practitioners	To identify the views of patients and care providers regarding the management of knee OA and to reveal potential obstacles to improving healthcare strategies	
Ali 2018[5]	Semi-structured face-to-face interview with hermeneutic phenomenology methodology	20 people with osteoarthritis aged >65 years	To better understand the lived experiences and identify ways to improve the care that is available to community-dwelling seniors with OA in urban and rural communities	
Al-Taiar 2013[3]	Focus groups with thematic analysis	Women with severe knee osteoarthritis on the waiting list for TKA	To explore the pain experience and mobility limitation as well as the patient's decision making process to undertake TKA	
Baird 2003[8]	An interpretative descriptive study using interviews with a phenomenological and naturalistic inquiry framework	Women aged over 70 with osteoarthritis	To understand the experience of living and caring for self with osteoarthritis and physical functioning difficulties	
Barlow 2018[11]	Focus groups and in-depth interviews using iterative thematic analysis	Focus group participants were patients who had had a knee replacement. Interview participants were those who were waiting for or considering a knee replacement	To explore what factors affect patient decision-making at different points in the patient pathway	
Baumann 2007[12]	Focus groups using qualitative analysis	Osteoarthritis patients	To evaluate the expectations of	

Study	Design	Population	Research aim	Comments
		purchasing medication at a pharmacy	osteoarthritis patients and to consider how this information may be used to improve healthcare provision and the patients-doctor relationship	
Bower 2006[18]	In-depth semi-structured face-to-face interviews with a grounded theory methodology	Seniors with a physician confirmed diagnosis of osteoarthritis	To explore with seniors what influences their choice of medication for osteoarthritis	
Brembo 2016[20]	In-depth semi-structured face-to-face interviews with an inductive thematic analysis approach	Patients with hip osteoarthritis	To investigate patients' need for information and their personal and emotional needs	
Campbell 2001[22]	Interviews in a qualitative study, nested within a randomised controlled trial	People with osteoarthritis of the knee interviewed 3 months after they completed the physiotherapy program, with some people being interviewed again 1 year later	To understand reasons for compliance and non-compliance with a home based exercise regimen by people with osteoarthritis of the knee	
Carmona-Teres 2017[23]	Semi-structured face-to-face interviews with a content thematic analysis	Patients with knee osteoarthritis	To identify current practice and advice of primary care physicians from the patients' perspective, and to understand the experiences, perceptions, evaluations, values, beliefs, and coping strategies of patients with OA	
Chan 2011[27]	Qualitative interviews with thematic analysis	Patients with a history of knee pain diagnoses as having knee osteoarthritis	To evaluate the influence of different pain patterns on quality of life and to investigate patients’ interpretation and coping strategies	
Churchill 2020[32]	Semi-structured interviews	People attending first consultation	To pilot educational	The data has come from a mixed

Study	Design	Population	Research aim	Comments
		with an arthroplasty surgeon for consideration for total knee replacement	videos with patients to determine their experiences and perspectives regarding the content and clarity of videos and to better understand their potential impact on patients' health behaviour	methods study which included survey information
Clarke 2014[33]	Qualitative interviews using thematic analysis	People with knee osteoarthritis	To examine the experiences of pain reported by participants with knee osteoarthritis	
Demierre 2011[37]	Semi-structured interviews with a thematic discourse analysis	24 adults aged <75 years awaiting arthroplasty	To explore the patient illness experience from the moment the decision is made to perform arthroplasty through 12 months post-surgery	
Dosanjh 2009[38]	Semi-structured interviews or focus groups using a grounded theory approach and content analysis	Patients who were scheduled for an upcoming total hip arthroplasty or had completed total hip arthroplasty	To explore patients experiences and their decision making processes to undergo total hip arthroplasty and examine the factors that influenced decisions about the type of surgical procedure	
Egerton 2017[42]	Semi-structured telephone interviews with an inductive thematic approach	11 GPs from metropolitan, regional, large and small practices	To identify potential factors influencing GPs engagement with a proposed new model of service deliver to provide evidence-based care for patients with knee OA and achieve better outcomes	In relation to a specific intervention
Erwin 2018[43]	Face-to-face focus groups with a phenomenological approach using	25 people with arthritis, including osteoarthritis and	To identify competencies that patients think non-specialist	

Study	Design	Population	Research aim	Comments
	deductive thematic analysis	inflammatory arthritis	community-based nurses and allied health professionals need to enable them to access, care for and manage arthritis appropriately	
Goldsmith 2017[49]	In-depth semi-structured face-to-face interviews using a thematic analysis approach	45 adults with primary or secondary osteoarthritis scheduled to undergo total knee arthroplasty surgery	To improve understanding of patient experience and patient satisfaction following total knee arthroplasty surgery	The data have come from a mixed methods prospective cohort study
Hall 2008[53]	In-depth interviews using a modified grounded theory method approach	15 people with knee osteoarthritis who were waiting total knee arthroplasty	To investigate the physical and psychological consequences of living with osteoarthritis and peoples' views of total knee arthroplasty and physiotherapy	
Hendry 2006[56]	Semi-structured interviews and a focus group	22 primary care patients with knee osteoarthritis	To examine the views of primary care patients with knee osteoarthritis towards exercise, explore factors that determine the acceptability and motivation to exercise, and to identify barriers that limit its use	
Hinman 2016[57]	Semi-structured interviews using thematic analysis informed by grounded theory	10 physical therapists, 4 telephone coaches, and 6 patients with painful knee osteoarthritis	To explore how stakeholders experienced and made sense of being involved in an integrated programme of physical therapist supervised exercise and telephone coaching for people with knee osteoarthritis	Relates to a specific intervention. Participants are part of an RCT.
Hudak 2002[60]	In depth face-to-face interviews	17 elderly individuals who were candidates	To explore the process by which elderly persons make decisions	

Study	Design	Population	Research aim	Comments
	using qualitative content analysis	for total joint arthroplasty	about a surgical treatment	
Ilic 2005[62]	Focus groups with qualitative thematic analysis	12 individuals diagnosed with chronic osteoarthritis	To evaluate the feasibility and user satisfaction of an Internet User's Guide to educate and assist patients to search for medical information about osteoarthritis	
Kao 2014[69]	Semi-structured one-on-one interviews with content analysis	17 adults (aged 43-55 years) with Ahlback stage 1-2 knee osteoarthritis with the ability to speak Mandarin or Taiwanese	To understand the illness experiences of middle-aged adults with early knee osteoarthritis	
Kamsan 2020[66]	Qualitative design using focus group discussions	Older adults aged 60 years and above with a clinical diagnosis of knee osteoarthritis	To explore older adults' knowledge about knee osteoarthritis and their perspectives on the information required to enable self-management	
Karlson 1997[70]	Focus groups using semi-quantitatively and qualitatively methods	30 people with moderately severely severe osteoarthritis of the hip or knee	To study gender specific preferences regarding timing of elective total joint replacement surgery	
MacKay 2020[83]	Qualitative study using semi-structured interviews	Physical therapists who worked with individuals with knee symptoms or diagnosed knee OA in the past 3 months, worked in community based or outpatient settings and could communicate in English	To explore how physical therapists approached management for early knee OA	
Mann 2011[87]	Focus groups and semi-structured interviews using the framework methodology to generate themes	16 people with hip/knee osteoarthritis took part in focus groups; 12 HCPs were interviewed	To explore the opinions of patients and health professionals about the provision of health care for people	

Study	Design	Population	Research aim	Comments
			with osteoarthritis and possible service improvements	
McGruer 2019[88]	Semi-structured interviews using thematic analysis	Māori adults with clinical knee or hip osteoarthritis	To explore the Māori lived experience of osteoarthritis	
McHugh 2009[89]	In-depth semi-structured interviews nested within a longitudinal study, using a framework approach	Patients who were newly referred to an orthopaedic consult for further investigation concerning their hip or knee osteoarthritis	To elucidate some of the factors that influence the decision to have or not have total joint replacement	
McKevitt 2021[90]	Individual semi-structured interviews (face to face)	Adults aged ≥ 45, with self-reported OA and at least one comorbidity located in the Northwest and West Midlands of England (N=17)	To investigate how people with OA experience physical activity in the context of comorbidity, and how best to support people with OA and comorbidity to be more active	Study was part of a larger multi method study that included quantitative and qualitative evidence
Mikhail 2007[91]	Focus groups using a qualitative content analysis approach	Five advanced general practice registrars, six experienced GPs, and 20 patients with osteoarthritis aged 54–85 years	To examine the effect of the debate on the safety of NSAIDs drugs on decision making by Australian general practitioners and patients with osteoarthritis, and to explore issues concerning the use of NSAIDs from both prescriber and consumer perspective	
Miller 2016[93]	Three-step peer-to-peer process including a focus group, creation of an interview guide, and a reflective focus group	Patients with osteoarthritis and trained in engagement methods	To assess the experience of what is important to osteoarthritis patients as they seek help for their symptoms	
Olsen 2017[101]	Individual semi-structured interviews using systematic text condensation	Patients with primary hip osteoarthritis	To explore how patients described their experiences and outcome from participating in patient education	

Study	Design	Population	Research aim	Comments
			and basic body awareness therapy	
Parsons 2009[105]	Unstructured interviews using a phenomenological approach	Patients who had been referred for a primary hip and knee replacement	To explore the lived experiences of patients with severe osteoarthritis of the hip or knew whilst awaiting joint replacement surgery	
Pitt 2008[107]	Focus group interviews using thematic analysis	GPs who had experience of managing people with osteoarthritis and with an opinion about self-management programmes	To examine the barriers to, and drivers of, referrals of patients with osteoarthritis to self-management programmes	
Rosemann 2006[112]	Semi-structured face-to-face interviews	20 patients, 20 GPs and 20 practice nurses	To identify health care needs of patients with osteoarthritis and to reveal possible obstacles for improvements in primary care management of osteoarthritis patients	
Sanders 2004[114]	In-depth interviews using a thematic constant comparison technique	People with high levels of hip or knee pain	To explore barriers to healthcare utilisation in people with moderate to severe hip or knee symptoms or pain and disability	
Smith 2014[117]	Systematic review and meta-ethnography	People with osteoarthritis	To determine the perceptions of people diagnosed with osteoarthritis towards their conservative management strategies	Review included a lot of themes other than just information. The relevant studies from this systematic review were included in our review.
Spitaels 2017[118]	Semi-structured interviews using directed content analysis	Patients with knee osteoarthritis	To investigate patients' perceived barriers and facilitators in current osteoarthritis care	Specific to a Belgian guideline.
Stone 2017[119]	Semi-structured interviews	Adults with osteoarthritis who	To investigate the potential	

Study	Design	Population	Research aim	Comments
	examined using interpretational analysis	were at least 30 years of age, actively seeking medical treatment for their arthritis and not currently enrolled in a regular physiotherapy/physical activity program	facilitators and barriers to physical activity for adults with osteoarthritis	
Suarez-Almazor 2010[120]	Focus groups using thematic analysis	Patients with knee osteoarthritis	To explore decision-making factors influencing preferences for TKA	
Thomas 2013[126]	Semi-structured face-to-face interviews using interpretative phenomenological analysis	Eleven participants (6 women and 5 men) ages 56–80 years who had radiographically confirmed symptomatic foot OA	To examine the experiences of primary care consultation among older adults with symptomatic foot osteoarthritis	
Thorstensson 2006[127]	Semi-structured interviews using a phenomenographic approach	Patients with symptomatic, radiographic knee osteoarthritis who had participated in an exercise intervention	To describe the conceptions of exercise as a treatment for people with moderate to severe knee osteoarthritis	
Victor 2004[131]	Structured interviews, diaries and patient education sessions using thematic and content analysis	Patients aged over 45 years with knee osteoarthritis	To enhance understanding of patients' experiences of living with arthritis and goals for care	

See Appendix D for full evidence tables.

1.1.6 Summary of the qualitative evidence

This review aimed to determine the information that people with osteoarthritis, their family and careers need, during and after diagnosis, to effectively understand and manage their condition.

Table 3: Review findings

Main findings	Statement of finding
Amount of information required	People want different amounts of information, but generally more information is required.
Information about the natural history of osteoarthritis	People needed more information about the origins of the disease as they could have misconceptions about why they have osteoarthritis.
Information and explanation of osteoarthritis diagnosis	It was important for people to get explicit information about what their diagnosis is and what it means for the

Main findings	Statement of finding
	future, to process their diagnosis better. They required, but did not know how to find, additional information on prognosis, self-management, and treatment options soon after diagnosis.
Sources of information – the HCP	There are a variety of health care professionals who can provide information to people with osteoarthritis, and it was thought important to have access to those with osteoarthritis expertise. People needed to know where they could get information regarding what health care providers could do and where they could get reliable information. The information from these professionals should be clear and understandable.
Sources of information other than the HCP: social networks	Many people preferred personal opinions of peers, friends, and families to inform them as often doctors were thought to not be a good source of information. Peer group support of people with similar issues made their present situation and future one less intimidating.
Sources of information other than the HCP: self-directed information and community services	People with osteoarthritis actively accessed other sources of information, including the internet but there were problems of reliability of the information, technicality, or specificity. There were other non-profit organisations which were useful for information, but there was not always awareness of services available and what they provided. There was a need for more community resources with ongoing support required.
Delivery of support. Subthemes: informing and support, communication skills	Informing and support: There was some contradictory evidence, but most of the evidence suggested a lack of information provision and support from practitioners. Some HCPs trivialised osteoarthritis, seeing it as a normal part of the ageing process and misunderstanding the impact it would have on the person. Patients often felt there was not enough time to listen, understand and explain anything to them. Leaving them feeling that they were not concerned or informed. They felt that the GP had a lack of knowledge on osteoarthritis and options to manage it. There were positive experiences when they were given recommendations for OA management, and felt listened to and hope for the future. Communication skills: they wanted clear explanations and did not want jargon which they could not understand. Body language and silence on a topic suggested the HCP did not know, and it would be better to admit this and get a second opinion. Computers created a barrier to communication. Some older people in one study wished a more authoritative model of interaction.
Self-management strategies. Subthemes: information required, self-help groups, pain management, treatment advice, exercise, and weight loss advice	Self-management was thought useful and efficacious. Information required: they required more trusty information which is specific to them so that they could manage their osteoarthritis. More advice on day-to-day management of OA. They wanted self-management skills to help manage their symptoms, to make decisions and have control of their OA.

Main findings	Statement of finding
	Self-help groups: they wanted more advice on the benefits of self-help groups and practitioners wanted to be able to signpost people to sources of help. Pain management: they had a lack of information about pain and how to deal with the changes in pain. They wanted to know how to manage it, heal it if possible, and make sure it does not get worse. They wanted more information on the explanations of pain and what their options were in relieving it. Treatment advice: they felt that medication was the default and alternative strategies were not recognised by their GPs. They wanted more details on the benefits between different drugs, which treatment matched the severity, and when to return to an HCP. Exercise and weight loss advice: there was some inconsistency in this with some feeling that their GP had tried to motivate them and explained the effects of lack of exercise and being overweight. They did not mention which type of exercise they should be doing, and directions were vague. They all agree the benefit of HCPs providing encouragement to exercise and giving specific exercise advice. However, some thought that they had received this, with specific exercises, referral to the gym and advice to walk, exercise in water or use an exercise bike to reduce the impact on joints. They wanted to get information and to be monitored for accountability to increase their motivation. Weight loss: patients wanted advice on weight management and exercise; some evidence indicated that they did get advice and recommendations on weight loss, but it did not focus on increasing motivation.
Management of osteoarthritis flare-ups	There was little evidence about this, but one participant wanted explanation of why and how the dose should be increased when there is a flare-up and why it decreased afterwards. Another study found most consultations focused on the person's presenting problem (typically a symptom flare) with less emphasis on long-term management.
Referral	Referrals were often by sealed letter, and they felt left out of the process and wished more information.
Surgery. Subthemes: prior to surgery; preparation and recovery from surgery; physiotherapy	People researched surgery through books, the internet and from learning from people they know. Advice on information about the surgical procedure, health maintenance issues, exercise, use of walking aids, weight control and symptom control were low and inconsistent education/information, guidance, advice, or support. One study found a video helped address knowledge gaps regarding surgery but shifted responsibility of decision-making from surgeons to themselves. Preparation and recovery: they felt overwhelmed and anxious before surgery. This made retaining information they received difficult. Surgeons were key

Main findings	Statement of finding
	sources of information, and they wanted more information than they received. Information on pain expectations and pain management were required. A go to person would be useful to discuss pain and recovery. Knowing the recovery trajectory would also be useful.
Knowledge and expectations of physiotherapy	Some had little knowledge of physiotherapy, whereas others knew from previous treatments and preoperative education, but all felt it was beneficial for recovery.

Narrative summary of review findings

Review finding 1: amount of information required (LOW confidence)

Participants wanted different amounts of information in one study,[11] but mostly people wanted more information.[12,66] Health professionals also identified the problem of insufficient information for OA patients.[87]

Review finding 2: Information about the natural history of osteoarthritis (LOW confidence)

People required more information about the origins of the disease otherwise they thought it was due to lifestyle, which often led to feeling guilt or that it was due to bad luck.[12] In one study they found no lack of information, or none was requested, in terms of the cause and pathomorphology, but required more about prognosis.[112]

Review finding 3: Information and explanation of osteoarthritis diagnosis (MODERATE confidence)

It was common for people at the initial stage to ask, “something is wrong, what is this hip pain?”[20] After being diagnosed they found it difficult to process osteoarthritis-related issues and lacked disease-related information, such as: disease and medication knowledge; daily life activities and movement; dietary and body weight control; management of symptoms; and how to seek support.[69] Doctors explained that osteoarthritis-related information was scant, and people felt ill-informed during the consultation. Often the information on osteoarthritis and treatment options was basic and variable, depending on the severity of their symptoms and the GPs’ and other HCP’s competence and communication skills.[20] They felt they were not explicit enough when explaining the diagnosis.[12] People did not know how to find this information and found little instructional tools to help.[69] Information helped them accept the diagnosis and reduced the uncertainty and doubt about the future. Knowledge helps patients start a dialogue with Clinicians and become partners in managing their OA.[12] Early education about osteoarthritis, its prognosis and self-management and treatment options was thought important to be discussed and information provided at diagnosis, or soon after, for maximum effectiveness.[87] They required more information to cope with daily life related to their disease, its origins, the outlook and the role and possible side effects of treatment.[12] GPs felt that diagnosing OA did not pose a major problem to them, it was during the course of OA that the situation was more difficult.[112] Some reported little contact following their diagnosis, and that regular review and information about the likely course of OA would be beneficial.[87]

Review finding 4: Sources of information - the HCP (MODERATE confidence)

Patients actively sought information on osteoarthritis and its management from various sources, such as GPs, pharmacists, physical therapists, doctors and health professionals, consumer medicine information leaflets.[18,27,91]

It was thought important to have access to professionals with osteoarthritis expertise. Family doctors usually offer advice on issues such as pain management and prescriptions after diagnosis, progression of OA and repercussions.[5,93] Other sources of professional expertise are orthopaedic surgeons and sometimes physiotherapists. There is a need for information about what HCPs can do for people with osteoarthritis and what they cannot. There were also concerns of continuity of care and reassessment services.[93] Pharmacists were perceived as being reliable sources of information, sometimes preferable to doctors. However, patients were displeased at the variability of the provision of CMI leaflets from pharmacies[91] or limited information provision.[18] Specialists were associated with more positive experiences in terms of information, however some reported that this information was unclear, or they could not understand it.[5,23] No participants received materials on these issues although some said it would have been useful.[23]

Review finding 5: Sources of information other than the HCP: social networks (MODERATE confidence)

While some preferred receiving information from professionals,[11] some felt doctors were not a good source of information.[85] Instead preferring the personal opinions of peers, friends, and families.[11,18,27,85,8] This provided the ability to compare experiences and gather anecdotal information, on new remedies; operations;[5,3] information about OA; methods of managing daily living.[85] Being in a peer group and learning that others had similar issues, made their present situation, and future one, less intimidating than they previously thought.[101] The experience of others could be positive, which facilitated activity,[85] but could also be negative for managing osteoarthritis.[85] Learning how they found ways to handle daily life challenges inspired them to take a positive attitude to coping with their disease and to support others by sharing their experiences with them.[101]

Review finding 6: Sources of information other than the HCP: self-directed information and community services (MODERATE confidence)

Participants also actively accessed various other sources of information such as the internet, the media, medical books, and experts on television or in classes.[5,18,91,112] However, there were often problems in understanding and trusting the information that they received from these sources.[18, 5] Some also found it could be overwhelming.[5] They actively and purposefully sought out information about arthritis and their health.[8] Often it was too hard to find relevant and credible information on the internet. It was often too technical and not specifically related to them.[62] It was often after diagnosis that people were wishing additional information (from that provided by their doctor), on the condition and potential treatments. They used the internet to find this as it was convenient to access the medical information. In one study people found the internet user's guide enabled them to search and identify more relevant and scientific website information.[62]

Non-profit organisations were used as a source of information regarding osteoarthritis, but not all participants were aware of what services were available. Those who were aware were unclear of the services that were offered. Some were disappointed that a hospital-led education programme was discontinued.[5] People felt that more dedicated osteoarthritis community resources, with ongoing support, were required.[5]

Review finding 7: Delivery of support

Subthemes: informing and support (LOW confidence), communication skills (MODERATE confidence).

Informing and support

There was some contradictory evidence for whether people were being well-informed about osteoarthritis. Some reported positive experiences with GPs,[33] however others reported a lack of information provision and support from their practitioners.[4,12,33,43] Some found GPs trivialised the condition,[4,43,] misunderstood its impact[43] and suggested it is part of the normal ageing process.[4] Some felt that professionals still thought of osteoarthritis as an old person's disease and were not aware that it can present differently, and in all ages.[43] Osteoarthritis was not treated as a priority and appointments and assessments were often rushed,[5,12,20, 87,126] with the practitioner having little time to listen, understand or explain.[4,12,33,87,91] This made the participants feel that the practitioners were distant, tactless, not concerned, or informed.[4,12] They wanted GPs to be more attentive, providing more care and information.[5,33] They felt GPs had a lack of knowledge of osteoarthritis,[4,126] and management options.[33] There were positive experiences from recommendations provided by doctors for knee OA management, and for being listened to and offering hope for the future.[33]

They did not expect nurses and AHPs to know everything about OA, but they did expect them to have basic rheumatology training and to know who can be affected. Suggested strategies for managing time pressured interactions, included tailoring information and providing essential information first. Presenting the risk in a patient-friendly way was perceived as a challenge to practitioners.[91] Advice and response to questions, particularly about topics highlighted in the media, were generally good, but patients often felt that they had to seek information rather than being given it spontaneously.[12] Most of the people did not actively seek information during consultations.[20] This was explained partly by the fact that they did not know what to ask specifically and because the GP was not perceived to have the necessary expertise about osteoarthritis. A common finding was that people did not receive general information about osteoarthritis and pain management from their GP.[20] The lack of post examination advice left some participants feeling at times that their concerns were invalid.[126]

Communication skills

People wanted practitioners to participate in an authentic teaching process, wishing more clarity, accessibility, and simplicity.[12] They wanted clear explanations, and thought their doctor would help them explain their disease and the difficulties they encounter.[12] They did not want doctors to use jargon, which they did not understand.[4] Communication skills were thought crucial in some exchanges, particularly regarding pain. When the practitioner was silent, the patient interpreted this as powerlessness and stopped asking questions. Saying 'I don't know' and be sent for a second opinion was more acceptable.[12] Inappropriate gestures generated anxiety, for example a shrug was not thought a substitute for a clear answer. Some lack of dialogue seems linked with avoidance strategies, such as minimizing suffering, using fatalistic wordings and being difficult to approach.[12] Computers were a barrier to communication while facial expression and body language enhanced communication.[12] It was thought that there was a strong requirement for practitioners to help in the sharing of information to older people due to their process and preferences, also they preferred a more authoritative model of interaction. If the physician does not make a direct recommendation, and the person wants a direct recommendation then they could defer the decision as a preferred interaction.[60]

Review finding 8: self-management strategies

Subthemes: self-management (MODERATE confidence), self-help groups (MODERATE confidence), pain management (MODERATE confidence), exercise (MODERATE confidence), and weight loss (LOW confidence).

Self-management

Patients found self-management useful and efficacious.[27] They wanted self-management skills to help manage their symptoms, to made decisions and have control of their OA.[66] Patients felt they required more than typical health literacy or self-help resources, preferring more detailed knowledge about how their osteoarthritis is likely to progress, the extent of their OA, evidence-informed management strategies, and how to deal with changes in mobility.[93] They wanted the information to be specific to them, comprehensive and straightforward.[93] Currently, patients scout out their own information, and need trustworthy information for a range of OA specific resources.[93] Several of the participants with OA felt that they had not been made fully aware of the different management options and had not been given adequate information to make an informed decision about how to manage their condition. Participants also felt that they could be given more advice on the day-to-day management of their OA[43,66]

Self-help groups

GPs mostly did not inform patients about self-help groups or community level offers because they had a lack of information and frustration about the impact of this information such as patients not participating in these services. However, patients wanted basic information on self-help groups, but were unsure of the possible benefits and had reservations about them.[112] Being able to signpost people to sources of help was an important aspect of care that participants strongly felt that all community-based nurses and AHPs should be able to do.[43]

Pain management

They felt they had a lack of information about pain and how to deal with the changes in pain.[93,66,112] They wanted explanations for the pain and reassurance regarding the cause of it, especially when there was increased intensity or frequency of abnormal symptoms (Thomas 2013)[126]. They wanted to know how to manage it, heal it if possible, and make sure it does not get worse.[66] Participants predominately saw their GP, despite additional health care options being available. There was a lack of knowledge regarding other options, and some perceived the view of the GP to be final.[126] The participants felt that community-based nurses and AHPs should be able to give some basic advice on pain management.[43]

Treatment advice

A small amount of participants in one study wished to be better informed of their problems and the related treatments.[27] Another study's participants thought there was too emphasis on analgesics for managing symptoms.[126] There was dissatisfaction with therapeutic options, which treat the symptom not the cause. They felt prescribed medication was the default and alternative strategies were not recognised or seen as efficient by their GPs[4, 5,] but they would prefer to hear about these from them.[5] They wanted to learn about possible non-pharmacological pain management options as they were worried about long term effects of medication and believed there were alternatives.[66] One study found that the debate about the safety of NSAIDs has led to more discussion between the patient and practitioner and patients sought out more information.[91] People felt that GPs were not explicit enough when explaining the benefits between different drugs.[12]They wished specific information about the type of treatment that will match the level of severity, and know when they should return to an HCP.[93]

Exercise and weight loss advice

Patients wanted advice on weight management and exercise.[66] Patients reported that their GP had tried to motivate them repeatedly and had explained the general effects of lack of exercise and being overweight. They did not mention any types of exercise or other possibilities, and any directions given were mostly vague.[112] Advice from health professionals, physiotherapists and social workers was mainly encouraging exercise, with advice about specific exercises, referring to gym and advice to walk (even if it is difficult);[56,23] some received positive feedback for exercising in water or using an exercise bike to reduce the impact on their joints.[23] Also advising people that group exercise would improve motivation.[23] Sometimes the advice was vague or absent, and occasionally exercise was discouraged.[56] In one study all people expressed a desire for advice and guidance, but in different ways, to exercise.[127]

Participants referred to the importance of giving and receiving information and of being monitored and, therefore accountable to someone else. The impact of this feeling of accountability was to increase their motivation to exercise. Patients with knee OA described feeling accountable to their physical therapist and not wanting to let the therapist down.[57] All people spoke about the instrumental role of health care providers in influencing and encouraging physical activity. People expressed that if their physician advocated exercise, they would be eager to adopt it. In addition, people desired more knowledge and specific guidance relating to physical activity indicating that if they were told what to do and how to do it by their doctor then they would do it.[119] Lack of knowledge regarding respective offers, lack of mobility and a lack of motivation for reasons for not exercising.[112]

GPs give advice and recommendations regarding behaviour interventions such as weight loss, but do not focus on increasing motivation, which was considered to have a low success rate. Participants were aware that they were overweight but found losing weight or keeping weight off after losing it difficult despite help from dieticians, endocrinologists, and acupuncture. Some had received leaflets about diets.[23]

Review finding 9: Management of osteoarthritic flare-ups (VERY LOW confidence)

There was little evidence pertaining to information about management of flare ups. In one trial it was noted that one participant wanted explanations of why and how the dose should be increased when there is a flare-up, and why it decreased otherwise.[12] In another study participants felt that most consultations focused on the person’s presenting problem, typically a symptom flare, with less emphasis on long-term self-management.[107]

Review finding 10: Referral (LOW confidence)

People who were referred to other practitioners by a sealed letter from their GP felt left out. They wondered about the relevance of such referrals, and the real benefits for themselves and their disease management.[12] GPs who were either more likely or less likely to refer reported they perceived information provision about the person’s condition as part of their professional role, and this constituted a barrier to referral if they perceived that information provision was the sole function of a self-management programme.[107]

Review finding 11: sources of information on surgery

Prior to surgery (MODERATE confidence)

Many of the participants had exhausted all other resources, including their failed treatments which led them to research arthroplasty through books and information over the internet. Some were informed by health professionals including physicians/surgeons.[53,38,89] They provided the participants with more technical information about the surgery such as what was going to be replaced. Information obtained from doctors influenced the participants’ expectations of surgery. Most were not expecting a perfect recovery.[53] Often participants preferred people lay sources who received surgery and shared their experiences[38,53,60,70,89,105] to see whether they would recommend it and gave them confidence to have the surgery.[53] Women expressed the need for more information about risks of surgery and surgical outcomes.[105] All the data they collected led to an increased understanding of the procedure.[53,38] When information was provided, participants’ anxiety about the procedure appeared to lessen.[89] They wanted to know if those who had surgery managed to resume their usual activities.[53] Of importance was the lack of questions surrounding the process or the acute postoperative phase. Many did not ask about the pain and limitations faced by these people just after their surgery. None of the participants asked about the rehabilitation that would be required. The focus was on the ultimate outcome of the surgery.[53] Participants sought out information from a variety of sources, and coupled with the pain and intrusiveness of the condition, the decision to undergo surgery was made.[53] There were a number of criticisms regarding the provision of information. Several participants perceived that they had not been given any other treatment options then a total joint replacement. Several searched for their own information. More information regarding medication would have been useful with many having been told that it was paracetamol or nothing to manage their pain.[89] Participants showed that improved communication about total joint arthroplasty is also needed. Many people showed evidence of poor information of trust in the procedure, despite having received detailed risk/benefit information. This casts doubt on their receptiveness to the utility of total joint arthroplasty in their individual cases, as well as on the effectiveness of the way the information was presented.[60] Specific education including specific information being available early to prevent the propagation of myths was thought as a strategy to help people better manage their OA.[5] Participants had received the advice to undertake TKA very late, part of the delay was thought that clinicians not taking into consideration treatments already received by previous Clinicians. A longer delay came from the persons deliberation on going for the operation with factors such as fear of operating, seeking encouragement and approval from family and lack of information about the procedure and the outcome.[3] Advice and information pertaining to the proposed surgical procedure, health maintenance issues, exercise, use of walking aids, weight control and symptom control were limited and, in many instances, considered by the participants to be completely absent. There were no consistent healthcare professional-led education/information sessions in place by which individuals could receive information, guidance, advice, or support. In the event of an individual knowing someone who had undergone similar procedures, those individuals considered themselves at an advantage in being able to share experiences and ask for ‘tips’ in coping with various activities. The level and type of information received was down to luck, opportunity, and persistence.

Review finding 12: Preparation and recovery from surgery (VERY LOW confidence)
Informational support: Information is very important in the preparation and recovery from TKA. Information was received though both formal clinical sources and informal personal sources. Although pre-surgical education was considered a key form of informational support, the provided information was often insufficient and some found it not meaningful due to being difficult to understand or remember, or due to conflicting messages. Participants felt overwhelmed and anxious before surgery making retaining information difficult. Surgeons were key sources of information also participants wanted more information than they received. Surgeons are often matter of fact, and not readily providing information, and participants felt overwhelmed which led to them not asking prepared questions. When surgeons took time to provide sufficient information, this was appreciated and improved the experience. The most frequent type of informational support identified as needing improvement was information on pain expectations and pain management. Participants felt that there should be a ‘go to’ clinical person to answer questions or that their surgeon should be available to discuss pain and recovery. Participants also wanted to understand the variety of TKA recovery trajectories so they could be assured they were on some sort of a track to recovery, and often compared their trajectory to others’[49]. One study[32] found educational videos provided opportunities to address any knowledge gaps and help in decision-making regarding surgery, but some felt the videos shifted responsibility of decision-making from surgeons to themselves.

Many participants wanted more personal and higher quality interactions with surgeons, including both emotional support and support with their health needs, including information support. Participants wanted empathetic surgeons though this was not often experienced, impeding patient reassurance. There is often a mismatch between the patients’ and surgeons’ perspectives, including surgeons lacking empathy for the patient experience and not seriously investigating unresolved post-surgery problems. Physiotherapists provided key clinical support and are critical. Communication skills, empathy, time, and tailoring were key. Inadequate physiotherapy was caused by waiting for too long after surgery, and patients sometimes have to self-advocate. Family doctors sometimes assist with pain and recovery advice.[49]

Review finding 13: Knowledge and expectations of physiotherapy (VERY LOW confidence)

There was a division among participants for knowledge and expectations of physiotherapy. Some did not have a lot of knowledge about physiotherapy. Others knew about it based on previous treatments and preoperative education. All believed that physiotherapy was beneficial for their recovery. Those who had expectations mentioned increasing their range of motion, learn to walk and use stairs, and strengthening the muscles as what they would be doing as part of their rehabilitation. Some expected therapy to be difficult and self-directed. They just wanted to perform regular daily activities without pain.[53] Participants receiving their first prosthesis have an imprecise idea of what rehabilitation will entail. They will need physiotherapy, but cannot evaluate its duration or its implementation. Participants with prior arthroplasty rely on their prior experience, and remember the difficulties encountered.[37] They would like personalised plans and professional opinions and face to face contact with an instructor to their confidence in carrying out the physical activity.[90] Many thought that education contributed to buy-in of treatment. Participants talked about pathology and consequences of OA and provided education about treatments like exercise. Most targeted treatment to a person's goals or interests, taking into consideration their personal context to fit in with daily life demands or focusing on a couple of important exercises to keep it manageable. Some told encouraging stories of people who had improved with physical therapy, to have buy in of management.[83]

Summary of the quality of evidence

Table 4: Summary of the quality of evidence: amount of information required

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
Amount of information required					
4	Combination of focus groups and individual interviews (2 studies) and focus	People want different amounts of information, but generally more information is required.	Limitations	Minor concerns about methodological limitations[a]	LOW
			Coherence	No concerns about coherence[b]	
			Relevance	Minor concerns about relevance[c]	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
	groups only (2 studies)		Adequacy	No concerns about adequacy	

(a) Three studies with minor limitations: the relationship between researcher and patients and HCPs could have influenced responses (Mann 2011). In two studies there was an unknown relationship between researchers (Barlow 2018 and Kamsan 2020) and a small sample size (Barlow 2018); another study (Baumann 2007) could have selection bias as the first people to arrive at the pharmacy were selected.

(b) In one study they wanted different amounts of information, in the other three studies the patients wanted more information, or the health professionals identified a lack of information for osteoarthritis patients. This was not thought enough to downgrade on.

(c) Amount of information was not one of the themes identified within the protocol but throughout the review lack of particular information was a key issue. One study was based on a French population so may not directly be applicable to the UK population (Baumann 2007), another study was in a Malaysian population (Kamsan 2020).

Table 5: Summary of the quality of evidence: information about the natural history of osteoarthritis

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Findings	Criteria	Rating	Overall assessment of confidence
Information about the natural history of osteoarthritis					
2	Focus groups (1 study) and individual interviews (1 study)	People needed more information about the origins of the disease as they could have misconceptions about why they have osteoarthritis.	Limitations	Minor limitations[a]	LOW
			Coherence	Minor concerns about coherence[b]	
			Relevance	No concerns about relevancy[c]	
			Adequacy	No concerns about adequacy[d]	

(a) Two studies with minor limitations: In one study there may be selection bias as the first people to arrive at the pharmacy were selected (Baumann 2007). Rosemann 2011 did not give details of the relationship between researcher and participants.

(b) One study detailed that participants required more information on the origins to avoid misconceptions but the other study did not find any participants requesting this.

(c) Baumann 2007 was based on a French population so may not directly be applicable to the UK population, however the theme could be transferable so was not downgraded.

(d) There were only two studies, but one had 100 participants, so this was not downgraded.

Table 6: Summary of the quality of evidence: information and explanation of osteoarthritis diagnosis

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Findings**	**Criteria**	**Rating**	**Overall assessment of confidence**
Information and explanation of osteoarthritis diagnosis					
5	A combination of individual interviews (1 study) and focus-groups (1 studies) and individual interviews (3 studies)	It was important for people to get explicit information about what their diagnosis is and what it means for the future, to process their diagnosis better. They required, but did not know how to find, additional information on prognosis, self-management, and treatment options soon after diagnosis.	Limitations	Minor limitations[a]	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevancy[b]	
			Adequacy	No concerns about adequacy	

(a) Four studies with minor limitations: the relationship between researcher and patients and HCPs could have influenced responses (Mann 2011). Baumann 2007 may have selection bias as the first people to arrive at the pharmacy were selected. Rosemann 2011 did not give details of the relationship between researcher and participants. Brembo 2016 had a very small sample. Those in the early stages of hip osteoarthritis were thought to be underrepresented in the sample and their experiences and questions less clearly explored. Kao 2014 had a small sample size and regional differences may be present.

(b) Baumann 2007 was based on a French population so may not directly be applicable to the UK population. Kao 2014 was conducted in Taiwan so this may not be transferable to the UK, but there was still enough data from other studies to not downgrade overall for relevance.

Table 7: Summary of the quality of evidence: sources of information – the HCP

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Findings**	**Criteria**	**Rating**	**Overall assessment of confidence**
Sources of information – the HCP					
6	Individual interviews (4 studies) and	There are a variety of health care professionals who can provide information to people with osteoarthritis, and it was thought important to have access to those with osteoarthritis expertise. People needed to know where	Limitations	Minor limitations[a]	MODERATE
			Coherence	No concerns about coherence	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Findings	Criteria	Rating	Overall assessment of confidence
	focus-groups (2 studies)	they could get information regarding what health care providers could do and where they could get reliable information. The information from these professionals should be clear and understandable.	Relevance	No concerns about relevance	
			Adequacy	No concerns about adequacy	

(a) *The 5 studies had minor limitations: in most studies the relationship between the researcher and participants was not reported (Ali 2018, Bower 2006, Carmona-Teres 2017, Miller 2016, Mikhail 2007). Chan 2011 had moderate limitations due to unclear relationship of the researcher and no discussion of ethical issues and data collection methods not supported by quotes from the patients. Miller 2016 could have been biased towards more motivated patients.*

Table 8: Summary of the quality of evidence: sources of information other than the HCP: social networks

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Findings	Criteria	Rating	Overall assessment of confidence
Sources of information other than the HCP: social networks					
8	A combination of individual interviews and focus groups (1 study) individual interviews (5 studies) and focus-groups (2 studies)	Many people preferred personal opinions of peers, friends, and families to inform them as often doctors were thought to not be a good source of information. Peer group support of people with similar issues made their present situation and future one less intimidating.	Limitations	Minor limitations[a]	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns of relevance[b]	
			Adequacy	No concerns about adequacy	

(a) The 8 studies had minor limitations: the relationship between the researcher and participants was not reported in several studies (Ali 2018, Al-Taiar 2013, Barlow 2018, Bower 2016, Chan 2011, Maly 2007). There was a very small sample size in a few studies (Barlow 2018 n=5, Maly 2007 n=3) Barlow 2018 had no details on setting or ethical issues. Barlow 2018 may not be generalisable to all patients with OA as the participants were selected for being more 'extreme' cases and the three participants were of the older age group. In Olsen 2017 people found it difficult to recall contents of the information derived specifically from patient education since much or the same information was conveyed in the BBAT groups. In Chan 2011 ethical issues were not being discussed and data collection methods not being supported by quotes from patients.

(b) The studies were from a range of different countries: Ali 2018, Bower 2006 and Maly 2007 were in a Canadian population, Baird 2003 was in the UK, Al-Taiar 2013 in Kuwait, Chan 2011 in Hong Kong, and Olsen 2017 was in Norway so these may not be directly applicable to a United Kingdom population, however the theme is likely to be transferable therefore the quality was not downgraded. Only Barlow 2018 was a UK population.

Table 9: Summary of the quality of evidence: sources of information other than the HCP: self-directed information and community services

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Findings**	**Criteria**	**Rating**	**Overall assessment of confidence**
Sources of information other than the HCP: self-directed information and community services					
6	Individual interviews (4 studies) and focus-groups (2 studies)	People with osteoarthritis actively accessed other sources of information, including the internet but there were problems of reliability of the information, technicality, or specificity. There were other non-profit organisations which were useful for information, but there was not always awareness of services available and what they provided. There was a need for more community resources with ongoing support required.	Limitations	Minor limitations[a]	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Partially applicable[b]	
			Adequacy	No concerns about adequacy	

(a) The 6 studies had minor limitations. Most did not report the relationship between the researcher and participants (Ali 2018, Bower 2006, Mikhail 2007 and Rosemann 2011). Ilic 2005 provides very limited information throughout that makes it difficult to interpret. Baird 2003 had a very small sample size (n=5).

(b) The studies were from a range of different countries: Ali 2018 and Bower 2006 were in a Canadian population, Baird 2003 in a USA population, Ilic 2005 and Mikhail 2007 were in an Australian population. Rosemann 2011 in a German population so these may not be directly applicable to a United Kingdom population. However, the theme of self-directed information is likely to be transferable, whereas community services may not be, so this was not downgraded as the majority of the evidence was about self-directed information.

Table 10: Summary of the quality of evidence: delivery of support

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Findings**	**Criteria**	**Rating**	**Overall assessment of confidence**
Delivery of support. Subthemes: informing and support					

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Findings	Criteria	Rating	Overall assessment of confidence
9	A combination of individual interviews and focus groups (1 study); Individual interviews (5 studies) and focus-groups (3 study)	Informing and support: There was some contradictory evidence, but most of the evidence suggested a lack of information provision and support from practitioners. Some trivialised osteoarthritis, seeing it as a normal part of the ageing process and misunderstanding the impact it would have on the person. They often felt there was not enough time to listen, understand and explain anything to them. Leaving them feeling that they were not concerned or informed. They felt that the GP had a lack of knowledge on osteoarthritis and options to manage it. There were positive experiences when they were given recommendations for OA management, and felt listened to and hope for the future.	Limitations	Minor limitations[a]	LOW
			Coherence	Minor concerns about coherence[d]	
			Relevance	Partially applicable[b]	
			Adequacy	No concerns about adequacy	
Delivery of support. Sub-theme: communication skills					
3	Individual interviews (2 studies) and focus groups (1 study)	They wanted clear explanations and did not want jargon which they could not understand. Body language and silence on a topic suggested they did not know, and it would be better to admit this and get a second opinion. Computers created a barrier to communication. Some older people wished a more authoritative model of interaction.	Limitations	Minor limitations[c]	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance[b]	
			Adequacy	Minor concerns about adequacy	

(a) Eight studies had minor limitations. Most studies did not report the relationship between the researcher and participants (Alami 2011, Ali 2018, Erwin 2018, Mikhail 2007, Thomas 2013). Erwin 2018 had moderate limitations due to lack of information on ethical issues, and limited information/ lack of rigorous approach to data analysis. Mann 2011 had moderate limitations due to the potential influence of the researcher on responses to interviews/ focus groups. Results may not be generalisable as both patients and primary care practitioners were from the same GP practice. Baumann 2007 may have selection bias as the first people to arrive at the pharmacy were selected. Clarke 2014 gave insufficient explanation about the methodology behind the analysis. Thomas 2013 had minor limitations as data analysis did not seem as rigorous as other studies. Brembo 2016 had a small sample (n=13), and it was thought the needs of the individual person were unlikely to be fully accounted for from this type of study. Those in the early stages of hip osteoarthritis were thought to be underrepresented in the sample and their experiences and questions less clearly explored.

(b) The studies were from a range of different countries: Ali 2018 was in a Canadian population, Alami 2011 and Baumann 2007 were in a French population, Mikhail 2007 was in an Australian population. Brembo 2016 was in a Norwegian population, so these may not be directly applicable to a United Kingdom population, but the theme. Clarke 2014, Erwin 2018, Mann 2011, and Thomas 2013 were UK studies, and therefore this was not downgraded for relevance.

(c) There may be selection bias in the studies (Alami 2011, Baumann 2007 and Hudak 2002).

Table 11: Summary of the quality of evidence: self-management strategies

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Findings**	**Criteria**	**Rating**	**Overall assessment of confidence**
Self-management strategies. Sub-theme: information required					
3	Individual interviews (1 studies) and focus-groups (3 studies)	Self-management was thought useful and efficacious. They wanted self-management skills to help manage their symptoms, to make decisions and have control of their OA. They required more trusty information which is specific to them so that they could manage their osteoarthritis. More advice on day-to-day management of OA.	Limitations	Minor limitations[a]	MODERATE
			Coherence	Minor concerns about coherence	
			Relevance	No concerns about relevance[g]	
			Adequacy	No concerns about adequacy	
Subthemes: self-help groups					
2	Individual interviews (1 study) and focus groups (1 study)	They wanted more advice on the benefits of self-help groups and practitioners wanted to be able to signpost people to sources of help.	Limitations	Minor limitations[b]	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance[g]	
			Adequacy	No concerns about adequacy	
Subtheme: Pain management					
4	Individual interviews (2 study) and focus groups (2 studies)	They had a lack of information about pain and how to deal with the changes in pain. They wanted more information on the explanations of pain and what their options were in relieving it and ensuring it does not get worse.	Limitations	Minor limitations[c]	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance[g]	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Findings**	**Criteria**	**Rating**	**Overall assessment of confidence**
			Adequacy	No concerns about adequacy	
Subtheme: Treatment advice					
7	Individual interviews (4 studies) and focus groups (4 studies)	They felt that medication was the default and alternative strategies were not recognised by their GPs. They wanted to know about non-pharmacological pain management options as they worried about the effects of medication. They wanted more details on the benefits between different drugs, which treatment. matched the severity, and when to return to an HCP.	Limitations	Minor limitations[d]	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance[g]	
			Adequacy	No concerns about adequacy	
Subtheme: Exercise and weight loss advice					
6	A combination of individual interviews and focus groups (2 studies) and individual interviews (5 studies)	Patients wanted advice on weight management and exercise. There was some inconsistency in the findings with some feeling that their GP had tried to motivate them and explained the effects of lack of exercise and being overweight. They did not mention which type of exercise they should be doing, and directions were vague. They all agree the benefit of HCPs providing encouragement to exercise and giving specific exercise advice. However, some thought that they had received this, with specific exercises, referral to the gym and advice to walk, exercise in water or use an exercise bike to reduce the impact on joints. They wanted to get information and to be monitored for accountability to increase their motivation. Weight loss: they did get advice and recommendations on weight loss, but it did not focus on increasing motivation.	Limitations	Minor limitations[e]	LOW
			Coherence	Minor concerns about coherence[f]	
			Relevance	No concerns about relevance[g]	
			Adequacy	No concerns about adequacy	

(a) Information required: the 4 studies had moderate limitations due to unclear relationship of the researcher (Chan 2011, Erwin 2018,Miller 2016 and Kamsan 2020) and a lack of information on discussion of ethical issues (Chan 2011, Erwin 2018) and data collection methods not being supported by quotes from patients (Chan 2011) or limited information/ lack of rigorous approach to data analysis (Erwin 2018). Miller 2016 may have had selection bias towards more motivated patients due to recruitment methods.

(b) Self-help groups: Both studies had a lack of details of the relationship between researcher and participants (Erwin 2018 and Rosemann 2011) and Erwin 2018 had moderate limitations due to a lack of information on ethical issues and limited information/ lack of rigorous approach to data analysis.

(c) Pain management: All studies did not report the relationship between researcher and participants (Erwin 2018, Kamsan 2020, Miller 2016, Roseman 2011, Thomas 2013). Erwin 2018 had moderate limitations due to a lack of information on ethical issues, and limited information/ lack of rigorous approach to data analysis. Miller 2016 may have had selection bias towards more motivated patients due to recruitment methods. Thomas 2013 had minor limitations due to unclear data analysis methods.

(d) Treatment advice: the relationship between the researcher and participants was not reported in a few studies (Ali 2018, Alami 2011, Alami 2011, Chan 2011, Kamsan 2020, Mikhail 2007, Miller 2016, Thomas 2013) Alami had unclear selection and data analysis process. Baumann 2007 may have had selection bias as the first people to arrive at the pharmacy were selected. Chan 2011 had moderate limitations due to ethical issues not being discussed and data collection methods not being supported by quotes from patients. Miller 2016 may have had selection bias towards more motivated pts. Thomas 2013 had minor limitations due to unclear data analysis methods.

(e) Exercise and weight loss advice: The relationship between the researcher and participants was not reported in a few studies (Carmona-Teres 2017, Kamsan 2020, Rosemann 2011). Hendry 2006 Three of the authors were clinicians and one was a sports psychologist, who were all in favour of exercise provision for this group, however they were aware of this potential for investigator bias and actively sought any negative comments about such schemes. Hinman 2016 Specific to this integrated programme. Stone 2017 had moderate limitations due to the methods used could not control for researcher bias. Generalisability may be limited due to the use of a convenience sample from a private medical office that only comprised of people with osteoarthritis with a relatively shorter mean during of osteoarthritis (due to the inclusion of an under-researched "younger adult" population with osteoarthritis). Thorstensson 2006 had moderate limitations due to small number of participants (n=16) and the potential for researcher bias to influence patient statements.

(f) The studies differed in whether they had received information from their HCP about exercising and how specific the details were.

(g) Many of the studies were in countries other than the UK but the themes are relevant to the UK.

Table 12: Summary of the quality of evidence: management of osteoarthritis flare-ups

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Findings**	**Criteria**	**Rating**	**Overall assessment of confidence**
Management of osteoarthritis flare-ups					
2	Focus-groups (2 studies)	There was little evidence about this, but one participant wanted explanation of why and how the dose should be increased when there is a flare-up and why it decreased afterwards. Another study found most consultations focused on the person's presenting problem (typically a symptom flare) with less emphasis on long-term management.	Limitations	Minor limitations[a]	VERY LOW
			Coherence	Minor concerns about coherence[b]	
			Relevance	Minor concerns about relevance[c]	
			Adequacy	Minor concerns about adequacy[d]	

(a) Baumann 2007 may have selection bias as the first people to arrive at the pharmacy were selected. Pitt 2008: the study reported that the sample size was small but noted that increasing the size was unlikely to yield any additional information. However, convenience sampling of participants in this study may limit the generalisability of results.

(b) The two studies were not coherent.

(c) Baumann 2007 was based on a French population and Pitt 2008 an Australian population, so may not directly be applicable to the UK population.
(d) Only two studies and only one participant mentioned it in one study.

Table 13: Summary of the quality of evidence: referral

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Findings**	**Criteria**	**Rating**	**Overall assessment of confidence**
Referral					
2	Focus-groups (2 studies)	Referrals were often by sealed letter, and they felt left out of the process and wished more information.	Limitations	Minor limitations[a]	LOW
			Coherence	No concerns about coherence	
			Relevance	Minor concerns about relevance[b]	
			Adequacy	No concerns about adequacy	

(a) Baumann 2007 may have selection bias as the first people to arrive at the pharmacy were selected. Pitt 2008: the study reported that the sample size was small but noted that increasing the size was unlikely to yield any additional information. However, convenience sampling of participants in this study may limit the generalisability of results.
(b) Baumann 2007 was based on a French population and Pitt 2008 an Australian population, so may not directly be applicable to the UK population, particularly given the theme referral.

Table 14: Summary of the quality of evidence: surgery

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Findings**	**Criteria**	**Rating**	**Overall assessment of confidence**
Surgery. Subthemes: prior to surgery					
9	A combination of individual intervie	People researched surgery through books, the internet and from learning from people they know. Advice on information about the surgical procedure, health maintenance issues, exercise, use of walking aids, weight	Limitations	Minor limitations[a]	MODERATE
			Coherence	No concerns about coherence	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Findings	Criteria	Rating	Overall assessment of confidence
	ws (1 study); individual interviews (5 studies) and focus-groups (2 studies); mixed method with semi-structured interviews (1 study)	control and symptom control were low and inconsistent education/information, guidance, advice, or support. One study found a video helped address knowledge gaps regarding surgery but shifted responsibility of decision-making from surgeons to themselves.	Relevance	No concerns about relevance	
			Adequacy	No concerns about adequacy	
Preparation and recovery from surgery					
1	Individual interviews (1 study)	They felt overwhelmed and anxious before surgery. This made retaining information they received difficult. Surgeons were key sources of information, and they wanted more information than they received. Information on pain expectations and pain management were required. A go to person would be useful to discuss pain and recovery. Knowing the recovery trajectory would also be useful.	Limitations	Minor limitations[b]	VERY LOW
			Coherence	No concerns about coherence	
			Relevance	Partially applicable[c]	
			Adequacy	Minor concerns about adequacy[d]	

(a) The studies had minor limitations: the relationship between researcher and participants was not reported in a few studies (Al-Taiar 2013, Ali 2018, Churchill 2020, Hall 2008, Karlson 1997). Dosanjh 2009 had minor limitations due to potential influence of the researcher on the focus group and ethics approval not mentioned. Hudak 2002 The study notes that they could have been selecting a population that did not have sufficient information about the procedure or were basing it on a hypothetical that was not appropriate for them at this time. A second limitation was the extent to which assumptions are applicable to a wider population. The sample size was small, but note that all the themes could be seen. In the study design they exclude any participants who are unsure or would choose to have total joint arthroplasty, and so misses a fair amount of the population in their aim and makes the research less applicable. McHugh 2009; the study notes that it is limited in its generalisability with the type of study design and small sample size, with selection bias. Karlson 1997: results were given 'semi-quantitively' and were specifically related to total joint replacement. Minor limitations due to unclear recruitment method and a lack of ethics reporting. Parsons 2009 focused on a relatively small sample of people living with advanced osteoarthritis while awaiting total hip/knee replacement surgery, therefore it may lack generalisability.

(b) Goldsmith 2017 had minor limitations due to the role of the researcher not being adequately addressed.

(c) Theme not completely relevant to review as it is related to recovery from surgery.

(d) Only one study contributed to the theme.

Table 15: Summary of the quality of evidence: knowledge and expectations of physiotherapy

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Findings	Criteria	Rating	Overall assessment of confidence
Knowledge and expectations of physiotherapy					
3	Individual interviews (2 studies) and focus groups (1 study)	Some had little knowledge of physiotherapy, whereas others knew from previous treatments and preoperative education, but all felt it was beneficial for recovery. People with OA personalised plans and professionals' opinions with an instructor was beneficial and physiotherapists felt targeted treatment to goals and interests and fitting into their daily life helped participant buy-in.	Limitations	Minor limitations[a]	VERY LOW
			Coherence	Minor concerns about coherence[b]	
			Relevance	Minor concerns about relevance[c]	
			Adequacy	Minor concerns about adequacy	

(a) Hall 2008, Kamsan 2020: Minor limitations due to the relationship of the researcher not being discussed. Hall 2008: used existing in-depth interview data from a prospective qualitative study. Demierre 2011 had minor limitations due to unclear recruitment methods and the relationship of the researcher not being discussed. The study relates specifically to patients undergoing surgery.

(b) Variations in knowledge.

(c) Knowledge of physiotherapy after surgery may not be relevant to review and was downgraded .

1.1.7 Economic evidence

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

1.1.9 The committee's discussion and interpretation of the evidence

1.1.9.2 The quality of the evidence

Overall, the evidence base had mainly moderate to low quality rating. Generally, the study limitations were minor, mainly due to unclear relationship between the researcher and the patient. The evidence was downgraded for relevance where it was thought not relevant to the UK or was not entirely related to the review question or where there was an inadequate amount of evidence to support the findings. The committee had confidence in a lot of the evidence as it represented the viewpoints of patients and health care practitioners.

The evidence on the theme 'amount of information required' had low confidence, there were minor methodological limitations from unclear or a possibly biased, relationship between researcher and patients; small sample size in one study and possible selection bias. Furthermore, two of the studies were in a non-UK population, therefore amount of information provided may differ by population.

The finding information about the natural history of osteoarthritis had low confidence, there were few studies informing this finding and there was possible selection bias and lack of information on relationship between researcher and participants. There was a lack of coherence between the studies in whether people wanted more information on the origins of the disease. One study was in a French population so may not be applicable to a UK population.

Information and explanation of osteoarthritis diagnosis was graded moderate as it had only minor limitations mainly from unclear researcher and patients' relationship and selection bias. There were no concerns about coherence or adequacy. The majority of studies (3/5) were in a UK population.

Sources of information – the HCP had moderate quality rating as it had an adequate number of studies contributing to the finding and it was a coherent theme. There were minor limitations from unclear relationship between the researcher and participant, one study had further limitations as there was not enough information and another could have been more biased towards more motivated participants.

Sources of information – other than the HCP: social networks had moderate quality rating as there were no concerns for coherence or adequacy and although the participants were from a range of countries, this theme was thought not to be specific to the UK. There were minor limitations such as unclear relationship between researcher and participants; and lack of details; lack of generalisability to all people with OA.

Sources of information other than the HCP: self-directed information and community services was graded moderate quality. There was an adequate amount of studies, and minor limitations included unclear relationship between researcher and participants; one study with a very small sample size and one with limited information. There was some studies which were from other countries which may not be directly applicable to a UK population, however the theme of self-directed information is likely to be transferable, whereas community services may not be.

Delivery of support. Subthemes: informing, support and communications had low ratings of quality as there were minor limitations and minor concerns about coherence and adequacy. The minor limitations varied by study. Self-management strategies: sub-themes of information required, self-help groups, pain management and treatment advice had moderate quality ratings due to minor limitations. There were no concerns about coherence, relevance or adequacy. Exercise and weight loss was graded as low quality due to minor limitations and minor concerns about coherence in findings.

Management of osteoarthritic flare-ups had a very low quality grading as there were minor limitations in the study due to sample size and the generalisability of results; the two studies were not coherent in their findings, here were concerns of relevance for the finding as it was in non-UK populations and the theme from one study was one participant.

Referral was graded low as there were only 2 studies with minor limitations, and concerns on the relevance due to non-UK populations and the theme being related to the services provided.

Surgery: subthemes: prior to surgery was graded as moderate quality as there were minor limitations and a lot of studies included in the theme; preparation and recovery from surgery was graded as very low as only one study was included and there were minor limitations. The theme was also only partially applicable to the review.

Knowledge and expectations of physiotherapy was supported by very low quality evidence as most was relevant to patients undergoing surgery and there was little coherence in findings.

1.1.9.3 Findings identified in the evidence synthesis

The evidence found suggested that more information is required, with some saying they had varying requirements. Most participants wanted more information about the origins of osteoarthritis to dispel any misconceptions they have about why they have it. They wanted explicit information about what their diagnosis meant for the future and to process their diagnosis. They wanted information on prognosis, self-management, and treatment options soon after diagnosis. There are a variety of HCPs who can provide information, but patients thought it important to have access to those with osteoarthritis expertise. They needed to know where they could get reliable information from and it to be clear and understandable. Many relied on sources of information from peers, friends and families as having people with similar issues made their situation less intimidating. They often accessed sources of information such as the internet, but it was thought unreliable and lacked relevance to them. There were non-profit organisations but there was a need for awareness of services available. There was a theme of a lack of information provision and support from practitioners. They wanted clear explanations and no jargon. Self-management strategies were thought to be useful and efficacious. They wanted self-management skills, in particular to help them manage their condition. They wanted to know about self-help groups and pain management. They felt medical treatment was the default and alternatives were not considered by HCPs. They wanted advice on exercise and weight loss that would be specific to them and to be monitored for accountability to increase motivation.

There was little evidence on management of osteoarthritis flare-ups, but one study found they wanted to know why and how the dose should be increased when there is a flare up. Referrals were often by sealed letter which left the patient out of the process. There were themes around surgery, but this was less relevant to this review. There was variation in knowledge of physiotherapy, but it was thought beneficial for recovery.

Overall, participants wanted information and they wished it to be tailored to them. From understanding the natural history, identifying, and addressing their misconceptions to managing their prognosis and the benefits of treatment. They wanted knowledgeable, reliable sources of information. They wanted information on exercise that was specific to them that would be motivational; and how to manage their day to day pain and any changes in pain. They wanted to know where they could get additional information from, such as support groups and peer support. The committee found most of the evidence to be representative of their experience of what patients' information requirements were and therefore used the findings with their expert opinion to form the recommendations.

The committee agreed that the patient experience guideline should be accessed for general guidance on patient information. In particular, they agreed that the recommendations relating to knowing the patient as an individual and tailoring healthcare services for each patient were particularly relevant. They discussed tailoring information and how each patient should have an individualised plan, with ongoing goals jointly agreed with the leading clinician. It was agreed that this should encourage patient motivation and ownership in sharing care. Furthermore, many of the people are likely to be elderly and have co-existing health conditions, therefore the lead Clinician should co-ordinate this information to ensure that the patient's other ongoing treatments can be optimised. The committee agreed we need to cross refer to the multi-morbidity guideline (NG56) for recommendations relating to this.

The committee decided to make research recommendations as there was no evidence which looked at the needs for information provision from different ethnic and socio-economic groups and those with learning disability, health literacy issues and severe mental illness and so research would be useful within these instances to see the different amount and provision of information required for these groups. Furthermore, there was little information on one of the areas that the committee had flagged prior to the review, information on management of flare-ups, therefore a research recommendation was made so this could be explored more.

1.1.9.4 Cost effectiveness and resource use

Cost effectiveness evidence was not sought as this was a qualitative review. The recommendations generally provide guidance regarding the content of information and support specific to people with osteoarthritis in line with the general principles of provision of information already established in the existing NICE Patient Experience Guideline and so were not considered likely to have a substantial resource impact over and above this.

1.1.9.5 Other factors the committee took into account

The committee agreed that the patient experience guideline covers how to inform the patient generally. This guideline suggests to 'advise the patient where they might find reliable high-quality information and support after consultations, from sources such as peer to peer support, national and local support groups, networks and information services.' This was added to with more specific details for those with osteoarthritis. The committee also discussed presenting the information in a format and language (simple English language or its translation) which will be understood by the patient.

The committee wished to highlight that the language which practitioners use within the consultation was important.

1.1.10 Recommendations supported by this evidence review

This evidence review supports recommendations 1.2.1 to 1.2.3. Other evidence supporting these recommendations can be found in the findings of various other evidence reviews.

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Appendices

Appendix A – Review protocol

ID	Field	Content
0.	PROSPERO registration number	
1.	Review title	2.1 What information on osteoarthritis, including the management of flare-ups, do people with osteoarthritis, their family and carers need during and after diagnosis?
2.	Review question	2.1 What information on osteoarthritis, including the management of flare-ups, do people with osteoarthritis, their family and carers need after diagnosis?
3.	Objective	To determine the information that people with osteoarthritis, their family and careers need during and after diagnosis to effectively understand and manage their condition.
4.	Searches	The following databases will be searched: • CINAHL • Embase • MEDLINE • PsychINFO Searches will be restricted by: • English language

		• Human studies • Letters and comments are excluded Other searches: • Inclusion lists of relevant systematic reviews will be checked by the reviewer. The searches may be re-run 6 weeks before final submission of the review and further studies retrieved for inclusion if relevant. The full search strategies for MEDLINE database will be published in the final review.
5.	Condition or domain being studied	Osteoarthritis (of any joint) in adults (defined as a clinical diagnosis of osteoarthritis with or without imaging)
6.	Population	Inclusion: • Adults (age ≥16 years) with osteoarthritis affecting any joint • Family members of adults with osteoarthritis affecting any joint • Carers of adults with osteoarthritis affecting any joint • Healthcare professionals or experts with an interest in osteoarthritis Exclusion: • Children (age <16 years)

		• People with conditions that may make them susceptible to osteoarthritis or often occur alongside osteoarthritis (including crystal arthritis, inflammatory arthritis, septic arthritis, diseases of childhood that may predispose to osteoarthritis, medical conditions presenting with joint inflammation and malignancy).
7.	Intervention/Exposure/Test	Views, opinions, and experiences relating to information and education at or after diagnosis of osteoarthritis, including mode of delivery. Of particular note, looking at information regarding the management of osteoarthritic flare-ups.
8.	Comparator/Reference standard/Confounding factors	N/A
9.	Types of study to be included	Qualitative interview and focus group studies (including studies using grounded theory, phenomenology, or other appropriate qualitative approaches). Survey data or other types of questionnaires were only included if they provided analysis from open-ended questions, but not if they reported descriptive quantitative data only.
10.	Other exclusion criteria	• Non-English language studies • Abstracts will be excluded as it is expected there will be sufficient full text published studies available.
11.	Context	N/A

12.	Primary outcomes (critical outcomes)	Themes will be gathered from the evidence identified for this review and not stated prior to this. Topics may include (but will not be limited to): • Self-management strategies • Management of osteoarthritic flares • Medication use (including rescue medication) • Future management options (e.g., surgery) • Delivery of support • Psychological support • Information sources other than healthcare professionals (e.g., support groups, online resources) • Addressing misconceptions related to osteoarthritis • Information about the natural history of osteoarthritis • Information and explanation of osteoarthritis diagnosis • Pragmatic ways of applying management plans to daily living
13.	Secondary outcomes (important outcomes)	N/A
14.	Data extraction (selection and coding)	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. A standardised form will be used to extract data from studies (see [Developing NICE guidelines: the manual](#) section 6.4). Once saturation is considered to have been reached (all the themes are already covered in the data extraction) data from other included papers will not be extracted or critically appraised, but the paper will still be read to check for any additional themes and will be noted in the included studies. The point at which data extraction is reached will be noted within the review.
15.	Risk of bias (quality) assessment	Risk of bias will be assessed using the appropriate checklist as described in Developing NICE guidelines: the manual. For qualitative reviews, the Critical Appraisal Skills Programme (CASP) qualitative checklist will be used to assess for the risk of bias of individual studies. 10% of all evidence reviews are quality assured by a senior research fellow. This includes checking: • papers were included /excluded appropriately • a sample of the data extractions • correct methods are used to synthesise data • a sample of the risk of bias assessments

		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.	
16.	Strategy for data synthesis	The synthesis of qualitative data will follow a thematic analysis approach. Information will be synthesised into main review findings. Results will be presented in a detailed narrative and in table format with summary statements of main review findings. GRADE CERQual will be used to synthesise the qualitative data and assess the certainty of evidence for each review finding.	
17.	Analysis of sub-groups	Not applicable	
18.	Type and method of review	☐	Intervention
		☐	Diagnostic
		☐	Prognostic
		☒	Qualitative
		☐	Epidemiologic
		☐	Service Delivery
		☐	Other (please specify)
19.	Language	English	
20.	Country	England	

21.	Anticipated or actual start date	23/08/2019		
22.	Anticipated completion date	25/08/2021		
23.	Stage of review at time of this submission	Review stage	Started	Completed
		Preliminary searches	☑	☐
		Piloting of the study selection process	☐	☐
		Formal screening of search results against eligibility criteria	☐	☐
		Data extraction	☐	☐
		Risk of bias (quality) assessment	☐	☐
		Data analysis	☐	☐
24.	Named contact	5a. Named contact National Guideline Centre 5b Named contact e-mail [Guideline email]@nice.org.uk [Developer to check with Guideline Coordinator for email address]		

		5e Organisational affiliation of the review National Institute for Health and Care Excellence (NICE) and the National Guideline Centre
25.	Review team members	From the National Guideline Centre: Carlos Sharpin [Guideline lead] Julie Neilson [Senior systematic reviewer] George Wood [Systematic reviewer] Emma Cowles [Senior health economist] Joseph Runicles [Information specialist] Amber Hernaman [Project manager]
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 Developing NICE guidelines: the manual. Members of the guideline committee are available on the NICE website: https://www.nice.org.uk/guidance/indevelopment/gid-ng10127
29.	Other registration details	N/A
30.	Reference/URL for published protocol	N/A
31.	Dissemination plans	NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as: • notifying registered stakeholders of publication • publicising the guideline through NICE's newsletter and alerts • 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.

32.	Keywords	Carers; Family support; Flare-ups; Information; Osteoarthritis; Patient information; Post-diagnosis; Qualitative
33.	Details of existing review of same topic by same authors	
34.	Current review status	☒ Ongoing ☐ Completed but not published ☐ Completed and published ☐ Completed, published, and being updated ☐ Discontinued
35..	Additional information	N/A
36.	Details of final publication	www.nice.org.uk

Appendix B – Literature search strategies

- What information on osteoarthritis, including the management of flare-ups, do people with osteoarthritis, their family and carers need during and after diagnosis?

The literature searches for this review are detailed below and complied with the methodology outlined in Developing NICE guidelines: the manual.[98]

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

B.1 Clinical search literature search strategy

Searches were constructed using an Osteoarthritis population combined with search filters

Table 16: Database date parameters and filters used

Database	Dates searched	Search filter used
Medline (OVID)	1946 – 17 November 2021	Qualitative studies Exclusions (animals studies, letters, comments)
Embase (OVID)	1974 – 17 November 2021	Qualitative studies Exclusions (animals studies, letters, comments)
CINAHL, Current Nursing and Allied Health Literature (EBSCO)	Inception – 17 November 2021	Qualitative studies
PsycINFO (ProQuest)	Inception – 17 November 2021	Qualitative studies

Medline (Ovid) search terms

1.	exp osteoarthritis/
2.	(osteoarthriti* or osteo-arthriti* or osteoarthrotic or osteoarthros*).ti,ab.
3.	(degenerative adj2 arthritis).ti,ab.
4.	coxarthrosis.ti,ab.
5.	gonarthrosis.ti,ab.
6.	or/1-5
7.	letter/
8.	editorial/
9.	news/
10.	exp historical article/
11.	Anecdotes as Topic/
12.	comment/
13.	case report/
14.	(letter or comment*).ti.
15.	or/7-14
16.	randomized controlled trial/ or random*.ti,ab.
17.	15 not 16

18.	animals/ not humans/
19.	exp Animals, Laboratory/
20.	exp Animal Experimentation/
21.	exp Models, Animal/
22.	exp Rodentia/
23.	(rat or rats or mouse or mice or rodent*).ti.
24.	or/17-23
25.	6 not 24
26.	limit 25 to English language
27.	Qualitative research/ or Narration/ or exp Interviews as Topic/ or exp "Surveys and Questionnaires"/ or Health care surveys/
28.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
29.	(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.
30.	or/27-29
31.	26 and 30

Embase (Ovid) search terms

1.	exp osteoarthritis/
2.	(osteoarthriti* or osteo-arthriti* or osteoarthrotic or osteoarthros*).ti,ab.
3.	(degenerative adj2 arthritis).ti,ab.
4.	coxarthrosis.ti,ab.
5.	gonarthrosis.ti,ab.
6.	or/1-5
7.	letter.pt. or letter/
8.	note.pt.
9.	editorial.pt.
10.	case report/ or case study/
11.	(letter or comment*).ti.
12.	or/7-11
13.	randomized controlled trial/ or random*.ti,ab.
14.	12 not 13
15.	animal/ not human/
16.	nonhuman/
17.	exp Animal Experiment/
18.	exp Experimental Animal/
19.	animal model/
20.	exp Rodent/
21.	(rat or rats or mouse or mice or rodent*).ti.
22.	or/14-21
23.	6 not 22
24.	limit 23 to English language

25.	health survey/ or exp questionnaire/ or exp interview/ or qualitative research/ or narrative/
26.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
27.	(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.
28.	or/25-27
29.	24 and 28

CINAHL (EBSCO) search terms

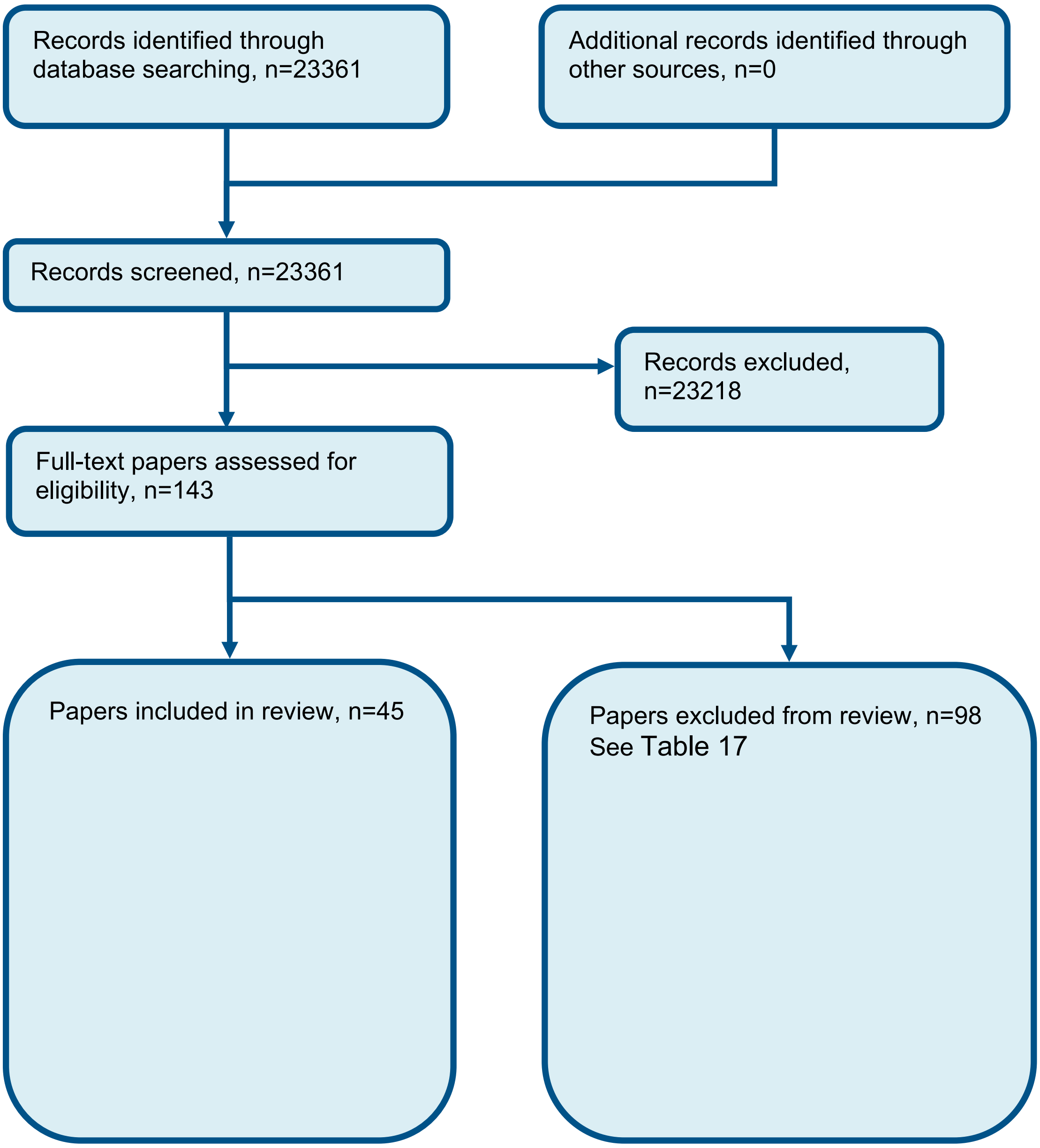
S1.	MH osteoarthritis
S2.	(osteoarthriti* or osteo-arthriti* or osteoarthrotic or osteoarthros*)
S3.	(degenerative n2 arthritis)
S4.	coxarthrosis
S5.	gonarthrosis
S6.	S1 OR S2 OR S3 OR S4 OR S5
S7.	(MH "Qualitative Studies+")
S8.	(MH "Qualitative Validity+")
S9.	(MH "Interviews+") OR (MH "Focus Groups") OR (MH "Surveys") OR (MH "Questionnaires+")
S10.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*)
S11.	(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*)
S12.	S7 OR S8 OR S9 OR S10 OR S11
S13.	S6 AND S12

PsycINFO (ProQuest) search terms

1.	(ti,ab(osteoarthriti* OR osteo-arthriti* OR osteoarthrotic OR osteoarthros*) OR ti,ab(degenerative NEAR/2 arthritis) OR ti,ab(coxarthrosis OR gonarthrosis)) AND ((su.exact.explode("qualitative methods") 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*)))

Appendix C – Qualitative evidence study selection

Figure 1: Flow chart of qualitative study selection for the review of patient information



Appendix D – Qualitative evidence

Study	**Al-Taiar 2013[3]**
Aim	To explore the pain experience and mobility limitation as well as the patient's decision making process to undertake TKA among women with knee pain in the waiting list for surgery.
Population	Patients with severe knee osteoarthritis on the waiting list for TKA. Patient characteristics: n=39; 0 males/39 females; mean age (SD) 62.5 (7.5) years.
Setting	Focus groups took place in the orthopaedic hospital in Kuwait and were led by a local female facilitator who is a clinical psychologist and proficient in both English and the local Arabic dialect.
Study design	Qualitative study using focus groups.
Methods and analysis	Five focus groups using a question guide with questions focused on the pain experience of patients and its impact on their social, emotional, and physical lives as well as on the factors considered to be important in the decision-making process to undergo TKA. The question guide including eighteen questions with probes were developed in Arabic for use in the group discussions, but one question was removed after the first group discussion due to redundancy. The groups discussed the impact of knee OA in broad terms and then turned to the process of decision-making about the surgery. All focus group discussions were audio-recorded and transcribed verbatim using the audio-records and supplemented by the notes. The transcripts were checked against the audio-tapes for completeness and accuracy by another person. Each transcript was coded for themes by two researchers who then met to compare themes and their organization, working out a set of final themes and subthemes by consensus. Analysis began with identification of key themes and patterns from the data using the process of coding that involved assigning labels to the different themes that emerged from each question. Transcripts were coded by assigning labels to segments of text in themes and then writing descriptive accounts based on these themes. Coding was also checked by another researcher. A final reading of all transcripts was done to confirm the validity of the themes and conclusions. Qualitative data analysis was conducted on the original Arabic transcripts with no translation to any other language.
Findings	**Process of decision making to undergo TKA and pathway of care** Pathway of care showed that participants had received the advice to undertake TKA at least once locally and once abroad, but this was very late and came after a long and unnecessary suffering from their perspective. There was consensus that the medical advice to undertake TKA was very late. One participant said, "they wasted our life, they should have told us to have the operation from the beginning" while another noted "doctor do not advise their patients to undertake the operation until the knee is completely destroyed then they give their advice". Part of the delay in medical advice to have TKA came from the fact that patients sought second, third and

Study	**Al-Taiar 2013[3]**
	probably fourth opinion on their OA from different clinicians who failed to consider the treatment which patients had received from previous clinicians and thus started another trial of painkillers; as one of the patients put it “every doctor wants to try from the beginning to see if we need surgery”. When the participants were asked about those with whom they had discussed the possibility of having TKA, most of the participants mentioned their sons, daughters, and husbands. One participant said her sons were not happy that she was going to have the operation because they believed she is too old. Another participant said that initially her husband was against the operation asking her to wait until new advancements in medicine occur but changed his mind when he saw the successful outcome among those who had TKA. There was a long debate within the participants’ families on whether to have the surgery at all and, if so, whether to have it done locally or abroad. Many participants knew someone who had TKA and some of whom were their own relatives (23 participants in five groups). People who had the operation were mentioned as a source of information and their experience was brought up several times. All participants cited positive experiences of people who had undergone the operation. Knowing someone who had knee arthroplasty increased the knowledge of the participants about the procedure and raised their expectations about the positive outcome of the surgery. Participants attributed this indecisiveness to the poor quality of clinical advice, which did not include explanations of the expected outcome in terms of pain relief, improved mobility, or the life-expectancy of the prosthesis. Some participants noted a difference between private and public sector doctors in the way they explain treatment options to patients. They explained how clinicians in the public sector simply ask, "do you want the surgery or not", and do not provide any written or verbal information about the surgery. Most participants gleaned their information on TKA from those who had previously experienced it, and this took time to occur and caused substantial delay. Participants on the waiting list had many unanswered questions about their upcoming surgery and sought the answers from the moderator. One participant said, “you have to ask and persist in order to get any piece of information”.
	Expectations of total knee arthroplasty When the participants were asked about their expectations from the surgery, their answers ranged from “Do not know” to “God knows”, or citing the positive experiences of those who had TKA. The experience of those who had TKA appeared to improve the participants' expectations of surgery. Overall, lack of information has contributed to poor and non-specific expectations of TKA among the participants.
Funding	Funded by Kuwait University, grant MC01/09.
Limitations and applicability of evidence	Minor limitations: the relationship between researcher and participants was not reported. Based on a population from Kuwait so may not be directly applicable to a United Kingdom population.

Study	**Alami 2011**[4]
Aim	To identify the views of patients and care providers regarding the management of knee OA and to reveal potential obstacles to improving healthcare strategies.
Population	Patients with knee osteoarthritis and 29 practitioners. Patient characteristics: n=81; 22 males/59 females; age 45–60 years, n=29, 61–80 years, n=38, >80 years, n=14; professional activities yes n=34, retired n=57 Practitioner characteristics: n=29; 18 males/11 females; age 11 <45 years; speciality 11 GPs, 6 rheumatologists, 4 orthopaedic surgeons, 8 delivering alternative medicine
Setting	France. Participants were interviewed at home or in public places. The patients were selected from files of care providers not involved in the interview process. Care provider interviews took place at practice locations.
Study design	Qualitative study.
Methods and analysis	Semi-structured interviews with thematic analysis. Interviews had questions with open ended questions. Interview guides for both groups were as similar as possible to allow comparison across groups. The interview guides were structured by combining a ‘‘funnel shaped’’ structure and the ‘‘itinerary method’’. The funnel-shaped structure was adopted to ensure that the interviews allowed for an inductive comprehension of the social reality at stake beneath the knee OA situation. The itinerary method of data collection was derived from anthropological data collection techniques and focused on objects, practices and the decision making process. The interview guides thus combined a thematic structure (views of OA, its effects and the following adjustments, description and evaluation of the patients’ therapeutic journey, expectations, and fears and beliefs) with chronological sequences to detail the therapeutic journey and the course of consultation: diagnostic routines, information giving, prescribing, advice for lifestyle, and referrals. For physicians, the interview guide covered practitioners’ views of arthritis and knee OA (specificity, causes, limitations and social impacts, evolution); the description of the management of knee OA to analyse decision-making processes (different sequences were detailed, such as the diagnosis process[es] and routine[s]) [interrogatory, physical examination, announcement of the diagnosis, counselling, etc.]; and therapeutic decision-making processes [including renewal, adjustment and modification of prescriptions, referral to another physician, uncertainties encountered], the description of the patient–practitioner interactions at all steps of the therapeutic journey (identifying questions asked, information delivered, subjects discussed, patients’ resistance or specific demands, and social strategies adopted), and practitioners’ expectations. The mean time for these interviews was 1.5 hr for patients and 1 hr for physicians Interviews for 8 patients were structured as ‘‘life history interviews’’ focusing on knee OA and lasted 2 hours.
Findings	**Sources of dissatisfaction** Patients often receive unclear explanations or insufficient knowledge, reporting that they are sorely in need of information and sometimes do not clearly understand what the jargon that doctors sometimes use.

Study	Alami 2011[4]
	Practitioners sometimes trivialise osteoarthritis and describe it with a fatalistic attitude saying that it is a part of normal aging. This led some participants to feel that physicians are not concerned and not informed. There was also some dissatisfaction surrounding therapeutic options in terms of classical versus alternative medicine, where classical medicine is often palliative and treats the symptom but not the cause. Alternative options were reportedly not recognised by physicians or seen as efficient.
	Treatments Views of treatments are varying and may depend on the chronicity of the knee OA. Drug treatments are viewed as both therapeutic and noxious leading to fear and avoidance. There is concern regarding side effects, especially for opioids and NSAIDs. There is also fear surrounding tolerance due to the limited treatment options, which may result in limiting drug use. Some people took drugs during an acute crisis or to prevent pain for special events. Dietary supplements were taken when prescribed by physicians or recommended by relatives or friends, and considered a natural alternative to pharmacological drugs that do not have side effects. Local topical treatments are associated with pain relief and self-administration along with massage may be importance for a mental image of pain relief. Patients recognise that the effect might be psychological, and have lower expectations compared to drug therapy so are less likely to be disappointed by this treatment. Views regarding non-pharmacological treatments are mixed, with some such as exercise being considered essential, and others having mixed opinions regarding efficacy (such as spa therapy). Wheelchairs are not well accepted because of a loss of autonomy and image or old age. There are various opinions regarding alternative therapies, but reasons for use include avoiding long term drug therapy, delaying surgery and an emphasis on prevention.
Funding	Pfizer. The funders had no role in study design, data collection, data analysis, decision to publish, writing the manuscript.
Limitations and applicability of evidence	Moderate limitations: patients were selected from files of care providers not involved in the interview process, overall, unclear. Relationship between researcher and participants not reported. Analysed by 4 researchers (unclear if this was independent). Did thematic analysis which was explained.

Study	Ali 2018[5]
Aim	To better understand the lived experiences and identify ways to improve the care that is available to community-dwelling seniors with OA in urban and rural communities.
Population	Community-dwelling seniors (aged >65 years) with OA Characteristics: n=20; 4 male/16 female; average age (range) 72 (67-83); urban participants n=11, rural participants n=9; employed part time n=3, retired n=17; self-rated assessment of health, excellent n=3, good n=8, fair n=8, poor n=1; self-rated assessment of osteoarthritis, good n=3, fair n=7, poor n=7, extremely bad n=2, no response n=1.
Setting	Canada. Interviews took place at the participants' home or a local community centre. Participants were purposefully sampled using posters and flyers were distributed to local businesses, health and community centres, and additional participants were identified through snowball sampling, where existing study participants recruited potential participants from their social network.
Study design	A qualitative study with a hermeneutic phenomenology approach.
Methods and analysis	Hermeneutic phenomenology was used to go beyond mere description of the phenomenon and enable interpretation of the meaning that individuals assign to the lived experience. Interviews were conducted over a period of 7 months. An interview guide with 3 open-ended questions was used to guide the discussion; the questions were as follows: 1) Where do you get information related to OA? 2) How do you manage your OA pain? and 3) What can be done to improve OA management for seniors? Additional probes were used to maintain and enrich conversation over time. Interviews lasted an average of 45 minutes. Inductive thematic analysis was carried out for all transcripts through line by line, selective, and wholistic analyses. Groups of words and phrases that reflected the same concept were labelled using codes. Through discussion, codes were grouped into subthemes with shared meanings, and interpreted within the social, cultural, and historical context of the individual's experiences with OA. From these, themes emerged.
Findings	**Community services** Some participants used a non-profit organisation as a source of information regarding arthritis, although not all were aware of it. Those that were aware were unclear about the services that were offered by this organisation. Some participants were disappointed that a hospital led education programme had been discontinued.
	Social networks Information regarding OA management was often obtained through a family member or friend. Participants use this network to compare experiences and gather anecdotal information, particularly in relation to new remedies.
	Self-directed information seeking Some participants accessed information through various sources and were willing to try new things, however there were barriers in terms of interpreting and trusting information available in the public domain and some found it overwhelming.
	Attitudes toward medication Participants were often prescribed medication by default, however, prefer to hear about alternative strategies and thought that GPs should provide this information.
	Formal support

Study	Ali 2018[5]
	Some participants reported positive experiences with GPs, whereas others expressed a lack of information and support, with rushed appointments where OA was not treated as a priority. Specialists were associated with more positive experiences in terms of information, however some reported that this information was unclear.
	Trial and error Participants described a trial and error approach to new strategies to reducing OA symptoms. Most participants were willing to try new strategies whilst others felt it was futile given the lack of a cure.
	Facilitators of OA management Several strategies were identified that would help people better manage their OA, including OA specific education including specific information being available early to prevent the propagation of myths. More attention to OA from GPs and dedication OA community resources were also mentioned, with the need for ongoing support emphasised.
	Individual contextualisation of OA There was a distinction between those who felt hopeful about changing their prognosis, and those who felt helpless. Whilst some expressed determination, stubbornness, and motivation from peers, others report worry, frustration, and lack of engagement in strategies despite being aware of them.
	Access to local care Rural participants had difficulty obtaining appointments and maintaining a GP, resorting to local emergency departments.
Funding	Author supported by a Transdisciplinary Bone & Joint Training Award from the Collaborative Training Program in Musculoskeletal Health Research and the Sam Katz Community Health and Aging Research Unit at the University of Western Ontario.
Limitations and applicability of evidence	Minor limitations: no details of the relationship between the researcher and the participants.

Study	Baird 2003[8]
Aim	To understand the experience of living and caring for self with osteoarthritis and physical functioning difficulties. The research question was, “What is the meaning of self-caring for older women with physical functioning difficulties and osteoarthritis?”
Population	Purposive sample of women older than 70 attending activities of a senior citizen centre. The study included five women with self-reported osteoarthritis and physical functioning difficulties. Patient characteristics: n=5; 0 males/5 females; Mean age (range): 78 (72-91) years; Joint involvement: Knee (4), Spine (3), Hip (2), Neck (1), Shoulder (3), Hand (2), Wrist (1); Marital status (4 widows, 1 single); mean education in years: 12; mean number of years since symptomatic: 17; mean number of years since diagnosed: 13 years.

Study	Baird 2003[8]
Setting	2-3 in-depth interviews in a community based setting (not explicitly stated, but researcher appears to be from the United States of American, so presumedly this study was completed there).
Study design	Semi-structured individual interviews.
Methods and analysis	Interviews following a semi-structured interview guide. The number of interviews depended on the richness of the data or clarification needed. Audiotaped interviews were transcribed. Data were the transcribed narratives of the participants, field notes taken of observations and impressions, theoretical memos, coded unis of the narratives, and categories noted. Analysis consisted of a process of deconstruction and reconstruction. Deconstruction was the reduction of the narratives to the smallest section or unit, often a sentence or small paragraph, that had meaning. Reconstruction was a process of grouping similar units, coding units in the words of the participants. The continual comparison progressed with regrouping into intermediate categories, labelled with gerunds. Final grouping led to the meaning of living with osteoarthritis and was labelled by the researcher as Holding On. Because the assumptions of naturalistic inquiry were different from the assumptions of the logical-positivistic research tradition, the criteria for the quality or worth of the findings were also different.
Findings	**Holding On to Present Self** The present self is the product of becoming. Through many years and a multitude of experiences, the participants have become and are still becoming. The participants recognized themselves as aging women with osteoarthritis. They described themselves of living with multiple symptoms and explained that living with osteoarthritis is living with hurting. Besides hurting, the participants describe living with osteoarthritis as a life of having difficulties with achieving the activities they need to do in a day. Having difficulty is who they are now.
	Holding On to Ableness All the participants desired to hold on to their ableness, their capability and their competence in moving. Keeping physically and socially active contributes to maintaining ableness.
	Holding On to Being Interested and Being Interesting Continuation in interest in learning about the world: being curious, being vital and being inquisitive. People demonstrated this by maintaining an attitude for growth. This is shown through desiring to be interesting to others. In addition to being attractive to others and by having a growing intellect, which causes the individual to experience pleasure. Attitude was seen as essential to the feeling of being healthy.
	Holding On by Seeking to Know The participants involved themselves in a determined exploration to perform self-care and to be self-caring. The participants seek to know through print media, through experts at classes or on television, by consulting nursing and by listening to friends so that they might learn what to do. They actively and purposefully seek information about arthritis and their health status. All except one attended arthritis classes at a senior citizen centre. In addition, participants seek advice related to health care and self-care from nurses, physicians, and other health professionals in clinics and physician offices. They also gain information by comparing themselves to others.

Study	**Baird 2003[8]**
	Holding On by Purposefully Choosing and Acting The intentional selection of self-caring activities that the participants then act on to relieve some of the pain, difficulties and worry with which they live. This is demonstrated in the stories of the participants as maintaining control and modifying activities.
Funding	Not reported.
Limitations and applicability of evidence	Based on a USA population so may not be directly applicable to a United Kingdom population. Includes a very small sample size (n=5). Moderate limitations: Unclear recruitment strategy, relationship between researcher and participants and no details on ethical considerations.

Study	**Baumann 2007[12]**
Aim	To evaluate the expectations of osteoarthritis patients in France and to consider how the information gathered may be used to improve the health care provision and patient-doctor relationship they received.
Population	The first ten customers who came to purchase medication, of whatever nature, for their osteoarthritis were recruited at 10 pharmacies in 10 towns in 10 regions (selected at random from 22 French regions). Patient characteristics: n=100; 19 males/81 females; mean age (range) 65 (42-89) years; joints affected (knee = 66%, finger 50%, hip 46%); living in flats (55%), living alone (48%), living with a partner (42%), living with another family member (10%). Education levels: primary (28%), secondary (37%), baccalauréat or higher education (26%), non-response (9%).
Setting	10 focus groups made up of 10 participants from 10 pharmacies in 10 towns in 10 regions (selected at random from 22 French regions).
Study design	Semi-structured interviews using focus groups.
Methods and analysis	Ten focus groups were interviewed by two teams of two interviewers using a semi-structured interview guide. The focus groups lasted for about 2 hours. The main topics selected were about: 1) set up phase (each participant answered the following on a piece of paper: What is osteoarthritis? What are your expectations with respect to osteoarthritis?; 2) Each person read their answer to the rest of the group; 3) Next stage (activities about the main themes): presentation of osteoarthritis discussing what do you know about osteoarthritis?; living with illness discussing pain, mobility, sleep, weight, social relationships, professional life, everyday activities, morale and information received; 4) medical assistance discussing care, explanations, undesired effects, quality of the relationships with the contributors; 5) information discussing communicating with the Doctor, clarity of the explanations given, preoccupations of the changes with osteoarthritis, informing your next of kin; 6) expectations discussing foreseen improvements, ideals, new treatments.

Study	**Baumann 2007**[12]
	In the focus groups generally, participants provided mutual support and shared feelings, knowledge, and experience. Each interviewee also completed a self-administered questionnaire covering socio-demographic characteristics and details of their osteoarthritis (joints affected, degree of pain) and its treatment (medications). Two teams of senior academic sociologists and rheumatologists conducted qualitative analyses of focus group transcripts. The information derived was classified into categories, the labelling of which was determined by consensus; items were then entered verbatim into the relevant category.
Findings	**Expectations in terms of information: knowing as a way to better understanding** The main issues people required more information about to cope between with daily life related to their disease, its origins, the outlook and the role and possible side effects of treatment. Information about recent developments was seen as inadequate. Without information there was a tendency to think of the disease as a consequence of lifestyle - leading to guilt – or as bad luck. In order to cope, people said they needed information that would help them accept the diagnosis and the uncertainty and doubt about the future that goes with it. Knowledge helps patients develop a dialogue with practitioners and become partners in managing their osteoarthritis. The ability of patients to communicate their daily experience to the practitioners is a priority if they are to build genuine agreement and if the best treatment strategy for each individual patient is to be identified. Specific questions asked by participants included: Causes and course of OA: • ‘are there young people with this disease?’ • ‘does work involving repetitive movements and being always in the same position cause the disease?’ • ‘what causes it?’ • ‘is it common?’ • ‘can it get worse again?’ • ‘am I likely to go on to worse disability?’ • ‘am I likely to become bedridden?’ Daily life and prevention: • ‘do climates or food have an effect?’ • ‘is walking a good thing?’ • ‘are there things you should or should not do – a lifestyle to be avoided? • ‘what predisposes (people to OA)?’ Treatment and its effects • ‘I would like someone to explain to me why and how the dose should be • increased when there is a flare-up, and why it is decreased afterwards.’’

Study	Baumann 2007[12]
	• 'why is it important to avoid getting too used to these drugs?' • 'are there side-effects?' Training and new developments • 'are there any new developments – with lesser side effects?'; • 'can you graft cartilage?' • 'is there an • efficient treatment other than operation?' Outlook and research • 'is it inherited?' • 'will our children and grandchildren get it too?' • 'is there a way to prevent it in young people?' • 'is research progressing?' • 'are there a lot of researchers working in this field?'; • 'do they have means available? • 'are there experimental centers?'
	Expectations in terms of communication skills: improving dialogue Issues in this area included finding better ways to talk to patients, giving explanations in suitable form, and facilitating transfer of knowledge and information. People wanted practitioners to participate in an authentic teaching process. There is a need for more clarity, accessibility and simplicity. Computers may facilitate information management, but do nothing to improve communication because they 'steal' time from relationships, and may upset the patient by 'hiding' the practitioner's face. Facial expression and body language enhance communication. People said that practitioners were often not explicit enough when discussing the seriousness of the diagnosis of the value of certain drugs compared to others. They were frequently seen as being distant, with little time to listen, understand or explain, and were often perceived as tactless. Inappropriate gestures generate anxiety; for example, a shrug is no substitute for a clear answer. Some lack of dialogue seems linked with avoidance strategies, such as minimizing suffering, using fatalistic wordings and being difficult to approach. Lack of communication skills is crucial in some exchanges, notably regarding pain. Silence from the practitioner was interpreted as powerlessness, and patients stopped asking questions. Yet they would be prepared to hear the practitioner say, 'I don't know' and to be sent for a second opinion. Advice and response to questions, in particular about topics highlighted in the media, were seen as generally good, but patients often felt that they had to seek information rather than being given it spontaneously. People referred to other practitioners by sealed letter felt left out. They wondered about the relevance of such referrals, and the real benefits for themselves and their disease management.

Study	Baumann 2007[12]
	Expectations in terms of support: recognitions as a way to better involvement People did not see much interest in their disorder among practitioners, whereas they experienced its growing impact day-to-day (having to give up what they used to enjoy, having to stop caring about appearance, feeling that people are looking at them). In the medium term, physical limitations and emotional distress made life hard, and made it difficult to plan. As self-reliance is gradually eroded, and dependency sets in, the support provided by practitioners was considered an integral part of care provision. More understanding and support were also expected from the person's immediate circle (at home and at work), particularly when friends and family did not see osteoarthritis as a real disease. It was reassuring to be able to talk to other people who have the same illness. People saw their GP as being the person to talk to day-to-day, and looked to them to facilitate social recognition, act as a mediator with their close circle, and help them to explain their disease and the difficulties they encounter. People trusted their GPs and did not plan to change practitioner.
Funding	Supported by the steering Committee and an unconditional grant from Laboratories Pharmasicence, Paris, France.
Limitations and applicability of evidence	Based on a French population so may not be directly applicable to a United Kingdom population. The population selects for the first people to arrive at a pharmacy which may only pick up a certain population (for example: people with worse morning pain may not go to the pharmacy first thing in the day and may have different responses). Minor limitations: unclear recruitment strategy and relationship between researcher and participants.

Study	Barlow 2018[11]
Aim	To explore the decision-making for knee replacement at different points in the patient pathway.
Population	Focus groups included 12 patients after knee replacement: 5 males: 7 females; aged 67 to 82; Interviews included 6 patients awaiting knee replacement 4 males: 2 females; aged 52 to 78; the other group included 4 patients having arthroscopy for knee replacement: 3 males; 1 female; aged 51 to 70.
Setting	Not stated.
Study design	Focus groups and interviews qualitative study with iterative thematic analysis.
Methods and analysis	Two stages: focus groups to generate a range of patient views; the second used in-depth interviews to test and explore these views. The focus groups were patients who had already had a knee replacement, and interviews took place with patients either waiting for a knee replacement (decision-making phase) or considering having one (deliberation phase); even those deliberating had osteoarthritis severe enough to be reviewed in secondary care. Using a predominant semantic development of themes (Braun and Clarke, 2006; Miles, 1994). The process took place within the bounds of the theoretical framework of deliberation/decision-making. Purposive sampling across age and gender used. Iterative thematic analysis used to analyse the data and the process of searching for themes, reviewing themes, and defining and naming themes was conducted in line with Braun and Clarke's (2006) recommendations.

Study	**Barlow 2018[11]**
Findings	Factors affecting decision-making:
	Stress from deliberation There was a constant stress during the deliberation process, which was relieved when the decision was made. Suggestive that it was unlikely that they move back to the deliberation stage once the decision was made, and the decision was either right or wrong.
	Expectation of outcome This involved expectations if treated with a knee replacement or not treated. Some had unrealistic expectations, such as getting back to the same or higher level of functioning than they had after the operation. There was consistency in that they felt they would get worse if not treated, and better if treated, with differences in the degree of change in their health status.
	Preferred model of care There were differences in model of care experienced and preferred. Some had experienced informed or shared decision-making, where they were asked to make the decision. Others preferred a more paternalistic approach. Different preferences for consultation style are not clear and may make their decision before meeting surgeon (having reached their threshold of coping) and are therefore happy with this process when it occurs. Despite this ambiguity, it is clear that in these patients, a paternalistic interaction leads to a relief (perhaps related to trust in the doctor, the stress from deliberation and decision-making threshold), and increased confidence.
	Sources of information This is linked to expectation of outcome, as it is the information that was received that shaped the expectation. Participants wanted different amounts of information. Some had a predisposition towards personal opinions (e.g., from their family), while some others preferred it from professionals. A preference existed for information from friends and family.
	Personal situation An individual’s situation can, and sometimes did, have a large effect on deliberations. Subthemes included: motivation, financial concerns, or a return to ‘normal life’ which linked into social pressures (loved ones) and personal commitments.
	Mental state The psychological effects of having knee osteoarthritis and the emotional aspects of considering a knee replacement. Fear was main emotion, others suffered included anxiousness, low mood, lack of pleasure, feelings of dread, feelings of inadequacy, social withdrawal and frustration when suffering from knee osteoarthritis. The fears included: damaging the knee by not getting treatment, visiting the doctor, fears of the procedure and anaesthetic, and fears over the recovery period and outcome.
	Coping strategies Coping strategies affected how people understood or coped with their symptoms. There were physical and mental coping strategies, mental varied but there was a common theme of stoicism and a positive mental attitude.
	Loss of control Physical loss of control from everyday life being affected by knee problems. Mental loss of control involved not having control over process of having an operation and adapting to their new limitations.

Study	Barlow 2018[11]
	Trust in doctor Opinions of their surgeon appeared to affect deliberation, with trust affecting people's mental state positively and negatively. Congruence of preferred consultation style and that which they received affected the establishment of the relationship.
Funding	Not reported.
Limitations and applicability of evidence	The setting was not stated and there were no details of researchers or ethical issues. Small sample size. Data saturation not discussed. Minor limitations: the relationship between researcher and participants whas not reported. Ethical issues were not reported.

Study	Bower 2006[18]
Aim	To explore with seniors what influences their choice of medication for osteoarthritis.
Population	Seniors with OA. Characteristics: n=16; no further details reported.
Setting	Participants were interviewed in their homes in two urban areas in Nova Scotia. Participants were purposively sampled, and were then randomly selected from the pool of people who had agreed to take part.
Study design	Qualitative study.
Methods and analysis	Individual interviews were used because they increase participants' privacy and disclosure. An unstructured interview guide was used. The interviewer repeatedly revised the questions between interviews to seek out alternative views. All interviews were audiotaped and transcribed verbatim. Analysis was guided by grounded-theory methods, which seek to develop and understand connections between and among theoretical categories. Each transcript was read independently by all members of the research team to identify key words and phrases. The team then collaboratively grouped these words and phrases into conceptual categories that accommodated the range of words. The final set of conceptual categories formed the basis of a coding structure within qualitative analysis software, and reports were generated for each code to confirm or quantify the coding structure.
Findings	**Physicians' role** Many participants started taking coxibs following free samples from their physicians, and physicians' recommendations were very influential in their decision to take them as their first prescription medication. Some participants accepted physician recommendations whilst some questioned their judgement. Physicians were reportedly not always receptive to participants bringing information to appointments.

Study	**Bower 2006**[18]
	Effect of fear making medication choices Fear of side effects was common for participants. Some also reported fear of a deterioration in health even if they were not convinced the treatment was effective, which led to 'pharmaceutical inertia' (i.e., resistance to make changes to drug regimen). Some were unwilling to change drugs without a guarantee of improvement.
	Reasons for discontinuing coxibs Participants discontinued due to side effects of ineffectiveness.
	Views on other information sources Pharmacists, social networks, and the media were used as sources of information along with family physicians. Some viewed pharmacists as important sources, whereas others only reported receiving limited information. Some found social networks important, whereas others were sceptical of their reliability. Drug advertising had little effect on their decisions as they were deemed untrustworthy.
Funding	Nova Scotia Department of Health through the Drug Evaluation Alliance of Nova Scotia.
Limitations and applicability of evidence	Minor limitations: the relationship between the researcher and participants was not reported.

Study	**Brembo 2016**[20]
Aim	To investigate patients', need for information and their personal and emotional needs, how these needs change over time as the disease progresses, and how decision-making about total hip replacement takes place.
Population	Patients with hip osteoarthritis. Participant characteristics: n=13; 6 males/7 females; Age range 59-88 years; 7 participants underwent elective hip replacement the day after interviews, 1 participant was accepted for surgery, 2 participants were referred and awaiting evaluation; time with hip-pain 2-3 years n=1, 4-5 years n=3, 6-7 years n=3, 8-9 years n=1, >10 years n=5.
Setting	Interviews took place in two settings; the hospital setting prior to scheduled surgery and the GP setting. Participants were recruited purposively from an orthopaedic outpatient clinic at a local hospital in the South-eastern part of Norway.
Study design	Qualitative design.
Methods and analysis	Semi-structured interviews were used so that participants were given an opportunity to speak openly about their personal "hip OA journey". The interviews were audiotaped and conducted in the manner of a conversation, although a semi-structured interview guide was prepared. This explorative approach gave the participants an opportunity to freely disclose and discuss issues that were important to them, rather than respond to specific pre-selected questions. A typical interview was initiated by highlighting essential information

Study	Brembo 2016[20]
	about the study and its purpose, and then letting the participant talk freely about his or her “hip journey”, prompted by an open question like “can you start by telling about yourself and how your life is affected by your hip OA?”. Recurrent follow-up questions were “can you describe in words how your pain feels?”, “what strategies help you cope with your hip pain?”, “what/how have you learned about osteoarthritis?”, “does your pain have any consequences for your social life?” and “can you tell me (if) how and why you have decided to undergo hip replacement?”. Interviews were transcribed and an indicative approach to thematic analysis guided by a six-phased analytical process was used to analyse the interviews.
Findings	**Phase 1: Symptom debut and diagnosis** (the early hip osteoarthritis stage where the first symptoms emerge, diagnosis is set, and an initial treatment plan is discussed). Some people experienced hip pain as vague or generalized, characterised by intermittent pain and stiffness. Many people also described concurrent pain experiences in other joints than the hip. Depending on the person’s health care seeking behaviour and the perceived severity of pain and its interference with daily function, people visited their GP to get an explanation of what it was. Some people waited some time before seeking help from their GP. Some tended to trivialize their experiences or play down their concerns by referring to possible natural causes, like getting older, pain conditions running in the family, or by comparing their problems with others. Some indicated a feeling of shame attached with talking about their emergent hip pain or osteoarthritis diagnosis, and felt that their hip disease was lower in the hierarchy than other diagnoses (such as cancer and diabetes type 2). Some people clearly stated that they did not exclusively visit their GP to discuss their hip problems, but that it was brought up as an implicit concern at the end of the consultation. A common finding was that people did not receive general information about osteoarthritis and pain management from their GP. Most of the people did not actively seek information during consultations. This was explained partly by the fact that they did not know what to ask specifically and because the GP was not perceived to have the necessary expertise about osteoarthritis. Many discussed available time as a barrier. The common experience people have at this initial stage may be summarized in the question: “something is wrong, what is this hip pain?” The person generally receives basic and variable information about osteoarthritis and available treatment options depending on the severity of the symptoms and the GP’s and other health professional’s competence and communication skills.
	Phase 2: Symptoms increasingly interfere with physical function in daily living (moderate hip osteoarthritis stage, indicating a deterioration of symptoms, leading the person to seek and try out more treatment options that might help the situation). As hip problems evolved, people experienced increased pain, causing difficulties in performing regular and self-care activities. Most of the people had several x-rays, hoping that it would provide some answers. Most had clear objections about taking pain killers daily, although the doctor had prescribed it. They felt there were too many pills to consume with potential troublesome side effects. A recurrent description was not being comfortable with taking pills in general. One person thought pain killers would worsen the situation in the long-run. Some felt that taking regular painkillers helped them when they tried to cope with the situation. Some used alternative strategies to deal with pain. Most did not attend physiotherapy on a regular basis, with some explaining they felt it was unnecessary because they had other ways of staying physically active. Experiences can be summarized in the question “my hip really bothers me, what can I do?”
	Phase 3: Symptoms significantly decreases quality of life (severe hip osteoarthritis stage, where the symptoms are perceived as severe and more or less refractory to conservative treatment, leading up to a need for referral for orthopaedic evaluation)

Study	**Brembo 2016[20]**
	When the symptoms significantly restricted abilities to do desired activities in daily living, some people expressed that they had explicitly requested referral to an orthopaedic surgeon. A decision for surgery may be driven by the hope of a better life. Work responsibilities can influence a decision or desire to undergo hip replacement. One person wanted surgery to be able to work, but was advised to wait. Most people explained that their social network of friends, neighbours and family was an important source for information and advice relating to decision-making about total hip replacement. Learning from others' experiences provided hope for a better future. Undergoing hip replacement was perceived as a common procedure with excellent outcomes. Topics concerning possible risks for pre- and postoperative complications seemed to be of little importance in deliberation about undergoing total hip replacement. One stated that there are no guarantees in life. Others relied heavily on the experience and competence of the orthopaedic surgeon. One participant brought up personal experiences with surgery performed earlier as grounds for deliberation about possible risks. The common experience may lead to the question: "I can't stand the pain, is it time for surgery?". As the disease progresses and interferes with the person's physical function and well-being, the GP prescribed pain medication, refers the person to a physiotherapist and gives some advice on how the person should adapt and self-manage. While some people find satisfactory ways to cope at this stage, some do not respond effectively and experience that the disease continued to progress, leading to significantly decreased physical function and quality of life.
	Phase 4: Orthopaedic evaluation in surgical decision making (the surgical decision making phase with three possible options for the person and orthopaedic surgeon to discuss whether the person will benefit from hip replacement surgery. A) people who are accepted for surgery, B) people who are rejected or choose to wait for surgery, C) people who are not suitable for surgery or do not prefer to undergo surgery). People stated that pain was the main reason for considering hip replacement surgery. A common finding was that it seemed important for people to discuss experiences with others who had undergone hip replacement. People who were denied hip replacement were told by their GP or orthopaedic surgeon that the features of the x-ray did not show significant changes that would allow for a hip replacement, or they were categorized as too young and therefore advised to postpone the procedure as long as possible. This phase represents the process of surgical decision making and can be summarised by the question "will a hip replacement help me with my problems?". After having updated x-rays, the surgeon and the person review the current situation together. Many people said that reaching this phase was a relief, something they knew existed as a final option and that might help the situation significantly. Decision making starts before the actual meeting with the surgeon, either as a result of advice from health professionals or after observing other's experiences from undergoing total hip replacement. There are three possible scenarios that occur after the meeting with the surgeon (see above). The people in the non-surgery group need to accept the situation, but not let go of the hope that help could be obtained.
	Phase 5: The perioperative period Most people who were due for total hip replacement had been advised to do joint muscle-strengthening exercises prior to hospital admission. However, one person had been informed that muscle strengthening was contraindicated in the preoperative period. Elective patients received standardized information prior to admission that explains what to expect and what they should do to prepare for the recovery period. Most people in the study expressed satisfaction about the information provided by hospital staff. After admission, people follow a standardized treatment and rehabilitation program. Most are discharged during the first or second postoperative day,

Study	**Brembo 2016[20]**
	but with an expectancy of a 6-12 month recovery period to regain full physical strength and energy. This phase is reflected by the question “what will happen at the hospital?”
	Phase 6: The postoperative recovery period People are normally not offered in-house rehabilitation following total hip replacement in Norway. Most of the people in the group who had surgery expected to return to their home the next day. While on person in a separate group had previously undergone total hip replacement and explained the value of admission to a rehabilitation unit. The question “what can I expected after having surgery” reflects the needs of people who had undergone hip replacement.
Funding	Not reported. Authors state they have no competing interest.
Limitations and applicability of evidence	The needs of the individual person are unlikely to be fully accounted for from this type of study. A relatively small sample of people were included; therefore, they expect that other important aspects related to the person’s information and emotional needs are missing from this presentation. A majority of the people included in the study had developed severe hip osteoarthritis and were due for or contemplated surgery. It is therefore likely that people wat the early stages of hip osteoarthritis are underrepresented in the sample and their experiences and questions less clearly explored. Minor limitations: the relationship between the researcher and participants was not reported.

Study	**Campbell 2001[22]**
Aim	To understand reasons for compliance and non-compliance with a home based exercise regimen by people with osteoarthritis of the knee.
Population	20 people from the intervention arm of a randomised trial interviewed first 3 months after they had completed the physiotherapy program. 8 people were then interviewed 1 year later. Participant characteristics: n=20; 14 females/6 males; Age groups: 45-59 years = 6, 60-69 years = 5, 70 and over = 9.
Setting	People recruited from the intervention arm of a randomised controlled trial.
Study design	Interviews in a qualitative study, nested with a randomised controlled trial. Study conducted in the United Kingdom.
Methods and analysis	People were selected using a list of people in the intervention arm to obtain a “maximum variation” sample including a balance of full and partial compliers, men and women and older and younger people. 20 people were interviewed after completion of the physiotherapy programme but before the five month trial follow up period. All interviews were conducted in informants’ homes by one investigator who was kept blind to the physiotherapist’s assessment of level of compliance. Interviews lasted between 30 and 90 minutes and were guided by a checklist of topics to ensure that similar issues were always explored, including history and severity of knee symptoms, recall of a compliance with physiotherapy programme, and previous experiences of treatment, but were also open ended to allow other issues of importance to emerge and be considered.

Study	Campbell 2001[22]
	Interviews were audio taped, transcribed verbatim and checked by two investigators for accuracy. Interviews and preliminary analyses were undertaken sequentially to allow emerging analysis to influence subsequent interviews. Interview transcripts were read repeatedly, and emergent themes used to code sections of the text, which were copied to new word processing files. Codes were applied to subsequent interviews and further codes added as new themes emerged, according to the constant comparative method. Data analysis was conducted largely by one researcher with collaboration from three other researchers who checked the plausibility of the data interpretation and agreed on the meaning of the thematic categories to be used to index interview transcripts.
Findings	**Initial compliance** The reasons for maintaining initial compliance during the trial included a sense of reciprocity and obligation to the researchers, an altruistic ethic (conducting research may help others in the future) and a dislike of taking prescription drugs and a positive view or experience of physiotherapy.
	Continued compliance The reasons for continued compliance or non-compliance were more complicated and revolved around the interplay between the condition, the perceived effectiveness of the intervention, and “motivation”.
	Attitudes towards exercise While a positive disposition towards exercise could increase motivation, more important was the willingness and ability to accommodate the exercises into everyday life. Those who stopped exercising often cited conflict with regular routines to explain while continuing the exercises was not possible. It was more difficult to maintain exercises when a person stopped seeing the physiotherapist. Some people stopped because it was difficult to do the exercise alone and they didn’t notice much improvement in symptoms.
	Perceived severity of knee symptoms Those experiencing severe pain and/or loss of mobility were most likely to continue to exercise (as they experienced the most benefit). The reduction of symptoms was also important in allowing people to continue using tape. The existence of other comorbidities, comparison with others with more limiting disease or a stoic attitude to knee symptoms all seemed to be associated with an attenuation of the motivation to comply.
	Ideas about the cause of arthritis Those who thought that arthritis was caused by immutable factors such as age, obesity and “wear and tear”, tended to have a resigned attitude towards their arthritis. Consequently, they found it hard to believe that the intervention could be effective, and this weakened the resolve to comply. These ideas were shaped by people’s previous experience of health care. Internalising the notion that nothing was wrong with the knees contributed to a participant stopping the home exercises, which may have been contributed to by feeling they did not deserve the physiotherapy intervention. Several people mentioned being overweight as contributing to their symptoms. A person felt guilty about being overweight, but considered any improvement in their knees to be dependent on weight loss. In contrast, those most likely to be continued compliers tended to believe that although there was no cure to arthritis, there were thing they could do to minimise its impact, including the physiotherapy.
	The perceived effectiveness of the intervention

Study	**Campbell 2001**[22]
	High levels of continued compliance were closely related to the perception that the physiotherapy intervention was effective. Those who noticed an improvement in their knee symptoms were much more likely to comply than those who did not. If the benefits were not perceived as enough, or there was an allergic reaction to the tape, non-compliance was a rational outcome.
Funding	Funded by a grant from the South and West Regional Research Directorate.
Limitations and applicability of evidence	Participants may have presented themselves to an interviewer as good, proficient members of society, which may have led to reporting bias. They tried to account for it by having the interviewer be independent to the trial. Minor limitations: unclear recruitment strategy and no details about whether ethical issues were considered.

Study	**Carmona-Teres 2017**[23]
Aim	To identify current practice and advice of PCPs from the patients' perspective, and to understand the experiences, perceptions, evaluations, values, beliefs, and coping strategies of patients with OA.
Population	Patients with symptomatic knee OA with clinical and radiographic OA grades 1–3 in the Kellgren-Lawrence classification.
Setting	Participants were selected from four primary health care centres in Barcelona. Participants were recruited by general practitioners in each centre. Characteristics: n=10; 3 males/7 females; Age range 60-85 years; Years since onset of knee OA (range) <1-20.
Study design	An interpretative qualitative design.
Methods and analysis	Face to face individual interviews were conducted lasting between 30-60 minutes. The interview guide followed five sequences (impact of knee OA; interaction with health professionals, physiotherapists, and social workers; coping strategy; recommendations toward the design of the intervention; and use of information technology techniques - ICTs). The interviewer used open, non-directive formulation consistent with the participant’s language. All interviews were recorded and transcribed literally and systematically by trained personnel. After successive readings of the transcriptions, researchers reached preanalytical intuitions. A content thematic analysis was then performed.
Findings	**Experiences and perceptions of patients’ interactions with health professionals, physiotherapists, and social workers** 1. **Information-education on knee OA** Information is mostly provided by family doctors, who explained the repercussions, progression of OA and provided advice. Some participants do not understand the information given or are not satisfied with information received, particularly from specialists. No participants received materials on these issues although some said it would have been useful.
	2. **Professional advice on diet and weight loss** Participants were aware that they were overweight but found losing weight or keeping weight off after losing it difficult despite help from dieticians, endocrinologists, and acupuncture. Some had received leaflets about diets.

Study	**Carmona-Teres 2017[23]**
	3. Professional advice on physical activity Participants are given advice to walk which they enjoy even if it is difficult. Some receive positive feedback for exercising in water or cycling on a stationary bike to reduce impact on joints. Group exercise would improve motivation.
	4. Experiences with the different treatments provided Participants are anxious about side effects of painkillers and NSAIDs which are often prescribed by healthcare professionals. Gels and creams are well accepted but not covered by the public health system. Positive experiences are reported with physiotherapy, magnesium supplements and knee prostheses.
Funding	A research grant from the Carlos III Institute of Health, Ministry of Economy and Competitiveness (Spain).
Limitations and applicability of evidence	Minor limitation as the relationship between the researcher and participants was not reported.

Study	**Chan 2011[27]**
Aim	To evaluate the influence of different pain patterns on their quality of life and to investigate their interpretation and coping strategies for the disease using patient interviews.
Population	• 20 patients with Knee Osteoarthritis in China (66% females, 80% were over the age of 50 years old, 46% reported having OA of the knee for more than 10 years, 45% reported a pain score of between 4 and <8). The mean pain score of all 20 patients was 4.725 (SD 2.16).
Setting	A private general practice clinic in Hong Kong.
Study design	Qualitative study using semi-structured interviews.
Methods and analysis	Content was analysed using grounded theory independently by two researchers, one male and one female, who had not conducted the interviews. Codes were extracted by the individual researcher based on what the interviewees discussed, as well as the issues that the researcher believed to be salient based on his/her knowledge. The results and analyses were compared and discussed between the two researchers using constant comparative approach until final code was agreed.
Findings	Adjustment: Patients learned their coping strategies from the media, Internet, physical therapists, doctors, and health professionals, as well as from fellow sufferers. Patients found self-management useful and efficacious.
	Expectations from treatment: a small proportion (10%) indicated the wish to be better informed of their problems and the related treatments.
Limitations and applicability of evidence	Moderate limitations due to unclear relationship of the researcher, ethical issues not being discussed, and data collection methods being supported by no quotes from patients.

Study	**Churchill 2020**[32]
Aim	To pilot educational videos with patients to determine their experiences and perspectives regarding the content and clarity of videos and to better understand their potential impact on patients' health behaviour.
Population	A convenience sample of patients attending their first consultation with an arthroplasty surgeon for consideration for total knee replacement (TKR) - (purposive sampling used to ensure sample represented both sexes). N=13; mean (SD) age 64 (9), 9 females, Race: White: n=11; Asian: n=1, Aboriginal: n=1.
Setting	Joint replacement clinic in Ontario, Canada.
Study design	Qualitative study using semi-structured interviews (part of mixed methods approach which included survey information).
Methods and analysis	In-depth interviews (30-45 minutes) with each patient after they watched each of the 5 educational videos. All interviews were audio recorded and transcribed verbatim. Transcripts were reviewed against the audio recording by primary researcher. Interviews were analysed immediately after transcription to allow for an iterative process in revising the interview guide. Recruitment stopped when data saturation was reached. Iterative qualitative thematic content analysis approach was used combining both inductive and research question driven coding, category formation, and theme identification of the qualitative interview data. Three members of research team coded data independently, implementing a thematic analysis.
Findings	**Challenge of decision making** *Subthemes:* **Nature of decision**: In response to education videos, some participants were usure about the elective nature of the decision process for this type of surgery. *"Yeah, it's just confusing, can you decide that you want to have a conservative treatment, you know, not have surgery or you know should you go ahead and have the surgery if you are having all these symptoms?"* **Surgeon opinion as key factor**: Some decided not to have TKR based on the videos but also from discovering their symptoms were not severe enough to warrant surgery. Many struggled to understand their equal role in the decision-making process, and they assumed that the surgeon would decide if they needed the elective surgery. **Preference didactic consultation:** Some patients felt the educational video shifted the responsibility of decision making from the surgeon to themselves, while they preferred to be advised on the best course of action rather than taking that difficult responsibility on themselves. "*Yeah, and it kind of made me feel that you are putting the responsibility up to what I want, to me, I'm here to ask you what I need".*
	Education as supportive to patient decision making *Subthemes* **Education enhancing confidence for surgical consultation:** Several people thought the education videos improved their confidence for the discussion with the surgeon and were helpful in supporting them to decide whether they should have surgery. Others described how their new knowledge would provide a better discussion and collaborative consultation. "*I feel a little bit that I know what I'm talking about and not just listening to what he's telling me".* One patient felt what to expect from surgery information increased his fear of the risks of surgery. However, this would provide him with more focused questions to ask during the consultation. Overall, most patients supported the benefits of the videos in providing a more effective meeting with the surgeon and empower them to participate in

Study	Churchill 2020[32]
	the decision making. Some patients did not think the videos increased their confidence, but they tended to already have a good baseline knowledge and wanted the surgery. **Education as influencing decision to undergo TKR:** Most participants commented that the videos either reinforced that they should undergo TKR or preference to try non operative treatments. It sometimes provided new information on non-surgical options and provided more control over their own management options. Conversely, many patients felt that the videos reinforced previous education from other healthcare professions and reassured them that they were on the correct treatment path. These patients were reassured by the consistency of the information with their own non operative management care pathways and that it would be useful to people earlier in their disease management. Some people with pre-existing fears around surgery found the education video reassuring.
	Education addressing knowledge gaps in patient understanding Most participants in this study had some baseline knowledge surrounding their knee condition. Education came from allied health professionals, from their occupation in a healthcare related field, their own surgical experience, a friend, or family member who had a TKR or media sources. However, many patients still felt that there were opportunities for learning throughout all five videos. *Subthemes* **Video1 what is the knee**: patients reported a better understanding of the structure and function of the knee joint in context of OA. They also reported increased understanding of their own risk factors for OA progression. **Video 2 imaging:** Most participants felt this gave them new information or clarify around the role of imaging. Several patients had believed that MRI was the gold standard for imaging, and this helped clarify the role of imaging in OA. "*Well yeah, learning about the MRI isn't necessarily best because I used to think it showed more, but that was good, that was a good point. So, it has points that we have misconceptions about".* **Video 3 non-operative (conservative management):** Most had trialled many of the non-operative treatment options, but some patients got new ideas from the video for management including medications, PT, weight loss, activity modification. *"Yes, physio was all new to me, big time. Like I would have gone to a physiotherapist long ago if I knew that's what I was supposed to be doing".* **Video 5 what to expect from surgery**: pre-operative considerations including losing weight, quitting smoking, risk of surgery and post-operative satisfaction rates were highlighted by patients as new information. Additionally, post-operative information such as medications, degree of post-operative mobility and possibility of same day discharge were considered new information.
	Barriers to implementing recommendations *Subthemes* **Issues surrounding physical therapy:** A few patients mentioned the financial burden of physical therapy and knee braces may limit access by some patients who would benefit from them. **Challenge of the implementation**: A patient suggested better education around expectations for treatment was needed. The challenge of losing weight, manual labour occupations not being able to modify their work-related duties and pain were cited as barrier to remaining physically active. **System-related factors:** long waiting times to receive orthopaedic specialist care was stated as a possible reason to seek a surgical referral by one patient.

Study	**Churchill 2020**[32]
Funding	Supported by the Academic Medical Organization of Southwestern Ontario Innovation Grant (joint initiative of the Ministry of Health and long-term Care and the Ontario Medical Association resulting from the Academic Health Science Centre Alternative Funding Plan.
Limitations and applicability of evidence	Minor limitations as the relationship between the researcher and the participants was not reported. The study relates specifically to patients undergoing surgery.

Study	**Clarke 2014**[33]
Aim	To examine the correspondence between qualitative and quantitative methods of coding experience of pain reported by participants with osteoarthritis of the knee.
Population	24 people with physician diagnosed knee osteoarthritis. Characteristics: median age (range): 62 (48-84) years; 7 males/17 females.
Setting	People in the United Kingdom.
Study design	Individual semi-structured interviews lasting 30 minutes-1 hour.
Methods and analysis	Semi-structured interviews lasting 30 minutes-1 hour that were audio-taped and transcribed verbatim. The data was analysed using thematic analysis. Data were analysed by a member of the research team who had not been involved in either the questionnaire or interview studies. The study was combined with evidence from a separate quantitative review to see similar themes.
Findings	**Illness representation** Subthemes include: pain omnipresence, mechanical understanding, factors that affect pain, prognosis/curability, and beliefs about causes. Pain omnipresence: the overriding sensations of pain being at the core of people's experience of living with knee osteoarthritis Mechanical understanding: Understanding of osteoarthritis derived from a medical perspective (e.g., loss of cartilage, bones that grow abnormally). Factors that affect pain: A common range of factors that exacerbate osteoarthritis pain, including exercise, the weather, weight bearing etc. Prognosis/curability: How participants perceived their condition to progress and specific expectations about the course of illness (e.g., progressively deteriorating, linked to old age etc.). Beliefs about causes: A wide range of beliefs about the possible causes of knee osteoarthritis, including both multidimensional and single factor accounts.
	Change in previous functioning

Study	Clarke 2014[33]
	Subthemes include: physical limitations and social roles/participation Physical limitations: Difficulties with physical activities, such as walking, or walking for long distances, bending, kneeling, going up and down the stairs, standing up for too long, performing house chores or having difficulties sleeping. Social roles/participation: Changes in previous functioning, in terms of participating in previous pleasurable leisure activities, and/or a change in performed social roles.
	Emotional impact Subthemes include: negative emotions/future worries, impact on identity, fluctuation of emotions Negative emotions/future worries: Negative emotions stemming from changes in previous functioning, physical restrictions or having to deal with intense and constant pain, and/or serious concerns and worries about the amount of pain expected in the future Impact on identity: Changes in how participants perceived themselves and how this has affected their sense of identity Fluctuation of emotions: Emotions fluctuating according to 'good and bad days' depending on the amount of pain experienced.
	Belief about medical control of pain Subthemes include: pain relief/partial pain relief, side effects/dependency/ambivalence Pain relief/partial pain relief: Relying on a medical control of pain, using pain killers, patches or receiving steroid injections etc. Side effects/dependency/ambivalence: Beliefs about the impact of medication, including side effects and dependency, and a sense of ambivalence towards relying on medication.
	Managing pain and osteoarthritis Subthemes include: Keep active, adjustments/modifications, social support, life philosophy, humour/sarcasm Keep active: Trying to keep active and continue engaging with pleasurable activities despite the pain and physical limitations set by knee osteoarthritis. Adjustments/modifications: Modify activities or use certain strategies to alleviate pain and manage everyday routines Social support: 'Important others' who were offering emotional support, and/or relying heavily on support from friends and family to perform everyday tasks, particularly when physical limitations were severe. Life philosophy: A general philosophy of life, ranging from an active fighting spirit to a more passive attitude of 'grin and bear it' Humour/sarcasm: Using humour or sarcasm when describing experiences of living with knee osteoarthritis.
	Interactions with the medical team Subthemes include: positive experiences, negative experiences, limited expectations, impact of diagnosis Positive experiences: The positive impact of recommendations made by doctors in terms of managing knee osteoarthritis, as well as the positive impact of 'being listened to' and being offered some hope for the future. Negative experiences: Dissatisfaction stemming from either limited information provided by doctors in terms of options available to manage the conditions, or from a sense of not being 'listened to' and given sufficient attention. Limited expectations: Low expectations in terms of treatment, which resulted in limited or no contact with medical professionals

Study	Clarke 2014[33]
	Impact of diagnosis: Diagnosis as a positive step towards a more successful management of the condition.
Funding	Supported by funding from Arthritis Research UK.
Limitations and applicability of evidence	Minor limitations due to insufficient explanation about the methodology behind the analysis.

Study	Demierre 2011[37]
Aim	To explore the patient illness experience from the moment the decision is made to perform arthroplasty through 12 months post-surgery.
Population	24 adults with hip or knee OA aged <75 years (mean age 60.04 years, SD 11.09), awaiting arthroplasty. 8 had previously received one or more prostheses (hip, shoulder, hip and knee or hip and shoulder).
Setting	University hospital in Switzerland
Study design	Qualitative study using semi-structured interviews.
Methods and analysis	Patients were interviewed one month before arthroplasty of knee or hip. A coordination nurse contacted the participants at the hospital during a surgery-planning consultation. The researcher was a psychologist not part of the hospital staff. Interviews were conducted using an open reflexive method. An interview schedule was used to guide the interviewer, and the exploration of common themes. Interviews were recorded and transcribed verbatim. A qualitative thematic analysis was performed.
Findings	The decisional balance for surgery: Physicians and surgeons take the lead in the arthroplasty decision process. Participants express feelings of helplessness towards their lack of control and/or participation. Health status and/or other physical, medical risk factors (e.g., overweight, cardiac problems) may lead the physician to postpone or cancel surgery. Patients do not always understand the reasons for this decision.
	Expectations about arthroplasty: expectations are influenced by information received from different sources. Information from medical sources is considered to err on the side of caution: ‘Anyway, the physician has informed me that it won’t be the knees of my 20s I shall experience less pain, but I shall not be able to do all I want.’ In comparison, information obtained from persons with a prior prosthesis is positive overall: ‘persons who already had surgery, they all tell me that they do not hurt anymore. “It is wonderful, it is as if I had never had anything.” So, I rely a little bit on that’, but also moderate their expectations: ‘So, well… I hope it will bring me a relief from pain. But I do not want to fool myself, and afterwards being disappointed.’ Participants receiving their first prosthesis have an imprecise idea of what rehabilitation will entail. They will need physiotherapy, but cannot evaluate its duration or its implementation. Participants with prior arthroplasty rely on their prior experience, and remember the difficulties encountered: finding a suitable position when sleeping on their backs, not putting too much weight on the operated leg, and in other practical aspects such as how to use canes or when

Study	**Demierre 2011[37]**
	exercising how to walk up or down stairs, as well as how to deal with the frequency of physiotherapy sessions or with the necessity of intense walking required to reach optimal recovery results. Participants discussing living with a prosthesis, half of whom thought they will have to learn about and deal with the functional limitations imposed upon them by the prosthesis: 'The physician has given me a leaflet, I read it all. It tells us the way you have to behave after surgery. There are some movements you should not do at all… it is a complete re-education.'
Funding	The study was supported by funds of the project IRIS 8A, Sante et Societe, Psychologie de la sante (2003-2008).
Limitations and applicability of evidence	Minor limitations due to unclear recruitment methods and the relationship of the researcher not being discussed. Study relates specifically to patients undergoing surgery.

Study	**Dosanjh 2009[38]**
Aim	To explore patients experiences and their decision-making processes to undergo total hip arthroplasty and to examine the factors that influenced patient decisions about the type of surgical procedure.
Population	Patient characteristics: 18 patients scheduled for an upcoming THA or had completed THA. The interviews included 9(5 males, 4 females; 3 Latinos, 5 Caucasians, 1 African American) ranging in age from 55 to 79 years) who completed a 2-hour face to face interview with a physician 5 were post-surgery for THA, (follow up ranged 3 months - 4 years) 4 were awaiting surgery. The focus group included 9 (4 females and 5 males; 2 African Americans, 1 Latino and 6 Caucasians) ranging in age from 52 to 78 years. Of these 9, 8 had completed THA.
Setting	An ambulatory orthopaedic care facility in California, USA.
Study design	Qualitative design with semi-structured interviews and a focus group.
Methods and analysis	Interviews conducted by a trained, experienced interviewer, who had not met any of the participants prior to the study. All interviews were conducted independent of the operating surgeon. A general interview guide approach was used, and notes taken of responses. Data were coded and content analysed according to the grounded theory approach. Transcripts were examined, coded, and analysed independently by two of the authors. Comparisons were made between the two and any discrepancies resolved through discussion. Coding was consistent with the principles of grounded theory, open coding, axial coding, and selective coding.
Findings	Data gathering: many of the participants had exhausted all other resources including failed treatments which led them to thoroughly research hip arthroplasty by using reading books and getting information over the internet. Others were informed about hip arthroplasty by using reading books and getting information over the internet. Others were informed about hip arthroplasty by health professionals including their physicians/surgeons and allied health professionals. Some of the participants knew of other patients that had undergone hip arthroplasty and had shared their experiences. Additionally, participants stressed the importance of finding a trusted and

Study	**Dosanjh 2009**[38]
	experienced surgeon in this area. The collection of data led participants to have an increased understanding of the hip arthroplasty procedure.
	Personal health priorities: one comment about researching techniques for surgery on the internet and finding the surgeon to do that.
Funding	No funding receive in preparation of the manuscript. The author is supported, in part, by a Canada Research Chair, McMaster University.
Limitations and applicability of evidence	Minor limitations due to potential influence of the researcher on the focus group, ethics approval not mentioned.

Study	**Egerton 2017**[42]
Aim	To identify potential factors influencing GPs engagement with a proposed new model of service deliver to provide evidence-based care for patients with knee OA and achieve better outcomes.
Population	GPs. Characteristics: n=11; 64% female; Mean age (range) 50.8 (34-67); Mean number of years' experience (range) 21.6 (5-44) years; Mean self-reported number of knee OA patients seen per month (range) 12 (1-40).
Setting	Interviews were conducted by telephone. Participants were purposively sampled from metropolitan, regional, large, and small practices.
Study design	Qualitative study nested within a larger project.
Methods and analysis	Semi-structured telephone interviews were carried out. Interviews ranged from 30 to 90 minutes in length with most lasting 1 hour. The interview guide was semi-structured to prompt consideration of potential barriers and facilitators, whilst allowing flexibility for participants to raise issues and contribute their own ideas. The interview questions were informed by the COM-B Capability/Opportunity/Motivation-Behaviour) theoretical framework. Interviews were analysed using interpretive inductive thematic analysis techniques directed towards identifying barriers and facilitators to GP engagement with the model. Telephone interviews were chosen for their convenience due to GPs' high workload and geographical spread. Interviews had two sections: the first explored GPs views on diagnosing OA and delivering exercise and weight loss interventions within the current service model. This section is not reported in this paper. The second section, reported here, explored GPs' perceptions of the proposed new model.
Findings	**Affordability** GPs were concerned that uptake would be negatively impacted if patients were required to pay and felt that it should be funded by other sources.
	Practicability

Study	Egerton 2017[42]
	GPs were concerned about several practicability issues, including efficiency of the referral procedure to minimise the impact on their busy schedules and minimising burden for patients and care support providers, efficiency, and effectiveness of ongoing communication with emphasis on the need for effective, useful, and timely communication, and fitting in with existing initiatives to avoid complicated and confusing management, as well as issues with existing schemes and payment structures.
	Effectiveness Some GPs felt there may not be a need for the service whilst others felt it vital. Some believed there were already adequate skills and resources to support OA patients, whereas others felt that the service would reinforce their advice, integrate care, and provide extra encouragement. GPs also expressed mixed views about whether the proposed service would lead to better patient outcomes.
	Acceptability There were several issues relating to acceptability of the service, including trust, with some GPS hesitant to embrace an unfamiliar service and emphasising the importance of all involved to accept it to allow for long term continuation, as well as confidence in staff to deliver the new service and some concerns regarding the safety of patient data. GPs expressed the preferences of having a personal relationship with those providing the service and a concern that handing over patient care may reduce job satisfaction. Finally, the burden of care on GPs of managing this group being taken away was appealing.
	Side effects/safety The service may lead to a worsening of outcomes through a disconnection with their patients care and confusion about the treatment plan. There may also be conflicting advice and information between the two teams.
	Equity GPs were concerned the service would not be able to provide individualised management for a very diverse population, such as those with hearing or cognitive difficulties. There were concerns that staff would just be “following a script”. They also questioned whether those with very mild symptoms would benefit. GPs were also concerned that patients may not engage with the service.
Funding	The National Health & Medical Research Council (NHMRC) Centre of Research Excellence (CRE) in Translational Research in Musculoskeletal Pain (#1079078).
Limitations and applicability of evidence	Minor limitation in relevance as all themes are related to a specific new service.

Study	Erwin 2018[43]
Aim	To identify competencies that patients think non-specialist community-based nurses and allied health professionals need to enable them to access, care for and manage arthritis appropriately.
Population	People with inflammatory arthritis and osteoarthritis.

Study	**Erwin 2018[43]**
	Characteristics: n=25; 16 females/9males; Age (range) 28-84 years.
Setting	Focus groups were held in Bristol, Exeter, and Cornwall. Participants were recruited through posting on the National Rheumatology Arthritis Society and Arthritis Research UK websites and Facebook pages, posters in GP surgeries, advertisements in local newspapers and through local support groups.
Study design	Focus group study.
Methods and analysis	Four focus groups were carried out, including two groups attended by people with IA (RA and psoriatic arthritis); one group by patients with RA and OA, and a fourth group by people with OA only. The focus groups varied in size, the largest having eight participants and the smallest having four. Each focus group lasted approximately 1 hour. The focus groups participants were asked about their experiences of receiving care for their arthritis from community-based nurses and AHPs; how this care might be improved and what they would want nurse and AHPs working in the community to know about arthritis. The study used a phenomenological approach to the focus groups which facilitated the gaining of insights into people's perceptions, perspectives and understanding of receiving arthritis-related healthcare. Data from the focus groups was transcribed and analysed using deductive thematic analysis.
Findings	**To understand and be able to distinguish between IA and OA** While participants didn't expect nurses and AHPs to know everything about arthritis, they did expect them to have basic rheumatology training and who can be affected. Some felt professionals still thought of arthritis as an old person's disease and were not aware that it can present differently and in all ages.
	To be able to take a holistic approach The need for a holistic approach was strongly emphasized by all participants. Those with osteoarthritis felt that often health professionals dealing with their condition were reductionist and did not look at the impact on the whole person.
	To take OA seriously and understand its impact Participants felt that their condition was not taken sufficiently seriously by health professionals, and that they did not understand its impact.
	To understand the unpredictability of IA Participants felt that community-based health professionals did not sufficiently understand flares, the unpredictability of the condition and the impact of this. It was felt that this understanding was needed to enable them to give appropriate advice.
	To understand and be able to give basic advice on pacing Pacing was recognized by participants as an important tool to manage their arthritis, but many felt that nurses and AHPs did not have a good understanding of this and did not give sufficient advice.
	To be able to adjust normal practice Participants expressed the need for health professionals to be able to adjust normal practice for people with arthritis.
	To understand the psychological adjustment needed

Study	Erwin 2018[43]
	Participants agreed that health professionals needed an understanding of the psychological impact of being diagnosed with IA and the adjustment that patients needed to make. Others reported that health professionals need to be aware of the isolation some patients can feel. This would help health professionals understand why patients respond in certain ways.
	To understand the social impact Arthritis affects all aspects of your life, including your relationships with others. Health professionals need to understand this.
	To understand the impact on mental health Participants felt that the mental health impacts of having a long-term condition such as arthritis was not understood or fully addressed.
	To have a broad understanding of drug treatments Participants did not expect community staff to be experts in drug treatments but to have a basic understanding of the treatments used for IA, an awareness of major changes in effective treatment options and an understanding of the implications of using immunosuppressive drugs. They felt that there was also an important role for patients in sharing their knowledge.
	To understand the pain associated with arthritis People with OA talked about the need for nurses and AHPs to understand the severity of OA pain.
	To be able to advise on pain management The participants felt that community-based nurses and AHPs should be able to give some basic advice on pain management.
	To be able to advise on different management options for OA Several of the participants with OA felt that they had not been made fully aware of the different management options and had not been given adequate information to make an informed decision about how to manage their condition. Participants also felt that they could be given more advice on the day-to-day management of their OA.
	To be able to signpost to sources of help Being able to signpost people to sources of help was an important aspect of care that participants strongly felt that all community-based nurses and AHPs should be able to do.
	To be able to signpost to sources of education and information Participants with RA shared learning through communicating with other patients. However, they found that often information online was contradictory, particularly that relating to complementary therapies. Several people with OA felt that they hadn't received suitable information about their condition.
	To be able to make multidisciplinary referrals Patients felt it important that community-based nurses and AHPs knew about the services available and were able to make multi-disciplinary referrals and to communicate effectively between referral points.
	To understand that patients know their own disease

Study	Erwin 2018[43]
	Participants also wanted community-based nurses and AHPs to understand that patients who have had a diagnosis for a long time know best about their own disease.
	To have good communication skills Participants highlighted the importance of good communication skills for community-based nurses and AHPs. They drew attention to the quality of communication available with AHPs, such as physiotherapists and OTs, who have longer appointments over a period of time. They also highlighted the need for better communication between health professionals.
Funding	Supported by an Education Project Grant from Arthritis Research UK (grant number 20536).
Limitations and applicability of evidence	Moderate limitations due to ethical issues not being addressed, the role of the researcher not being addressed and limited information/ lack of rigorous approach to data analysis.

Study	Goldsmith 2017[49]
Aim	To improve understanding of patient experience and patient satisfaction following TKA surgery.
Population	Adults aged 19 years or older with a primary or secondary diagnosis of osteoarthritis scheduled to undergo primary TKA. Characteristics: n=45; 15 males/30 females; Mean age 65 years.
Setting	Interviews took place where convenient for participants, including participants' homes and medical clinics. Participants were recruited from the mandatory pre-surgical total joint replacement education sessions at six sites across the province, including at least one site in each of the five geographic health regions. Of the 515 participants taking part in the quantitative study, the qualitative sample was selected by considering all those apart from the 6-month survey non-respondents and those having survey completion assistance. As many people reporting dissatisfaction with their TKA results on their 6-month post-surgery questionnaire as possible were interviewed, and further purposive sampling was done to ensure variation on other key characteristics.
Study design	Qualitative study embedded within a mixed methods prospective cohort study.
Methods and analysis	Interviews were conducted in English by experienced interviewers. The semi-structured interview guide was designed to understand the individual's knee surgery experience and outcomes. Interviewee-specific probes were also created based on their answers to the baseline and 6-month surveys. Interviews generally lasted 45–65 min. Interviews were transcribed and then thematically coded using NVivo software.
Findings	**Informational support** Information is very important in the preparation and recovery from TKA. Information was received though both formal clinical sources and informal personal sources. Although pre-surgical education was considered a key form of informational support, the provided

Study	Goldsmith 2017[49]
	information was often insufficient and some found it not meaningful due to being difficult to understand or remember, or due to conflicting messages. Participants felt overwhelmed and anxious before surgery making retaining information difficult. Surgeons were key sources of information also participants wanted more information than they received. Surgeons are often matter of fact, and not readily providing information, and participants felt overwhelmed which led to them not asking prepared questions. When surgeons took time to provide sufficient information, this was appreciated and improved the experience. The most frequent type of informational support identified as needing improvement was information on pain expectations and pain management. Participants felt that there should be a 'go to' clinical person to answer questions or that their surgeon should be available to discuss pain and recovery. Participants also wanted to understand the variety of TKA recovery trajectories so they could be assured they were on some sort of a track to recovery, and often compared their trajectory to others'.
	Clinical support Few participants received the clinical support from surgeons that they were expecting. Many participants wanted more personal and higher quality interactions with surgeons, including both emotional support and support with their health needs, including information support. Participants wanted empathetic surgeons though this was not often experienced, impeding patient reassurance. There is often a mismatch between the patients' and surgeons' perspectives, including surgeons lacking empathy for the patient experience and not seriously investigating unresolved post-surgery problems. Physiotherapists provided key clinical support and are seen as critical. Communication skills, empathy, time, and tailoring were seen as key. Inadequate physiotherapy was caused by waiting for too long after surgery, and patients sometimes have to self-advocate. Family doctors sometimes assist with pain and recovery advice.
	Personal support Family and friends were important sources of personal support. Patients need assistance with normal activities following surgery so rely on friends or family. Some family members/friends were unable to provide personal physical support due to anxiety, feeling unskilled, not understanding what was needed, their own impairments or being busy. Physical support made patients feel emotionally supported. Explicit emotional support came from family members, friends, and other patients. Employers could also be a source of personal support by allowing them to work from home or covering healthcare expenses, whereas others reported negative experiences such as not getting enough sick days for recovery.
Funding	Supported by the Canadian Institutes of Health Research Partnerships for Health System Improvement (CIHR PHSI) operating grant (number 114106), the Michael Smith Foundation for Health Research (MSFHR; number PJ HSP0004(10-1)), and the BC Rural & Remote Health Research Network. Funding also from Vancouver and in-kid support from Vancouver Coastal Health Authority and Fraser Health Authority.
Limitations and applicability of evidence	Minor limitations due to the role of the researcher not being adequately addressed.

Study	**Hall 2008**[53]
Aim	To examine individual's experiences living with OA of the knee and what their expectations are of arthroplasty and physiotherapy.
Population	15 participants (10 males and 5 females aged 52 to 80 years) with knee OA who were awaiting TKA.
Setting	A specialised orthopaedic tertiary care facility in Toronto.
Study design	Qualitative study.
Methods and analysis	Grounded theory method using existing interview data. Purposive sampling.
Findings	The overall theme was the breakpoint, the time when a person with knee OA has come to the realisation that they require TKA in the near future. It was thought to include three experiences, two of which are not related to this review: 1. The exhaustion of past medical treatment of the affected knee and living with pain; 2. Living with limitations in functional mobility, leisure and social activities and the consequences to the individual.
	The third theme which was relevant was: **The sources of knowledge the individual seeks out.** The expectations they had for TKA were linked to their knowledge of the procedure and its outcomes, the main sources being acquaintances, friends and family members, and doctors. Subthemes: **Lay sources of knowledge: Acquaintances and friends** Participants said they were interested in what acquaintances, friends, or their families thought of the surgery and if they would recommend it. This information gave them the confidence to have the surgery. They wanted to know if those who had a TKA managed to resume their usual activities. Of importance was the lack of questions surrounding the process or the acute postoperative phase. Many did not ask about the pain and limitations faced by these people just after their surgery. None of the participants asked about the rehabilitation that would be required. The focus was on the ultimate outcome of the surgery. **Sources of knowledge: Physicians** Doctors were also a significant source of knowledge for these participants. They provided the participants with more technical information about the surgery such as what was going to be replaced. Information obtained from doctors influenced the participants' expectations of surgery. Most were not expecting a perfect recovery. **Knowledge and expectations of physiotherapy** There was a division among participants for knowledge and expectations of physiotherapy. Some did not have a lot of knowledge about physiotherapy. Others knew about it based on previous treatments and preoperative education. All believed that physiotherapy was beneficial for their recovery. Those who had expectations mentioned increasing their range of motion, learn to walk and use stairs, and strengthening the muscles as what they would be doing as part of their rehabilitation. Some expected therapy to be difficult and self-directed. They just wanted to perform regular daily activities without pain. One of the major goals of TKA was to be able to walk without pain and for longer distances, an additional goal was to resume leisure activities.

Study	**Hall 2008[53]**
	The analysis indicates a trajectory of OA of the knee that culminates in breakpoint experiences of pain, loss of activities, and social contact. Participants sought out information from a variety of sources, and coupled with the pain and intrusiveness of the condition, the decision to undergo TKA was made.
Funding	Not reported.
Limitations and applicability of evidence	Minor limitations due to the relationship of the researcher not being discussed. The study used existing in-depth interview data from a prospective qualitative study.

Study	**Hendry 2006[56]**
Aim	To examine the views of primary care patients with osteoarthritis knee towards exercise, explore factors that determine the acceptability and motivation to exercise, and to identify barriers that limit its use.
Population	People with a diagnosis of osteoarthritis of the knee from practice registers in general practices across North Wales Participant characteristics: n=25; 17 females/8 males; Mean age (range): 65 (47-77) years; duration of symptoms: 6 months to 25 years; pain varied from mild to severe, disability varied from slight to severe, two were on the list for knee surgery.
Setting	People were recruited from general practices across North Wales, including practices from: urban, rural, ex-mining village, and seaside town settings. Interviews were conducted in participants' homes. After this, all people were invited to participate in a focus group.
Study design	Qualitative design.
Methods and analysis	Semi-structured interviews using a topic guide developed from a literature review and then refined in an iterative manner throughout pilot interviews. People were encouraged to express any views of ideas related to their experience of osteoarthritis of the knee, particularly with regards to the effect of exercise on their osteoarthritis symptoms and vice versa. The interviews were conducted in participants' homes by one interviewer. The transcripts were transferred to the QSR NUD*IST computer programme, which aids the management and indexing of qualitative data. Transcripts were initially read and coded independently by two reviewers into categories, themes and sub-themes after each interview had taken place. Disagreements were resolved by discussion and previously coded transcripts were reviewed in an iterative fashion as themes developed. Further analysis was conducted after the completion of all interviews. Subsequently, all the interviewees were invited to participate in a focus group where emerging themes were presented using Microsoft PowerPoint, and participants were invited to give feedback. The focus group discussion was recorded, fully transcribed, and coded in the same way as the interviews. The purpose of the focus group was to enhance the validity of the study by using a different method to triangulate the findings. As well as confirming the interview findings, the focus group generated additional accounts from individual perspectives within the group, thus adding to the richness of the data and extending the comprehensiveness of the study. The key points were summarised in a thematic chart, retaining the context and language in which it was expressed, according to the principles of the Framework method of qualitative analysis. The chart was then used to describe the relationship between the themes in a conceptual framework; followed by a typology of exercise behaviour.

Study	**Hendry 2006**[56]
Findings	**Physical capacity** – This category included two themes: knee-specific limitations to exercise and general limitations to exercise. Ability to exercise was limited by the pain and stiffness in their knees, which restricted both the type and amount of exercise that was possible. Ability was also limited by a perceived general lack of physical fitness, sometimes attributed to old age, as well as co-morbidity including angina, lymphoedema, congenitally malformed hip and osteoporosis.
	Knee-specific limitations to exercise – This theme included seven elements: I can't walk as fast or as fast as I used to because my knees hurt; my knee is stiff, especially first thing in the morning or after resting; going downhill or downstairs is particularly painful; anything that would job or jar my knee would really hurt; I can't swim any more because breaststroke is bad for my knee; It's hard to get going on a bike and very painful; it's absolute agony in spite of painkillers, so any activity is very limited.
	General limitations to exercise – This theme included two elements: I've reached an age where exercise doesn't help, I just get tired; I'm not fit and agile enough to do exercises.
	Beliefs about exercise – This category included three themes: personal experience, exercise advice and aetiology of arthritis
	Personal experience – This theme included two subthemes: Exercise for osteoarthritis knee; exercise for health and well-being. Some people found exercise was helpful for relieving pain; others found that pain persisted, but stiffness and mobility improved; others found not improvement in knee symptoms.
	Exercise for osteoarthritis knee – This subtheme included three elements: exercise is the best thing for relieving the pain; exercise doesn't help pain but it gets it going, improves stiffness and mobility; exercise doesn't help my knee at all.
	Exercise for health and well-being – This theme had two elements: you feel great when you exercise, it gives you a buzz; exercise is part of a healthy lifestyle, it improves fitness and I feel better for it.
	Exercise advice – This theme included three subthemes: in favour of exercise, against exercise, vague advice, or no advice. Advice from health professionals was mainly in favour of exercise and consisted of encouragement to exercise, advice about specific exercises and referral to a gym. Sometimes the advice was vague or absent, and occasionally exercise was discouraged.
	In favour of exercise – This subtheme included five elements: my doctor told me to keep exercising and not to stop; the physiotherapist told me to exercise; my doctor showed me how to do quads exercises to strengthen the muscles; my doctor gave me a referral to the gym; I was given advice about exercise at the gym.
	Against exercise – This subtheme included one element: at the hospital they told me I shouldn't overdo exercise; I should look after my knees.
	Vague advice or no advice – This subtheme included three elements: he told me to take painkillers and keep my knees moving but he didn't advise any particular kind of exercise; I haven't had any advice about exercising and what exercises to do; doctors could give you more encouragement to exercise, I had to get the referral form from the gym myself and ask him to sign it.
	Aetiology of arthritis – This theme included two subthemes: wear and tear and excess weight. Many were worried that exercise was wearing out their joints. They reasoned that osteoarthritis is caused by wear and tear; therefore, exercise would exacerbate the disease process. Analgesics were used warily, as there was concern that they might disguise the warning function of pain.

Study	**Hendry 2006**[56]
	Wear and tear – This subtheme included three elements: It's caused by heavy work, always being on your feet and doing a lot of sport when young; if it's caused by wear and tear, exercise is only going to make it worse; pain is a reminder to slow down, a warning sign.
	Excess weight – This subtheme included two elements: being overweight has made my knee problem worse; it's a vicious circle, you put on weight because you don't want to exercise when your knees hurt and then they hurt more because of the extra weight.
	Motivational factors – This category included five themes: enjoyment, social support, taking control of disability, priority setting and context
	Enjoyment – This theme had two subthemes: positive and negative.
	Positive – This subtheme had three elements: I like cycling/swimming/walking; I really do enjoy the gym; I look forward to going; I enjoy dancing.
	Negative – This subtheme had three elements: I'm not keen on swimming/walking/going to the gym; I didn't like exercising on the machines at the gym. I think they're really boring; I can't enjoy exercise because it's so painful.
	Social support – This theme had four elements: I like the gym referral scheme because you're in a group of people who all have problems; I go walking/swimming/cycling to the gym with my husband/wife/friend; you meet people at the gym and make friends; I go out for walks with my dog.
	Taking control of disability – This theme had two subthemes: positive and negative. In some cases people were determined to take control, even though they thought osteoarthritis was caused by wear and tear and so would be worsened ultimately by exercise.
	Positive – This subtheme had five elements: I'm determined not to let my knee problem stop me from doing the things I want to do; I realised my mobility would get worse if I didn't do something about it so I started exercising; I asked my GP to refer me to the gym; the idea of becoming immobile made me determined to lose weight; the doctor can give advice but it's my body, it's up to me to do something about it.
	Negative – This subtheme had two elements: I've accepted my limitations and said goodbye to going out; there's no cure, only pain relief.
	Priority setting – This theme had two subthemes: positive and negative.
	Positive – This subtheme had two elements: I try to fit exercise into my weekly routine; I'm on a gym referral scheme, so I have a set time to go and that helps.
	Negative – This subtheme had three elements: I do my exercises when I remember but when I'm busy I forget; I don't have enough self-discipline to make me exercise regularly; finding the time to go to the gym is a problem.
	Context – This theme had three subthemes: amount of exercise, location, and supervision
	Amount of exercise – This subtheme had five elements: I get enough exercise leading an active life; you can't do too much exercise, take painkillers, if you need to, and keep going; there's a basic level of exercise that I have to do to keep the joints flexible, so I can get up and move around; day-to-day activity isn't enough to keep you mobile; you should do moderate exercise, overdoing it could make things worse.

Study	**Hendry 2006**[56]
	Location – This subtheme had eight elements: I'm happy to go the gym; I'd be too embarrassed to go to a gym; I would go to a gym if my doctor referred me; I imagined the people at the gym would all be young and fit and that I would feel out of place but it wasn't like that at all; the bikes at the gym are easier to use and safer than cycling in traffic; the gym is safer for women than going out walking alone; I prefer to do outdoor exercise like cycling or walking; I would rather do exercises at home. The location was important, with some people preferring to exercise at home, others preferring outside and some exercising at the gym. The gym was sometimes viewed as inappropriate places, while others found the opposite.
	Supervision – This subtheme had four elements: I think the physiotherapist or someone with a medical background is the best person to supervise exercise; the gym instructors advise you and give you confidence that you're not going to make things worse; at the gym they give you one-to-one attention and an individual programme that's right for your body; the supervision at the gym is very good; they monitor what you do.
Funding	Funded by the Stone form, which is supported by an educational grant from Merck, Sharp and Dohme Limited, also by the all Wales primary research network (CAPRICORN), which received funding from the Welsh Assembly Government.
Limitations and applicability of evidence	Participating general practices were unable to identify people referred to a gym specifically for osteoarthritis of the knee (could have been for other reasons). Could have a missed group of people referred for osteoarthritis of the knee who had not attended the gym. Three of the authors were clinicians and one was a sports psychologist, who were all in favour of exercise provision for this group. The clinicians frequently refer such people to exercise referral schemes as a part of their usual practice. They were aware of this potential for investigator bias and actively sought any negative comments about such schemes. Minor limitations.

Study	**Hinman 2016**[57]
Aim	To explore how stakeholders experienced and made sense of being involved in an integrated programme of physical therapist supervised exercise and telephone coaching for people with knee OA.
Population	10 physical therapists, 4 telephone coaches and 6 patients with painful knee OA.
Setting	Australia
Study design	Cross-sectional qualitative design alongside a randomised controlled trial evaluating the efficacy of adding telephone coaching to a physical therapy program of exercise and physical activity.
Methods and analysis	Semi-structured interviews. Interviews were audio-recorded, transcribed, and thematic analysed using grounded theory. Participants from the RCT were recruited for the qualitative study. People with knee OA were provided with an information booklet explaining the benefits of exercise and physical activity for OA, as well as information about behaviour change support processes. Telephone coaching calls were provided 6 to 12 times over the 6-month period, with calls occurring in weeks 2,4,8,13,21, and 25.
Findings	**Four themes: one of which was information and accountability**

Study	**Hinman 2016**[57]
	All 3 groups of participants referred to the importance of giving and receiving information and of being monitored and, therefore accountable to someone else. The impact of this feeling of accountability was to increase their motivation to exercise. Patients with knee OA described feeling accountable to their physical therapist and not wanting to let down the therapist.
Funding	The study was supported by funding from the National Health & Medical Research Council.
Limitations and applicability of evidence	Minor limitations as study is specific to the integrated programme within the RCT.

Study	**Hudak 2002**[60]
Aim	To explore the process by which elderly persons make decisions about a surgical treatment, total joint arthroplasty.
Population	People with severe disabling arthritis (later confirmed as osteoarthritis) confirmed on physical and radiographic examination, with no contraindications to surgery. Participant characteristics: n=17, no additional information.
Setting	The study took place in Toronto, Ontario, a large urban, ethnically diverse city.
Study design	A purposive sample of older adults with arthritis were obtained from individuals identified in a prior publication based survey. Trained physical therapists presented people in their homes with a standardized description of the consequences of not having surgery, alternative treatments, and risks and benefits of arthroplasty (including the projected life span of the replaced joints). They were asked who would be likely to consider having total joint arthroplasty. Only people who said probably or definitely not were recruited into the study. One investigator conducted in-depth, face-to-face interviews, with each participant guided by a semi-structured interview schedule (interview schedule available from authors on request). Interviews considered: 1) the sources and nature of information about total joint arthroplasty; 2) the values and preferences important to individuals in considering total joint arthroplasty. All interviews took place in the participants homes, except for 1 which was conducted in a private office at the hospital's research unit. Interviews lasted 2-3 hours.
Methods and analysis	All interviews were tape-recorded and transcribed verbatim. The method of data analysis was qualitative content analysis, the process of identifying, coding, and categorizing patterns. Analysis began with the identification of key themes and patterns using the process of coding. The analytic process began inductively and was iterative. Credibility and rigor of the analysis were aided by co-analysis of transcripts by 2 of the researchers, continual re-examination of the interview data throughout the research process, and ongoing discussion with the senior investigator.
Findings	**Deferral** Rather than the decision to say no to total joint replacement being an endpoint, some people's decision making involved ongoing deliberation of arthroplasty as an option, often resulting in a deferral of the decision until a different time. The decision was being put off

Study	Hudak 2002[60]
	to some ill-defined future point in time when an equally ill-defined threshold of pain and/or immobility might be reached. These participants did not appear to have a definite or distinct plan for when they would make this decision. Some were hopefully that things would get better, and a decision would never actually be required.
	Assumptions Do people consider their arthritis a "problem", do they see themselves as candidates for treatment and finally, should they be pursuing treatment? A person's individual thoughts of this may affect decision making.
	The nature of arthritis Some participants had adjusted to the changes in their body through their lifestyle to help them daily with their arthritis. Therefore, to those people they do not currently have a problem and so do not need to have it fixed.
	Candidacy Many people believed that they needed to be in constant pain and virtually unable to move before they would consider themselves a total joint arthroplasty candidate.
	Decision making process Some older person's process of, and preferences for, information gathering and synthesizing strongly suggest a need for physician responsibility for information sharing. In addition, a desire for a more authoritative model of patient-practitioner interaction and treatment decision making may be present. If the physician does not make a direct recommendation, and the person wants direct recommendation then they may defer the decision as a preferred interaction.
	Information and fears Participants showed that improved communication about total joint arthroplasty is also needed. Many people showed evidence of poor information of trust in the procedure, despite having received detailed risk/benefit information as part of the population-based survey. This casts doubt on their receptiveness to the utility of total joint arthroplasty in their individual cases, as well as on the effectiveness of the manner in which the information was presented. Participants often drew preferentially upon lay sources for total joint arthroplasty information, such as the satisfaction accounts of others who had undergone the surgery, to form perceptions about its efficacy. Although some had heard the surgery was "marvellous" and like having "new bones", others learned that surgical outcomes were not always ideal. Risk assessments were also formed on the basis of peer accounts.
Funding	Supported by grants from the Medical Research Council of Canada (MT-15469) and the Canadian Arthritis Society (99/093; renumbered to 99/0143 in 2001).
Limitations and applicability of evidence	Major limitations as the relationship between the researcher and participants was not reported, unclear statement of findings and uncertain how valuable the research was to this question. The research design and recruitment strategy were not considered appropriate for the aims of the research. The study notes that they could have been selecting a population that did not have sufficient information about the procedure or were basing it on a hypothetical that was not appropriate for them at this time. They argue that participants had spoken to clinicians about it before. A second limitation was the extent to which assumptions are applicable to a wider population. They note that the assumptions

Study	**Hudak 2002**[60]
	are not exhaustive. They note that the sample size is small but note that all the themes could be seen, to differing degrees, in all participants. In the study design they exclude any participants who are unsure or would choose to have total joint arthroplasty, and so misses a fair amount of the population in their aim and makes the research less applicable. Note for theme 'assumptions': unclear whether this is actually a theme, doesn't seem to state anything about the person in the study and more refers to another study.

Study	**Ilic 2005**[62]
Aim	To evaluate the feasibility and user satisfaction of the Internet User's Guide to education and assist patients to search for medical information about osteoarthritis on the Internet.
Population	12 adults who were able to speak and comprehend English and were affected by osteoarthritis. Participant characteristics: n=12; gender not stated; mean age (SD): 64 (8.8) years; 50% used the internet at least once a week.
Setting	People in Australia who were recruited through public advertisements between March and July 2004.
Study design	Two focus groups with structured interview questions.
Methods and analysis	Two focus groups that discussed the person's past and current use of the Internet as a medical resource and explore their level of satisfaction when conducting searches for health information online and the question of information located. After this people were asked to search the internet to identify five websites, they believed offered information of a good quality relevant to osteoarthritis. Once completed, people were provided with the internet user's guide, produced for the study, after which they were asked to search again. After this they provided feedback about the resource. People were given a 2-hour time limit to complete all internet simulations. Qualitative responses were analysed by extracting key themes and grouping the key comments made under these themes. An iterative process was employed in regrouping and identifying new themes as they emerged.
Findings	People found that it was difficult to use the internet to source relevant and credible health information ("I found that the information [available on the internet] was too technical, too commercial and not precise in relation to the topic"). Participants typically relief on their doctor for the provision of general medical information. Once diagnosed people were keen to accumulate further information on the condition and potential treatments through the Internet supplementary to information provided by their doctor. However, only 33% of the participants stated they eventually used the internet to achieve this. They noted that the convenience of accessing medical information was a benefit of using the internet.
	People found the internet user's guide enabled them to search and identify more relevant and scientific website information.
Funding	Not reported.
Limitations and applicability of evidence	Moderate limitations due to unclear relationship between the researcher and participants, data analysis was not sufficiently rigorous and limited statement of findings .The study provides very limited information throughout that makes it difficult to interpret.

Study	**Kamsan 2020[66]**
Aim	To explore older adults' knowledge about knee osteoarthritis and their perspectives on the information required to enable self-management.
Population	Older adults aged 60 years and above with a clinical diagnosis of knee osteoarthritis. Participant's characteristics: 3 men and 13 women; 3 participants had OA between 3-5 years and 13 more than 5 years; mean age (range): 73.2 (61-89) years; ethnicity: 4 Malay, 10 Chinese and 2 Indian.
Setting	Geriatric unit in a teaching hospital in Malaysia; participants were selected through purposive sampling strategy to obtain broad range of information, representing all main ethnic groups including Malay, Chinese, and Indian. Selected individuals were screened through telephone calls and those who fulfilled the criteria were invited to participate and scheduled for focus group discussions.
Study design	Qualitative design using focus group discussions to obtain a variety of information about any particular issues, topics, or phenomenon.
Methods and analysis	Three focus group discussions were held in a private space and conducted by the same researcher. The questions were guided by a specific framework. An extensive review of published literature was performed to determine the most relevant topics and questions for the discussion. The draft topics and questions were reviewed by the research team and consensus development through discussions; finalised topics were used in focus group discussion sessions. Each session lasted one to one and a half hours and was audio recorded. Sessions were scheduled until the data reached a point of saturation, determined through performing data collection and data analysis concurrently. Analysed using thematic content analysis.
Findings	**Information** **1. Disease information** Participants had a strong desire to learn more about knee OA, including the causes of the disease. They also wanted to better understand the management even though they had experienced various types of interventions. Comments included, "I want to know about how to go about without operation" and "All I want to know is how to manage it, how to heal it if possible, how you are going to sort of manage the pain, make sure it doesn't get worse, that's it" **2. Self-management skills** Most participants wanted to learn about possible non-pharmacological pain management options as they were worried about long term effects of medication and believed there were alternatives. They also interested in self-management skills to help manage their symptoms, to make decision and have control of their OA. One participant stated "Again I want to know how to manage the pain without taking pain killers. The pain killers lead to gastric (pain), and you know all kinds of other things. That's all. Self-practice, that one, self-practice to control". **3. Guidance on healthy lifestyle** Participants wanted information on weight management and exercise. Many participants repeatedly asked about appropriate types of exercises which are effective and convenient to perform. Some explained that they had forgotten the physiotherapist prescribed exercises as they did not practice them consistently. A few people were aware of the importance of a healthy lifestyle but did not

Study	Kamsan 2020[66]
	practice it due to lack of knowledge. “What are the exercises we should do and when, the things you know, certain movements(s) you shouldn’t do”.
	Understanding of knee OA 4. **Literacy on the nature of knee OA** Participants understanding of knee OA varied; one participant did not understand the meaning of OA and another two did not have any knowledge on knee OA development. Many were able to link the development of knee OA with factors such as ageing, occupation, inappropriate footwear, trauma and being overweight. Although, one participant was unaware that genetics and diet contributed to development. “Not much knowledge (about KOA development). Erm, not interested in biology….” “What is osteoarthritis in Malay? Is it swelling of the joint?” 5. **Consequences of knee osteoarthritis** Many participants considered the consequences were joint pain, followed by swelling, joint stiffness, joint instability, and muscle weakness. Most participants agreed that this led to functional difficulties (caused by joint pain and mobility impairment) and psychological distress (from emotional imbalance and lack of self-acceptance). A few people mentioned social participation was affected as they were less likely to go out and participate in social activities, while others mentioned frustration on becoming dependant on others due to their reduced mobility. Half of the participants were concerned that they could not participate in religious or ceremonial rituals, mostly sitting cross-legged or kneeling. There was a lack of knowledge on how these positions could be adapted to continue participation. 6. **Symptoms management** Participant could identify varied treatment strategies for the management of symptoms, these were suggested by physicians, family members or their peers. Some refused to take pain medications or supplements prescribed by physicians due to uncertainty about long term effects or experience with side effects. Many considered alternative therapies a beneficial approach (slat, herbs, traditional oils) and this approach was trialled on family or peer recommendations or personal beliefs. Most had attempted physiotherapy treatment and agreed it was important in reducing the impact of knee OA. Participants discussed the temporary effects of this treatment and complained of feeling exhausted after sessions. “Erm physiotherapy is good. But after some time, (the symptoms) come back again”. Some participants discussed management with knee support and waling aids which improved their comfort and confidence when performing daily activities. One person had concerns on long term effects of over reliance on the knee guard. Many participants were aware of intraarticular treatments or had been offered them. Several were doubtful of the benefits from these injections. Most of the participants refused any invasive management and had a fear of surgery. Only 2 participants though total knee replacement was a valid option due to the irreversible nature of OA. Several participants discussed the role of spiritual activities for OA; faith through religious practices gave hope to some to endure and accept this condition.
Funding	No specific funding received for this work.

Study	**Kamsan 2020**[66]
Limitations and applicability of evidence	Minor limitations due to unclear relationship between the researcher and participants.

Study	**Kao 2014**[69]
Aim	To understand the illness experiences of middle-aged adults with early knee osteoarthritis.
Population	Adults with Ahlback stage 1-2 knee osteoarthritis with the ability to speak Mandarin or Taiwanese. Participant characteristics: n=17; 14 females/3 males; mean age (range): 49.6 (43-55) years; mean BMI: 28.6 kg/m^2; mean time since diagnosis (SD): 26.6 (37.4) months; 88.2% had sought medical treatment for knee pain; mean time of symptom duration (SD): 39.7 (38.8) months.
Setting	Recruited from orthopaedic clinics of two medical centres in northern Taiwan. Conducted as one-on-one interviews conducted in Mandarin and later transcribed (from audiotapes) and translated from Mandarin into English.
Study design	Semi-structured one-on-one interviews.
Methods and analysis	Purposive sampling. One-on-one interviews were conducted with 17 participants. These were conducted in Mandarin and recorded using audiotapes. Relevant information (such as emotional content and non-verbal behaviour) was noted from memos and added to transcripts. All the transcripts were then analysed to reveal themes by content analysis. Transcripts were analysed individually using memos and the reflective journal to identify key points. After this, all key points were listed and clustered into groups to form initial categories, which were used to recode the transcripts. These were then listed and clustered into groups based on similarity and overlap, which was then refined to identify main themes. Coding and analysis continued until no additional themes were identified. Finally, the themes were labelled using the participants' own words and selected representative quotations. The themes were translated from Mandarin to English. The equivalence was validated by discussion among the authors and a bilingual expert in qualitative research.
Findings	**Unfamiliarity with osteoarthritis** Theme involved four subthemes: a) inconsistency of the disease with age, b) questioning why they have the disease; c) inability to control the disease progression; d) not knowing how to cope with the disease.
	Inconsistency of the disease with age In Taiwan, osteoarthritis is generally called 'degenerative arthritis', with this influencing people to think it is synonymous with 'ageing'. These ideas originate from observations of joint disease in senior family members, relatives, neighbours, colleagues, and friends.
	Questioning why they have the disease

Study	Kao 2014[69]
	People did not understand why they had osteoarthritis. They suspected that causes were based on individual aspects, such as occupation or previous disease. Several had doubts about their diagnosis being accurate.
	Inability to control the disease progression People thought that controlling progression of osteoarthritis was impossible, by medicine or any other treatment, and that only surgery could cure osteoarthritis.
	Not knowing how to cope with osteoarthritis After confirming osteoarthritis, people did not know how to process osteoarthritis-related issues and lacked disease-related information. This included: disease and medication knowledge, daily life activities and movement, dietary and body weight control, management of knee symptoms and how to seek support. Some felt they did not have anyone to talk to regarding osteoarthritis. Doctors had explained that osteoarthritis related information was scant, and people were not informed during consultation. People did not know how to find this information and found there were few instructional tools to help.
	Effects on daily life Theme involved two subthemes: a) daily activity and exercise were limited, b) reduction of work affected household income.
	Daily activity and exercise were limited Some participants stated that their knee joint ached when using stairs, made them unable to squat, forced the family to accept additional work, inconvenienced participants when they went out (having to look for a seated toilet) and having to take analgesic medicines before going out. Therefore, their activity was reduced, as was their exercise and they did not enjoy travelling.
	Reduction of work, affecting household income Most participants were labourers (85.7%) and 61.5% were the main household wage earners.
	Protection and alleviation People thought there were some factors that could protect the knee joint to avoid worsening and could delay further development of osteoarthritis. These included: changing lifestyles (adjusting posture and altering exercise habits to reduce knee joint attrition and pain, some altered eating habits, some adjusted their work pattern); avoiding medicinal side effects (people were concerned that side effects of medicine harm the body and therefore avoided frequent use of medicine. The ideas included: analgesics injure the kidneys, antibiotics are bad for the stomach, injecting hyaluronic acid damages the cartilage); and using auxiliary devices (kneecaps, braces, showering in hot water, bathing in hot springs and electrotherapy help with knee discomfort and/or powerlessness. People felt these reversed their function to what it was before their symptoms worsened).
Funding	No specific grant from any funding agency in the public, commercial, or not-for-profit sectors.
Limitations and applicability of evidence	Minor limitations as the relationship between the researcher and participants was not reported. The study noted that it was limited by recruiting from two hospitals in northern Taiwan. They also had 6 people decline from participating, 4 saying they had no time for interviews and 2 refusing to be audio-tapes. They reflect their study sample is small and that regional differences may be present. Questionable external validity due to the population being from Taiwan (for example: antibiotics are not routinely used for osteoarthritis in the United Kingdom). The translation of information from Mandarin to English may change the results.

Study	**Karlson 1997**[70]
Aim	To study gender-specific preferences regarding timing of elective total joint replacement surgery.
Population	Patients with moderately severe OA of the hip or knee. Participant's characteristics: 18 women and 12 men; mean age 69.4 years; 2 African American, 28 Caucasian.
Setting	Patients of the Brigham Arthritis Centre, Boston, USA.
Study design	Qualitative design using focus groups.
Methods and analysis	Convenience sample with focus groups of either men or women, running sequentially until saturation (around the 4th or 5th group). A professional expert in focus group methodology moderated the groups using a moderator guide developed by the research team. The moderator prompted discussion with open-ended probes. The groups discussed the impact of arthritis itself in broad terms and then turned to decision making about joint surgery. An iterative method of content analysis was used to code the transcripts for themes by two independent reviewers (one male, and one female) who were blinded to the gender of the group. Each reviewer identified sample comments which were pooled with the second reviewer. The group then met to compare themes and organise them, working out final themes and subthemes by consensus.
Findings	Conflicting advice about surgery: both men and women reported conflicts between themselves and their doctors and also among their doctors regarding whether they should have surgery. However, there were no apparent differences between men and women in the type of advice they received from their physicians.
	Knowledge of others having a similar operation: many knew others who had successful TJR. Women were more likely to mention specific friends and neighbours who had done well with the operation.
	Elements of decision-making: men and women felt it helpful to talk to family and friends about their decision to have surgery. Women in particular expressed the need for more information about risks of surgery and surgical outcomes from others and from other sources before making the decision.
Funding	Supported in part by NIH Supplement from the Office of Research on Women's Health: AR36308, an Arthritis Foundation Investigator Award and a clinical science grant from the Arthritis Foundation.
Limitations and applicability of evidence	Results given 'semi-quantitively' and were specifically related to total joint replacement. Most cases fit clearly into one topic or another with little dissension. Minor limitations due to unclear recruitment method, lack of ethics reporting, unclear role of the researcher.

Study	**MacKay 2020**[83]
Aim	To explore how physical therapists approached management for early knee OA.
Population	Physical therapists who worked with individuals with knee symptoms or diagnosed knee OA in the past 3 months, worked in community based or outpatient settings and could communicate in English.

Study	**MacKay 2020[83]**
	N=33; years (range) in practice 21 (1-45) years; 25 females and 8 men; 9 in publicly funded setting and 24 in private clinic.
Setting	Canada – Ontario, Alberta and British Columbia.
Study design	Qualitative – semi-structured interviews
Methods and analysis	Recruited using e-blasts form orthopaedic division, Canadian Physiotherapy Association, and using a snowball technique (participants recommend other therapists). Interviews were telephone or in-person and lasted 60-75 minutes. Data collection ceased when no new themes were identified. Interviews were digitally recorded and transcribed verbatim. Inductive thematic analysis was conducted. Data collection and analysis were iterative, and codes were inductively developed from the data.
Findings	Five themes: physical therapists experience and training, tailoring treatment from physical therapist toolbox, central role of exercise and physical activity in management, variability in support for weight management and facilitating buy-in to management. This evidence table has only extracted the relevant information from the theme of facilitating buy-in to management.
	Facilitating buy-in to management Adherence was considered an important role of the work of physical therapists. Participants accounts suggested they used different strategies to get buy-in to OA management. They believed buy-in was important in improving outcomes**.** **Sub-themes** **Providing information:** Most participants agreed that education contributed to buy-in of treatment. Participants talked about pathology and consequences of OA and provided education about treatments like exercise. Verbal descriptions, visual aids and demonstrations were used for education purposes. *"I usually get out a knee model to visually show them what is going on and how the muscles can have a big effect on the loading through the knee".* **Addressing interests and personal context:** Most participants targeted treatment to a person's goals/interests. *"You find out what they really want to do, not what you want them to do, and then you'll have better buy in".* They also indicated that it was important to consider the patients personal context so that it can fit in with their daily life demands or focusing on a couple of important exercises to keep it manageable. **Improving symptoms quickly:** Early improvement in symptoms provided buy-in for management. **Encouragement**: A positive attitude and giving encouragement for small changes was considered important to have buy-in of management. Some participants told encouraging stories about people who had improved with physical therapy.
Funding	Supported by a postdoctoral fellowship from the Canadian Institutes of Health Research.
Limitations and applicability of evidence	Minor limitations due to relationship between researcher and participants not being addressed. Only one theme extracted as other themes not applicable to this review question.

Study	**Maly 2007** [85]
Aim	To understand the experience of living with knee OA in older adults.
Population	3 participants (2 women and one man, age range 62 to 87 years) with knee osteoarthritis.
Setting	Canada.
Study design	Qualitative study using semi-structured interviews.
Methods and analysis	VanKaam method of phenomenological analysis was used. One interviewer who practiced as an orthopaedic physiotherapist, used the guidelines proposed by Seidman to design and conduct 3 separate interviews, each 90 minutes for 3 participants. Participants were asked to reconstruct their activities, symptoms and limitations over the past week using their calendar or day-planner.
Findings	Sharing the experience of living with knee OA: All participants gleaned information about knee OA and methods to manage daily living with the disease through the experience of others, particularly peers they identified with and trusted. In some cases, the experience of others was positive which facilitated activity. One female spoke about observing a woman while visiting pyramids in Mexico. However, the experience of others can also provide a negative influence on managing with knee OA. For example, while in the process of considering a total knee replacement, the owner of the bed and breakfast learned about this surgery from a guest. For this participant, knee surgery was the treatment choice suggested by a health care provider to resolve their knee problems; thus, it was particularly disconcerting for the participant to experience, through this acquaintance, a failed surgery. Unlike both women in this study, the male participant identified with his surgeon who also experienced pain during recreational sports. The surgeon's advice therefore was relevant to this participant, Take the medication before you go and play. I do that when I play gold and he did play tennis, I don't know, ten years ago this surgeon…he stopped playing tennis. He said he cannot play tennis anymore, but he still plays golf. The personal experience of the surgeon, combined with the surgeon's medical expertise, provided the participant with a pain management strategy specific to sport. From a different perspective, all participants described how they aimed to be a source of information and inspiration for others by sharing their personal experience. In doing so, the participants felt that the hardship they endured due to their knee problems would become meaningful. The tennis player hoped that sharing pacing strategies could provide an example to other friends who overexert themselves. The other participant hoped to provide inspiration for others to pursue a total knee replacement.
	Managing chronic pain: Knee OA resulted in chronic pain. Managing chronic pain required knowledge and information. This knowledge, most often, was gleaned from peers; doctors were not considered a useful source of information. One participant diligently followed the advice of a friend who facilitated better mobility and pain control with the use of alternative therapies including magnets, reflexology, and exercise.
Funding	Canadian Institutes for Health Research (grant #99034). Toronto Rehabilitation Institute, Natural Sciences and Engineer Research Council were acknowledged.
Limitations and applicability of evidence	Only three participants. Minor limitations due to the role of the researcher not being addressed and unclear whether the recruitment strategy was appropriate to the aims of the research. May not be generalisable to all patients with OA as the participants were selected for being more 'extreme' cases and the three participants were of the older age group.

Study	**Mann 2011**[87]
Aim	To explore the opinions of patients and health professionals about the provision of health care for people with osteoarthritis (OA) and possible service improvements.
Population	People living with osteoarthritis and health professionals from specialties providing health care for osteoarthritis. Patients' characteristics: n=16; Age (range) 56-81 years; Years with OA (range) 2-30 years. Health professional characteristics: n=12; Profession GP n=2, orthopaedic surgeon n=1, rheumatologist n=1, occupational therapist n=1, physiotherapist n=2, nurse practitioner n=1, practice nurse n=3.
Setting	Patients were recruited through the practice database of a large general practitioner (GP) practice. Once the first 4 patients had agreed to attend a focus group, purposive sampling ensured broad variation in the sample regarding age, illness severity, length of illness, comorbidity, and a balance of men and women. Health professionals working in primary and secondary care were approached. The GPs, nurse practitioner, and practice nurses all worked at the same GP practice where the patients were registered, but other health professionals were recruited from diverse sources. All were identified using known contacts and a "snowballing" technique.
Study design	Qualitative design using focus groups and interviews.
Methods and analysis	Focus groups were used as group interaction can generate freer, more broad ranging expression of ideas and opinions as well as facilitate clarification. One-on-one interviews with professionals were chosen as a means of generating data relating to each of their specialties, since interviews could be conducted in confidence and at times suited to the professionals' work commitments. Focus groups lasted 90 minutes and were conducted on the primary care premises. At the start of each focus group, each participant completed a questionnaire about OA history and related health care. The researcher used a topic guide to facilitate discussion about the patients' experiences of care, their perceptions of gaps in care, and suggestions for improvements. Interviews with health professionals lasted 15–50 minutes each and were semi structured with a topic guide. Questions focused on current care and the professionals' views about possible improvements to OA care. Probes and additional open-ended questions were used to achieve depth. Interview and focus group data were analysed according to the Framework method, which allows for the inclusion of new themes generated by the data, as well as the broad themes of interest contained in the topic guides.
Findings	**Focus groups** **1. Information** Most patients expressed a strong desire for improved information about OA and its likely progression particularly at diagnosis and in the early stages of OA, so that they could know what to expect, as well as feel confident in their management of the condition. Patient information needs included diet and exercise, how to minimize OA symptoms and progression, and practical information about aids and local services. When these needs were not met, some patients turned to the internet for information.
	2. Access to treatment and services Whilst all patients had seen their GP about their arthritis, some had difficulty getting a diagnosis. Some had not seen an HCP about their arthritis in the last year. Many patients were not aware of having received advice about exercise or weight control, only half had not received physiotherapy. None were aware of other services such as occupational therapy. Some report little contact following receiving diagnosis, and that regular review and information about the likely course of OA would be beneficial. Many felt

Study	**Mann 2011**[87]
	that OA was a low priority for HCPs and GPs were too busy to spend much time discussing their OA. The general view was that the only effective treatment was joint replacement surgery although access to joint replacement was a concern.
	Interviews **1. OA information** Every health professional identified the problem of insufficient information for OA patients. The need for early education about OA and its likely course was emphasized as it affects acceptance of self-management and treatment options. Patients should have the opportunity to discuss these options and be provided with more information to aid self-management at diagnosis, or soon after, for maximum effectiveness. Some had doubts regarding patients' willingness to make behavioural changes.
	2. Available treatment and services Health professionals reported that OA was not given enough attention, and symptoms were often dismissed or minimized in health care. There is not much provision for those who were not candidates for surgery, and some patients must wait for too long with severe symptoms before being considered for surgery. Patients lacked proactive follow up to support self-management. Lack of time to give patients sufficient opportunity to discuss their condition was a concern for most professionals. Quality of care was also thought to be adversely affected by general lack of expertise and interest in OA in the community. Access to services, such as occupational therapy and physiotherapy, and the provision of these services in the community was universally described as inadequate, with wait times too long.
Funding	Supported by a grant from the North Bristol NHS Trust small grant scheme.
Limitations and applicability of evidence	Moderate limitations due to the potential influence of the researcher on responses to interviews/ focus groups. Researcher was a rheumatology specialist nurse known to patients and HCPs. This was acknowledged in the paper and her role was made clear. However, this could have influenced responses, and affected analysis. Results may not be generalisable as both patients and primary care practitioners were from the same GP practice.

Study	**McGruer 2019**[88]
Aim	To explore the Māori lived experience of osteoarthritis.
Population	Māori adults (at least 30 years) with clinical knee or hip osteoarthritis diagnosed by a health professional or who fulfilled the American College of Rheumatology criteria for clinical knee or hip osteoarthritis: knee, hip, or groin pain; stiffness for >30 minutes; knee crepitus; bony tenderness and enlargement of the knee; no usual, palpable warmth. People were excluded if they had: a significant injury in the previous 3 months; a history of total joint replacement; a medical condition significantly affecting day-to-day function (e.g., fibromyalgia) or difficulty communicating verbally in English or Te Reo Māori. Participant characteristics: n=7; 7 females/0 males; Age range: 44-71 years;
Setting	People living in either Auckland or Tauranga regions who were identified as Māori.

Study	**McGruer 2019[88]**
Study design	A qualitative study guided by Kaupapa Māori principles. This is underpinned by three main assumptions: Māori have a distinctive world view and manner by which to organise knowledge in accordance with the distinctive nature of Māori knowledge; acknowledging the relationship between Kaupapa Māori and other bodies and forms of knowledge; Māori experiences are at the centre of the research activity.
Methods and analysis	Purposive sampling was used to recruit participants. Social media and advertisement flyers were used to recruit participants from the Tauranga and Auckland regions. The methodology was developed by three academic researchers, one of whom identified as Māori. Data was collected by a semi-structured and open-ended question method. Questions explored participants' personal history of osteoarthritis, their knowledge, and experiences of the condition (including treatment) and the effects of the condition on their wellbeing. Interviews were conducted in Te Reo Māori, English or both, at the persons' discretion. All interviews were recorded and transcribed by the primary researcher. Data was analysed using Te Whare Tapa Whā (a model of Māori health) as a guiding framework. Te Whare Tapa Whā uses the symbol of the wharenui (meeting house) as having four equal walls representing four equal dimensions of Māori wellbeing: taha tinana (physical health); taha hinengaro (mental health); taha wairua (spiritual health); taha whanau (family health). Themes were identified through kupu and phrases used by participants, as well as their stories. Each theme was considered in the context of Te Whare Tapa Whā and mapped to a particular dimension as applicable. Initial thematic analysis was carried out by the primary researcher. The associate researchers reviewed the transcripts and confirmed the identified themes.
Findings	Nine themes were emerged from the data: pain affecting daily activities; coping strategies; whakamā; frustration; Āhuatanga Māori; Whakapapa; Effects on whanau; experience of treatment; need for education.
	Pain affecting daily activities Pain was a strong and recurring theme. People described the unpleasantness of pain as well as how it affected their function, imposing limitations on their daily activities.
	Coping strategies All people discussed various ways of coping with their physical pain. Strategies described by people included heat and regular movement.
	Whakamā A term to describe being ashamed or embarrassed. People had this sense with regards to their physical limitations, in particular for younger women. This was also evident during interactions with health professionals. Some people told their doctor they understood what was being communicated to them despite having little or no understanding.
	Frustration All people experienced some level of frustration. This linked to how the condition affected their daily lives, as well as feeling as though little can be done.
	Āhuatanga Māori

Study	McGruer 2019[88]
	Related to the aspects, characteristics or attributes and traits of Māoritanga. People described how their symptoms affected their ability to participate in correct procedures or customs used by the Māori. This included limited how they could take part in funeral activities.
	Whakapapa Refers to the ancestral lineage from which one has descended. People described how certain characteristics of their ancestors, in particular stoicism, influenced how they managed their own pain and physical limitations.
	Effects of whanau People discussed the effect it had on their family. People felt that their ability to partake in activities was limited, and relationships were affected by the physical limitations and mental sequelae of osteoarthritis. Family also emerged as an important source of support and strength.
	Experience of treatment People told of mixed experience of treatment. Five people talked about using Western medicine for pain relief, although often mentioning adverse effects. Some had stopped taking medication altogether because of side-effects. Three of the seven participants mentioned using rongoa Māori (traditional Māori healing practices) as treatment. In some cases, people reported being offered limited options for treatment and were dissatisfied with their interactions with health professionals, although others spoke positively about the health professionals they had encountered.
	Need for education When people were asked about their knowledge of osteoarthritis, most people stated they had been given on a little, if any, information about the condition, although some reported doing their own online research. Almost all people felt that more education about the condition and available treatments was needed.
Funding	An Arthritis New Zealand Summer Research Scholarship supported the research.
Limitations and applicability of evidence	Minor limitations due to unclear whether data analysis was sufficiently rigorous. The study had a small sample size. Despite their use of purposive sampling, only female participants residing in urban areas agreed to take part. Therefore, this may not be total applicable to a Māori population.

Study	McHugh 2009[89]
Aim	To elucidate the factors that influence whether or not individuals with osteoarthritis decide to undergo a hip or knee replacement.
Population	People with hip or knee osteoarthritis who were referred for hip or knee joint replacement surgery. Participant characteristics: n=27; 18 females/9 males; mean age (range): 67.3 (49-89) years; 10 with knee osteoarthritis, 17 with hip osteoarthritis; mean VAS pain score (SD): 6.8 (1.63).
Setting	Qualitative interviews taking place in the Northwest of England during 2007.
Study design	A qualitative study nested within a longitudinal study using a purposive sample of individuals with osteoarthritis referred for consideration for total joint replacement. Uses in-dept interviews with a semi-structured interview guide. All interviews took place in the

Study	McHugh 2009[89]
	participants' homes, except for two where because of geographical reasons telephone interviews following the same interview guide were conducted.
Methods and analysis	The interview was conducted in the form of a conversation and focussed on four key areas: management of osteoarthritis; referral process; deciding to have a hip or knee joint replacement and information sources. Interviews lasted between one and one and a half hours. Permission to tape-record the interview was obtained. The interviews were transcribed, and transcripts were checked by the interviewer to ensure accuracy. Framework approach was used to analyse the interview data. The researchers familiarised themselves with the interview transcripts and developed a thematic framework using Microsoft Excel, and these were then developed into subthemes and sorted into themes. The data from each theme and subtheme were summarised in charts, and one chart for each major theme was developed. Rigour was aided by co-analysis of the data by another researcher. Initially 40 individuals were invited to take part and 21 were subsequently interviewed. However, as data saturation was not reached, another 12 individuals from the 52 person sample were invited to take part with 6 participants subsequently being interviewed providing a sample of 27 participants. After interviewing all participants data saturation was achieved with no new insights being forthcoming.
Findings	Four main themes emerged. These included: symptoms; opinion of others; weighing up the risks; benefits of surgical intervention and information sources.
	Symptoms Pain was the key symptom, and all people experienced severe pain at times hence why they wanted to be referred. When pain levels were severe, the individual was often influenced into deciding to undergo a joint replacement, which was the case for all 16 participants who underwent a total joint replacement. Two people who were initially not recommended to have a hip replacement felt that their pain became much worse so then went back again to see the specialist to push for a total hip replacement. As pain levels appeared to improve for two people with knee osteoarthritis, they reassessed their need and remained reluctant to have surgery. Despite high levels of pain, the remaining seven participants were not undergoing a joint replacement surgery because of the risks involved, as they felt they could live with the symptoms. Another key symptom was the reduction in physical functioning, restricting ability to walk, which for all participants reduced their quality of life.
	Opinion of others The opinion of the orthopaedic specialists and family members were equally important. These individuals were key influences in the participants' decision to undergo surgery. People appeared to accept having a hip replacement more than a knee replacement, with more individuals (five out of seven) unwilling to undergo a total knee replacement. When a surgeon considered that a replacement was not immediately necessary, the individual was asked to return to the clinic for follow-up. For some, this was the reassurance that was required and worked well for people who were not keen to undergo surgery. Others felt 'disappointed' as they were expecting a 'cure' of their symptoms. Three in particular were disappointed when they were told to 'wait' and see how things went, with two of these three ultimately ending up having a total joint replacement within the year. One of these people had a second opinion as they felt they had not been listened to and more information could have been provided on additional treatments.

Study	**McHugh 2009**[89]
	Family members appeared to influence the participants' decision. One person attended an appointment with their daughter and would have delayed their decision if their daughter had not intervened and encouraged them to go on the waiting list. The experience of others who had a joint replacement was another factor, which influenced individuals to have or not have a total joint replacement.
	Weighing up the risks and benefits of surgical intervention The participants appeared to understand the risks involved in having a joint replacement. The severe participants who were unwilling to have a total joint replacement highlighted particular concerns such as: risk of anaesthetic; post-operative complications; not being able to straighten knee after operation; 'more' pain and becoming 'more' disabled. Some participants were not aware of the different types of anaesthetic that were available to them and referred not wanting to be 'put to sleep'. At times when there appeared to be an improvement, in particular the symptom of pain, individuals appeared to weigh heavily on the risks of having the joint replaced and changed their mind against having it. The participants who had decided to undergo their hip or knee replacement felt the risks of having surgery would outweigh the anticipated benefits, such as an improvement of quality of life they would gain. One person referred to total hip replacement as a 'cure' for their osteoarthritis.
	Information sources Four participants sought a second opinion regarding their osteoarthritis. Three sought another opinion because they did not wish to have an operation; and the other because of not having confidence with the first consultation and wishing to have a specific type of hip procedure, which their hospital did not provide. When information was provided, participants' anxiety about the procedure appeared to lessen. Information appeared to be provided by health professionals and friends or relatives who had previously undergone the procedure. There were several criticisms regarding the provision of information. Several participants perceived that they had not been given any other treatment options then a total joint replacement. Several searched for their own information. More information regarding medication would have been useful with many having been told that it was paracetamol or nothing to manage their pain.
Funding	Not reported. Authors state they have no conflict of interest.
Limitations and applicability of evidence	The study notes that it is limited in its generalisability with the type of study design and small sample size. The study participants were a subsample of a select group of individuals at the end-stage of osteoarthritis, and recruited from a specialist orthopaedic hospital so there is an issue of selection bias. As the study was conducted in the UK, it is applicable to a UK population. Minor limitations due to unclear relationship between the researcher and participants.

Study	**McKevitt 2021**[90]
Aim	To investigate how people with OA experience physical activity in the context of comorbidity, and how best to support people with OA and comorbidity to be more active.
Population	Adults aged ≥ 45, with self-reported OA and at least one comorbidity located in the Northwest and West Midlands of England (N=17) Participants' characteristics: 4 men and 13 women; age range 49-95 years; all indicated that they engaged in some form of physical activity.

Study	McKevitt 2021[90]
Setting	Recruited from local community groups and third sector organisations (Arthritis Action, local library). Contact was made with community group leaders, to arrange brief face-to-face talk with group members and provide study information. Recruitment posters were also displayed in some community settings. Participant recruitment occurred between February and May 2018.
Study design	Individual semi-structured interviews (face to face); part of a larger multi method study that included quantitative and qualitative evidence and this study reports the qualitative evidence. A meeting with the Patient and Public Involvement group at Keele university shaped the study design.
Methods and analysis	Interviews were conducted at a convenient time, date, and location (participants home or community group location) and lasted approximately 60 minutes long. All interviews were conducted, transcribed, and anonymised by lead author. Data was transcribed verbatim and inductive thematic analysis was undertaken using a framework approach.
Findings	1. **<u>Barriers to physical activity in people with OA and comorbidity</u>** **Lack of concept of comorbidity with participants prioritising individual long-term conditions:** participants viewed their conditions as separate rather than co-morbidities and prioritised individual conditions (usually OA), based on their perceived disability and disruption of their quality of life (e.g., pain). Similarly, healthcare professionals prescribed exercise for one condition which meant that it was hard to execute as it did not consider their co-existing condition.
	Uncertainty about the management of long-term conditions and the effectiveness of physical activity: some participants thought that healthcare professionals preferred pharmacological and surgical treatments to physical activity for treating OA. There was an overall lack of knowledge whether physical activity was appropriate or effective in treating OA and co-morbidity. “I'd been about this to the doctor before and then again, ‘take some paracetamol…Nobody's ever said to me like, you know, you ought to try (physical activity).’ **Negative perceptions concerning long-term condition and ageing, and physical activity:** Participants believed their conditions would lead to an inevitable decline in health and did not expect to be able to carry out much physical activity in older age. These poor expectations were compounded by how they perceived healthcare professional viewed them. “She come she said, ‘it's just arthritis I'm afraid it's just something at your age, something you've got to live with.” The participants had negative perceptions of physical activity from personal experiences, including concerns of safety fears and negative ideas of gyms and classes. **Co-existing biopsychosocial barriers:** participants described multiple barriers to physical activity that included physical (e.g., physical impairment), psychological (fear of falling), socio-environmental factors (lack of partner, lack of transport) and biopsychosocial factors (pain). Participants experienced multiple barriers at the same time and pain was the most common one. **Solutions to barriers and barriers to solutions:** participants described solutions to barriers including identifying possible transport solutions, support and choosing enjoyable activities. Then they discussed further barriers to these solutions. 2. **<u>Facilitators of physical activity</u>** **Social support:** this was a key facilitator for physical activity and included encouragement, improved confidence, and shared learning from others. It was important that this was a shared experience with people with similar conditions, providing relatable experiences and confidence in their current and future abilities.

Study	**McKevitt 2021**[90]
	Healthcare professional support to facilitate self-management of physical activity: participants felt that it was beneficial to have a physical activity instructor who understood their individual needs and could advise them of a personalised plan. They also valued personable, professional opinion and input with face-to-face contact with the instructor to improve their confidence in carrying out the physical activity. "An instructor who, understands your condition…better than somebody who hasn't got a clue what it's all about…so they would know your limitations…to devise a programme around, various conditions that existed within the group." **Physical activity mode and type that is intermittent, adapted and fits into daily life:** it was important that the physical activity could fit into their daily life and consisted of an activity that was shorter in duration but done more frequently. Adapting the activity to their individual needs could improve participation, for example by tailoring the duration, type, environment, and equipment require. "If you can't move a lot then chair based activity" and "there is a tai chi class locally, but I can't do tai chi as it is, real tai chi, the one that I went to, she adapted…and it makes a big difference".
Funding	ACORN studentship; Keele University; NIHR; Haywood Foundation.
Limitations and applicability of evidence	Minor limitations due to unclear relationship between the researcher and participants and ethical issues not being considered.

Study	**Mikhail 2007**[91]
Aim	To examine the effect of the debate on the safety of non-steroidal anti-inflammatory drugs (NSAIDs) on decision making by Australian general practitioners and patients with osteoarthritis (OA), and to explore issues concerning the use of NSAIDs from both prescriber and consumer perspective.
Population	Advanced general practice registrars with less than a year of GP experience, experienced GPs with 3 to over 30 years' experiences, and patients with OA. GP characteristics: n=11; Profession: registrars n=5, experienced GPs n=6. Patient characteristics: n=20; 10 males/10 females; Age, range 54-85 years.
Setting	Location of focus groups not stated. GPs were selected using maximum variation sampling, and patients were proposedly selected for their extensive personal experience of using a wide range of therapies for their OA.
Study design	A qualitative study.
Methods and analysis	Focus groups were used. They were run between 15 May and 4 August 2006, and were audiotaped and transcribed. Each one lasted for an hour and was facilitated by two investigators, one of whom collected field notes. Field notes were used to triangulate findings and ensure accuracy and completeness of transcripts. Topic guides were used to facilitate discussion in the doctor and patient focus groups. A qualitative content analysis was undertaken to identify and explore key themes arising from the discussions.
Findings	**GP focus groups**

Study	Mikhail 2007[91]
	1. **Uncertainty** GPs expressed uncertainty about the safe use of NSAIDs in general, and COX-2 inhibitors in particular, with the literature being described as confusing and difficult to interpret.
	2. **Scepticism** GPs reported scepticism about medical information provided by some sources, particularly the pharmaceutical industry, including advice from specialists sponsored by a drug company.
	3. **Safety concerns** All participants were very concerned about safe practice to ensure patients' wellbeing and protect against medicolegal liability. Patients' acceptance of the risk was important in GPs' decisions to prescribe NSAIDs
	4. **Impact on current management of OA** There was increased use of other pharmacological (e.g., paracetamol) and non-pharmacological alternatives, which some patients prefer as an initial therapy.
	5. **Caution in prescribing NSAIDs** Uncertainty and safety concerns led to a cautious approach in prescribing NSAIDs. This involved prescribing the lowest effective dose, short-term use, shorter intervals between follow-up of patients, recommending breaks in taking NSAIDs, and use of other therapies. Patient related issues were the more important factor in the decision to prescribe NSAIDs. The decision making process involves a balance of risks and benefits.
	6. **Impact on the consultation** The debate about the safety of NSAIDs has led to more discussion with patients, and patients seeking more information. Time was a barrier to providing sufficient information. Strategies for managing time pressured included tailoring information and providing essential information first. Presenting the risk in a patient-friendly way was perceived as a challenge.
	7. **Patients' expectations from the doctors' perspective** The general perception was that patients expected doctors to prescribe a safe and effective drug, with regular monitoring for side effects, and to provide essential information
	Patient focus groups 1. **Insightfulness** Patients were aware that OA had no cure, and that all treatments were mainly for symptoms. Most patients were well informed, but one knew nothing about side effects.
	2. **Dealing with the pain of OA** Most patients had tried various NSAIDs and other treatments, such as paracetamol, cortisone injections, herbal remedies and diets, with varying degrees of success
	3. **Importance of function and risk taking**

Study	**Mikhail 2007**[91]
	Function was stated as a very important factor in their choice of treatment. There was a mix in terms of the degree of risk patients were willing to take for the benefit of function. **4. Need for information** Patients actively sought information from various sources, including GPs, pharmacists, medical books, consumer medicine information (CMI) leaflets, the Internet, and the media. Although pharmacists were perceived as reliable sources of information, sometimes in preference to doctors, patients were displeased at the variability of the provision of CMI leaflets from pharmacies. Despite satisfaction of most with their GPs, some patients complained that their GPs did not provide them with enough information. **5. Patients' expectations of their GPs** Patients wanted the GPs to be more attentive, providing more care and information.
Funding	The Authors acknowledge the doctors and patients who participated in ths study; General Practive Education and Training for funding one of the authors' posts. They also mention the Institute of General Practice Education, Whitlam Joint Replacement Centre, the Physiotherapy Department at Fairfield Hopstial, Arthritis Australia, Ms Vanessa Traynor, and the University of New South Wales Primary Care Research Capacity Building Initiative, but do not say whether they provided funding.
Limitations and applicability of evidence	Minor limitations due to relationship between researchers and participants not being fully discussed.

Study	**Miller 2016**[93]
Aim	To understand the experience of what is important to OA patients as they seek help for their symptoms
Population	People who self-reported as having OA and interacting with the healthcare system to manage their condition.
Setting	Participants were recruited from an arthritis public forum, from among those who had participated in other PaCER work, and via snowball links to acquaintances and friends. In the set phase, focus groups were held in two urban settings. The setting for the interviews and reflect stage focus groups is not reported.
Study design	The PaCER method, a peer-to-peer research method designed to create a robust collective patient voice while maximizing patient engagement throughout the research process. It uses an inductive process to come to an understanding of participants' experiences. There are three phases: ''set,'' ''collect,'' and ''reflect.'' In the set phase, participants become part of a co-design team where they clarify the scope and direction of the study and give advice on the data collection strategy. PaCER researchers then collect data (collect phase) from patients using focus groups, interviews, observation, or questionnaires. In the reflect phase, patients participate in another focus group where they come to a common understanding of the collect findings and make suggestions on future research directions and knowledge dissemination.
Methods and analysis	The set phase focus groups began with participants envisioning what a quality OA healthcare system would look like. Participants felt the general question encouraged them to think about their experience. They suggested the scope of the study include holistic and

Study	Miller 2016[93]
	efficient assessment, access to professionals with OA expertise, and reliable resources. Participants thought individual telephone interviews would give interviewees time for reflection and exploration of the issue. In the collect phase, nine interviewees considered what makes a quality care experience, how they dealt with OA when it first appeared, and how they learned about available support and made their choice. The interviews continued until no new concepts emerged. The interviews were analysed to create data categories, which were brough to the reflect focus groups.
Findings	**The right knowledge** The right knowledge goes beyond typical health literacy/self-help resources. Patients need detailed knowledge about how OA progresses, evidence-informed management strategies, and how to deal with changes in pain and mobility. This information needs to be specific and ‘‘comprehensive, no-nonsense. Patients also need to understand the likely progression and extent of their OA. They need specific information about the type of treatment that match the level of severity, and when they should return to an HCP. Currently, patients scout out their own information, and are in need of trustworthy information for a range of OA specific resources.
	The right professional support Access to people with professional OA expertise is an important component of quality care. Following diagnosis, family doctors may offer advice on pain management and prescriptions, but often offer little beyond that. The only other source of professional expertise available is orthopaedic surgeons, and sometimes physiotherapists, although this service required patients to pay. Therefore, most help comes from outside the healthcare system that patients have to pay for and requires time and energy to find. This impacts quality of care e.g., access issues. There is a need for more information about what health professionals can do for people with OA and what they cannot do. There are also concerns regarding continuity of care and reassessing services.
	The right professional relationship It is important that the relationship is a true partnership, which should revolve around individualized and evolving self-management plans, not standardized plans that are created by professionals and handed out to patients. While these plans need to be based on sound strategies, they should take into account personal circumstances, resources, and preferences. Choice is important, as is understanding the potential consequences of those choices. It is important that HCPs take time to listen and understand, and that there is continuity in order to build a relationship.
Funding	Funded by Canadian Institutes for Health Research (Planning Grant 20132PLH), funded through Priority Announcement Health Services and Policy Research), The Arthritis Society (Models of Care Catalyst Grant, Grant Number MOC-13-007), and Alberta Innovates- Health Solutions (Partnership for Research and Innovation in the Health System PRIHS Grant, Grant Number 201300472).
Limitations and applicability of evidence	Participants were recruited from arthritis forum, previous PaCER participants, snowball links. Biased to more motivated patients. Relationship between researchers and participants not being fully discussed. Furthermore, the findings are confusing – methods report 8 categories, and then results says there are 3 components which do not match up. The three components have been extracted. Minor limitations due to unclear relationship between researcher and participants.

Study	**Olsen 2017**[101]
Aim	To explore how people describe their experiences and outcome from participating in patient education and Basic Body Awareness Therapy (BBAT).
Population	People with primary hip osteoarthritis based on radiological and clinical findings in line with the American College of Rheumatology criteria for classification and reporting of hip osteoarthritis, and living within a traveling distance of one hour. People were excluded if they were not tolerating the movement therapy based on the person's perceived function; pregnancy (5-9th month); not understanding Norwegian. Participant characteristics: n=5; 2 females/3 males; Mean age (range): 67 (52-78) years; duration of pain: 8 months to 12 years.
Setting	People in Norway who had participated in a patient education and basic body awareness therapy program.
Study design	Qualitative semi-structured interview study methodologically anchored in a phenomenological philosophy.
Methods and analysis	Personal interviews using phenomenological philosophy. All data was transcribed verbatim by the first author and labelled with a constructed name for each person. All authors read the transcribed data and contributed to the analysis. The authors contributing to text analysis were physiotherapist and researchers with long clinical experience from the musculoskeletal, psychiatric, or rheumatologic field. None of them were involved in the interventions given, but two had previous experience working with BBAT and three had experience from qualitative research. Their preconceptions were influenced by theoretical knowledge about rehabilitation and experiences from treatment programs that focus on self-efficacy and health related quality of life. Being aware of this, authors paid particular attention to set those aside during the data analysis and be open to fresh perspectives of the studied phenomenon. Data from the first interview were analysed before conducting the follow-up interview, with the results influencing the questions asked in the second interview. After this, data from both interviews were analysed in one process by means of systemic text condensation, a thematic cross-case strategy suited for exploratory analysis (inspired by Giorgi's 4-step phenomenological analysis). In step one, all researchers read through the transcriptions repeatedly, searching for the main story and preliminary themes associated with the informant' experiences from participating in PE and BBAT groups. In step two, text units were identified and marked throughout the text, containing descriptions of single phenomena perceived as meaningful to the person. In step three, the units were coded, extracted from the text, and repeatedly reorganized in groups within each theme or in new emerging themes. In step four, data from the subcategories were interpreted according to the research question and synthesized to a structured presentation of essential patient experiences.
Findings	**Becoming motivated and involved** (this included two subthemes: expert advice, peer support through dialogue).
	Expert advice The information given at the sessions was perceived by people as important for understanding the form, location, and function of the hip joints. Previously it has been hard for them to visualise what was happening inside the joint and to interpret whether pain fluctuations were signs of increased joint damage or not. Most of the people described having had symptoms not only from the hip, but also from the lower back, shoulders, or neck. Hearing the physiotherapists explaining how movement training could help them take care of the whole body, including the hip joint, the people felt that their hope for improvement without surgery was supported.
	Peer support through dialog

Study	**Olsen 2017**[101]
	People experienced that participating in patient education followed by BBAT groups had changed the way they thought about hip osteoarthritis. Being in a group of peers and learning that others had similar complaints and functional problems, they started to define their present and future situation as less intimidating than before. Learning how the other group participants had found ways to handle daily life challenges, they were inspired not only to take a positive attitude towards coping with their disease, but also to support the others by sharing own experiences with them.
	Movement awareness learning (this included two subthemes: becoming aware of movement quality, experiencing own resources)
	Becoming aware of movement quality They had explored and become familiar with the inter-relationship between different regions in the body while moving, as well as how little energy was needed to perform movements. They described finding a stable balance and more adequate use of energy by searching alignment of the line of gravity and lowering the centre of gravity. Involving the toes and adjusting the step length when walking was experienced to give a better balance and more power in order to move forwards. People described moving with more ease when focusing on freedom in their breathing, identifying more healthy and functional ways to move.
	Experiencing own resources People regarded being aware of and respecting the body as a health promoting strategy, in contrast to pushing their body to perform. They generally described being more aware of themselves and their personal limits facing demands from by family members and other people, and they experienced less mental stress in relation to others. Taking better care of themselves, they experienced a growing sense of self-confidence. The change in attitude was described to help them support the body by avoiding strain and unnecessary effort in every-day activities at home or at work. They reported to use movement aspects such as rhythm, free breathing, and adjustment of energy as tools for responding adequately to bodily signals while moving. The experience of improved general functioning and well-being was also related to the ability to sleep comfortably, having less problems getting dressed and being able to walk longer distances than before. In situations where it was difficult to avoid over-exertion of the hip, the people still experienced episodes of pain and stiffness in the joint, but they found themselves enabled to identify and deal with such situations.
	Movement and disease in a long-term perspective (this included two subthemes: movement awareness practice and integration, thoughts about the future)
	Movement awareness practice and integration People stressed the importance of self-training in order to maintain and further improve their results in movement and functioning. Six months after completing BBAT groups, they described practicing movements several times weekly. They found support in a paper given by the therapist, showing pictures and text explaining the movement, and expressed giving particular attention to movements that they experienced useful based on their personal needs, or movements that were found to alleviate symptoms from the hip. People found it important not to provoke pain while practicing, but to search towards healthy movement functions and find softness in the movements.
	Thoughts about the future Despite experiencing general benefits from the interventions, one person said that they wanted replacement surgery due to persistent pain while walking. The other people described having pain after over-exertion, but mostly managing to handle pain in daily life. They

Study	**Olsen 2017**[101]
	regarded themselves enabled to interpret bodily signals and adjusting movements to their current needs. Still, they expressed being aware of the fact that osteoarthritis had damaged their hip irreversibly and that surgery could become necessary later in life.
Funding	The study received financial support from the Norwegian Fund for Post-graduate Training in Physiotherapy.
Limitations and applicability of evidence	During the study, it became clear that people found it difficult to recall contents of the information derived specifically from patient education since much or the same information was conveyed in the BBAT groups. They attempted to address the effect of the preconceptions of authors on data analysis and interpretation, but this is still a possibility. Minor limitations.

Study	**Parsons 2009**[105]
Aim	To explore the lived experiences of patients with severe osteoarthritis of the hip or knee joint while awaiting joint replacement surgery.
Population	Individuals attending the preoperative assessment unit who had a diagnosis of radiologically advanced osteoarthritis of the hip or knee joint and were awaiting primary total hip or knee replacement. People selected had not attended a formal education/information session from a healthcare professional regarding joint replacement or management of osteoarthritis. Participant characteristics: n=6; 3 females/3 males; Mean age (range): 69 (70-76) years; 5 married, 1 widowed; 1 employed full time, 1 employed part time, 4 retired; 3 scheduled for knee replacement, 3 scheduled for hip replacement.
Setting	People who had been referred to the National Health Service waiting list for a primary hip or knee replacement.
Study design	An exploratory qualitative approach using phenology.
Methods and analysis	An unstructured interview was considered to be the most appropriate method of collecting data in relation to the research question ‘What is it like to live with severe osteoarthritis of your hip/knee joint?’. The lack of structure was to allow the participant to lead the interview while sharing their thoughts, issues, and concerns. People were interviewed in their own homes. Each interview lasted between 35 and 50 minutes. Interviews were digitally recorded to allow for transcription of narrative verbatim. To ensure that veracity and rigour was applied throughout the process of data collection and analysis, Giorgi’s seven procedural steps were followed. The transcripts were read and re-read. The repeated listening to recordings allowed for previously un-noted features of the dialogue; moreover, pauses and expression of emotion could be noted within the context of the interview. In addition, interpretative ‘foot notes’ for the translation of meaning were provided when specific ‘Black Country’ language phases were used by the participants. Commonalities of themes were identified from the six transcripts. Peer validation and verification of data were performed by a researcher-practitioner with an orthopaedic nursing qualification and research experience. The next steps involved the identification of natural meaning units. From the central themes, it was then possible to identify a number of sub-themes or ‘focal meanings’. The experiences captured from each participant were interpreted and analysed by extracting sections of text relating to a particular theme from the main body of the transcript. The frequency of reference to each sub-theme by each participant was considered to be an important factor for the researcher to demonstrate. Focusing on a particular topic and repeating information often indicates that a particular subject is of significance to the participant or that they have a depth of experience concerning that specific topic.

Study	**Parsons 2009**[105]
Findings	**Living and coping with pain** Pain dominated the lives of people awaiting total joint replacement surgery. People shared their experiences of how pain affected them physically, psychologically, and socially. All people talked about their experience of living with pain, how pain disturbed their sleep pattern and how it affected and determined their lifestyle. People talked about the duration of their pain, location of pain, coping strategies, analgesia consumption and how their pain affected their state of mind. Pain was often accompanied by low mood and the feeling of 'being a burden', which impacted upon their quality of life. People described 'referred pain' to the opposing joint. This was often perceived to be confusing to the individual, as it led each to believe that there was also a problem with a second joint. All people made reference to their pain relief 'medication and subsequent side effects'. It emerged from the findings that individuals felt that there was no one to whom they could ask questions in relation to medications and their side effects. People expressed concerns regarding self-administration of analgesic medication. There was a pronounced lack of confidence in achieving relief from analgesic medication. The consensus of findings revealed a disparity between prescription of analgesia and concordance. All narratives referred to a reluctance to take prescribed analgesia (including 'trying not to become dependent on medication' and seeing that medication was 'bad for you').
	Not being able to walk and move around Immobility impacted considerably upon quality of life with a loss of independence experienced over a relatively short period of time. For those who were employed, continuity and routine were extremely difficult to maintain, and individuals experienced a high incidence of absenteeism owing to the inability to fulfil employment demands, or alternatively found themselves without any choice in seeking premature retirement. For those who were employed, lack of understanding on behalf of the employer in relation to the progressiveness of osteoarthritis was experienced. Absence from work due to uncontrolled symptoms and poor mobility was often unavoidable. People were reliant upon their spouse or other members of their families for assistance with activities that they were once able to do for themselves.
	Coping with everyday activities Maintaining daily personal hygiene was not considered to be difficult if the individual had a spouse whom they could depend upon for assistance. People experienced difficulty in tending to foot hygiene and dressing the lower half of the body. Individuals living alone sought advice from friends experiencing similar difficulties, hoping that they would share 'successful tips' on how to manage alone with dressing and hygiene. It was clear that advice was self-sought and not readily available. Personal safety was of prime concern to all participants. There was emphasis on the concerns of falling owing to the affected limb being prone to 'giving way'. This would often happen without any prior warning. Walking outdoors, crossing a road, accessing a flight of stairs, or attempting to ascend or descend a single step posed considerable concern to individuals. It was considered safer not to attempt these activities for fear of falling and sustaining a fracture. People experienced an increased sense of security and felt safer if they had a fit spouse who could accompany them outdoors, as they were often able to hold on to their arm while using a walking aid on the opposite side.

Study	Parsons 2009[105]
	How others see me Negative thoughts relating to personal body image was an important issue. There was an overwhelming sense of perceived negativity when resorting to using a walking stick in public. Many shared their experiences of people 'staring' at them while using a walking stick, which, in turn, would have a negative effect on personal confidence in their mobility outdoors. People also described the way they felt when people politely held doors open for them while they carried a walking aid: instead of feelings of gratitude, they were often left feeling inadequate and incapable of managing independently. In comparison, some experienced positive responses from members of the public, when seen using a walking stick.
	Help, advice, and support while awaiting surgery Advice an information pertaining to the proposed surgical procedure, health maintenance issues, exercise, use of walking aids, weight control and symptom control were limited and, in many instances, considered by the participants to be completely absent. There were no consistent healthcare professional-led education/information sessions in place by which individuals could receive information, guidance, advice, or support. In the event of an individual knowing someone who had undergone similar procedures, those individuals considered themselves at an advantage in being able to share experiences and ask for 'tips' in coping with various activities. The level and type of information received was down to luck, opportunity, and persistence. Support from family, friends and significant others who had undergone similar surgical procedures was regarded as invaluable in helping them to cope with the symptoms of the disease. From the point of referral to the waiting list, all participants expressed feelings of 'having no control over their lives', as they felt that they could be called at any time for their surgery, even though it was scheduled for four to six months later. Surgery was considered by participants to be the only solution to the pain. It was felt that there was no cure for the chronicity of the disease and then removal of the joint, with subsequent replacement, was the only way forward to improve quality of life. However, there was great reluctance and fear of being called in for surgery. There were also experiences of the negative impact of having severe osteoarthritis and having to put 'life on hold' because of future surgery. Holidays, family visits and large purchases were postponed until after surgery, as 'being called for surgery' dominated their thoughts.
	Effect upon family, friends, and helpers Family members, friends and carers were considered invaluable. However, people felt that they were a 'burden' on their loved ones owing to their dependency and constant reliance when attempting to perform activities of daily living. People talked about their frustrations in attempting to do things for themselves, only to be assisted without request by family members in a speedily manner. This action would leave the individual feeling demoralised and completely incapable. Individuals who felt that they had a purpose, such as shopping, housework, or employment, perceived themselves as having a positive psychological outlook, which allowed for a better coping mechanism. This was also supported by the expression of not 'giving in' to the disease, but to fight it and not allow it to 'rule one's lifestyle'. Intermittent periods of low mood would result from uncontrolled pain, immobility, and loss of independence, resulting in isolation from others.
Funding	The study was sponsored by the University of the West of England, Bristol, UK.

Study	Parsons 2009[105]
Limitations and applicability of evidence	The study focussed on a relatively small sample of people living with advanced osteoarthritis while awaiting total hip/knee replacement surgery. Therefore, it would not be considered appropriate to apply the findings of the study to individuals experiencing the early symptoms of the disease or, indeed, symptoms not assessed as requiring total joint replacement. The richness of the data is entirely dependent on the interviewer with the interviewer needing to know how much or how little to probe into the initial responses of the participants in order to gain a more detailed answer. Minor limitations.

Study	Pitt 2008[107]
Aim	To examine the barriers to, and drivers of, referral of patients with osteoarthritis to self-management programmes.
Population	A cohort of GPs in Victoria, Australia, who had experience managing people with osteoarthritis and had an opinion about self-management programmes. Participant characteristics: n=13; 5 females/8 males; mean age (range): 51 (35-68) years. 7 indicated they sometimes referred people with osteoarthritis to self-management programmes, 1 stated they rarely referred, the remaining 5 reported they never referred their patients with osteoarthritis to these programmes.
Setting	Recruited through metropolitan and rural Divisions of General Practice Victoria (Australia) by placing advertisements in member newsletters (hard copy and internet-based) and weekly faxes. GPs already participating in aligned research projects at the Monash University Department of General Practice were also invited to participate. The study was conducted as three focus groups attended by six, three and two GPs respectively. Two focus group sessions were attended by one GP each.
Study design	Focus group sessions conducted as semi-structured interviews using an interview schedule comprised of a series of open-ended questions. This was constructed by two researchers.
Methods and analysis	All interview sessions were conducted by one researcher for consistency and lasted approximately one hour. Sessions were audio-tapes and transcribed verbatim. Focus group interview sessions were conducted in a conversation-like manner using the interview schedule as a guide. In order to keep the discussion focused, self-management programmes were defined as programmes with a structured format and pre-set agenda aimed at promoting individuals' skills and confidence to self-manage their own disease. Key elements of programmes included: goal setting, coping strategies, sharing experiences, and undertaking activities that benefit the participant's health such as diet and exercise. Two researchers independently reviewed the transcripts and performed content analysis to identify circumstances and factors that would influence GP behaviour to refer, or not to refer, people to a self-management programme. Transcripts were reviewed and coded

Study	**Pitt 2008**[107]
	to theoretical domains considered relevant to understanding the behaviour of healthcare professionals. Specifically, enablers and barriers to referral identified from the transcripts were coded based on whether they related to GP knowledge, skills, professional role and identity, beliefs about capabilities, beliefs about consequences, motivation and goals, memory, attention and decision processes, environmental context and resources, social influences, emotion, behavioural regulation, and nature of the behaviours. Other themes that emerged from the data were iteratively identified, discussed, and coded for all the transcripts. These included patient factors and programme features. The coded transcripts were compared and any discrepancies in the analysis between the two researchers were identified and consensus reached through discussion. Where discrepancies were present consensus was reached upon further clarification of the theoretical domains. Facilitators for referral was matched to the GPs likelihood to refer people (see participant characteristics). Quotes representing typical views expressed by the GPs were extracted from the transcripts and are presented in the results to exemplify the themes identified.
Findings	Three categories of themes were identified: 1) factors associated with the GP; 2) factors associated with the person with osteoarthritis; 3) factors associated with self-management programmes
	Factors associated with the GP Consisted of the following subthemes: knowledge, beliefs about consequences, environmental context and resources, social influences, beliefs about capabilities, professional role, and behaviour regulation.
	Knowledge GPs who were less likely to refer, and some more likely to refer, demonstrated limited knowledge about the purpose and content of self-management programmes, including that they were limited to the provision of information or exercises. Several of the GPs less likely to refer indicated they did not know where to refer people in the local area. Only one GP was aware they could refer people to Arthritis Victoria. Several GPs who were less likely to refer perceived that their patients were not convinced of the value of the programme.
	Beliefs about consequences GPs who were more likely or less likely to refer identified both positive and negative beliefs about the consequences of referral, or involvement in programmes. Negative beliefs related to: losing control over the management of the patient; concern over encouragement of non-evidence-based alternative therapies; perception that the facilitators would espouse negative views about GPs; beliefs that people would either fail to attend, fail to change their behaviour, feel as if they did not fit in, become anxious in response to the information provided, or deteriorate with involvement in a self-management programme. Positive beliefs related to: patient access to relevant healthcare professionals (psychologists, occupational therapists); people becoming more informed on how to manage their condition and symptoms; people feeling more motivated and in control of their health; people likely to experience psychological benefits through sharing experiences and receiving support from other people; people benefiting from engaging in pleasant activities that take the focus off their condition.
	Environmental context and resources A few GPs, categorized as either more likely or less likely to refer, identified environmental factors that served as barriers to referral to self-management programmes. These included: 1) limited access to relevant self-management programmes in their local area; 2) a GP who was less likely to refer reported that access to other health services, such as physiotherapy, hydrotherapy and tai chi, prevented

Study	Pitt 2008[107]
	(or limited) the need for referral to self-management programmes because they perceived those services to be readily available and of immediate benefit to people with osteoarthritis; 3) factors associated with timing and purpose of patient consultations in general practice, such as lack of time in the consultation to discuss self-management options (with most consultations focussing on the person's presenting problem, typically a symptom flare, with less emphasis on longer term self-management); 4) financial incentives (could be a barrier or an enabler).
	Social influences One GP who was less likely to refer identified existing relationships with existing local healthcare providers, such as physiotherapists and osteopaths, as a potential barrier to referral. A few GPs more likely to refer identified social influences as enablers to referral, including when the person asked for additional help and when people reported back to the GP that they found participation in a self-management programme beneficial.
	Beliefs about capabilities GPs who were less likely to refer reported they felt confident in their capability to manage and address the needs of people presenting with osteoarthritis, and did not perceive a need for referral to self-management programmes. In contrast, several GPs who were more likely to refer indicated they would refer people to these programmes as an adjunct to GP care, particularly when they experienced difficulty managing the patient on their own and identified a need for a multidisciplinary approach.
	Professional role GPs who were either more likely or less likely to refer reported they perceived information provision about the person's condition as part of their professional role, and this constituted a barrier to referral if they perceived that information provision was the sole function of a self-management programme.
	Behaviour regulation One GP who was less likely to refer identified a lack of behavioural prompts in general practice for referral. GPs who were either more or less likely to refer identified strategies to increase the ease of referral as being necessary. Suggested strategies included electronic reminders, information available programmes for insertion in GP address books, provision of referral pads, and patient information leaflets for use in GP waiting areas. GPs who were more likely to refer, as well as GPs less likely to refer, also suggested it was important to receive feedback from self-management programme staff on the content covered and the progress of referred patients.
	Factors associated with the patient Consisted of the following subthemes: type of condition, type of patient.
	Type of condition A few GPs who were less likely to refer perceived that self-management programmes had less relevance to people suffering from osteoarthritis than to people with other conditions, such as diabetes, emphysema or rheumatoid arthritis. They perceived that osteoarthritis was a condition which provided less opportunity than the others to modify the underlying disease, and as such, that self-management has less of a role to play. One GP perceived that self-management programmes were not targeted to people with osteoarthritis. In contrast, people who were more likely to refer identified various circumstances in which they would refer people with

Study	**Pitt 2008**[107]
	osteoarthritis, including: people with chronic pain, patients with osteoarthritis affecting their lumbar spine, people who frequently presented with symptoms, people who considered their condition to be serious and difficult to manage.
	Type of patient GPs who were more likely to refer and GPs less likely to refer both identified characteristics associated with their patient that influenced their decision to refer or not to refer to self-management programmes. These included: whether their patients were ambulant and able to travel to the programme venue, patient age, patient motivation, whether the patient requested more information, the patient's availability of time, the degree of social isolation of the patient, the patient's physical activity level, their mood (e.g., anxious, depressed) and the patient's perception of their ability to cope with their condition.
	Factors associated with the programme GPs who were more likely or less likely to refer also identified factors associated with the actual self-management programmes that influenced their referral behaviour. Factors such as the location, cost of attendance, frequency and duration of the self-management programmes were identified. Also, familiarity with the programme, ease of referral for the GP, the length of any waiting time, the availability of public transport to facilitate attendance, the services offered, whether GPs had an opportunity to be involved in the programme, and the degree of tailoring of the programme to the needs of individual patients.
Funding	Funded as part of a Public Health Research Project grant funded by the Victorian Department of Human Services, Australia.
Limitations and applicability of evidence	The study reported that the sample size was small but noted that increasing the size was unlikely to yield any additional information. However, convenience sampling of participants in this study may limit the generalisability of results (for example: rural GPs may have additional barriers related to availability of resources than GPs within metropolitan regions). Only one rural area was targeted for recruitment and this region was relatively well resourced in terms of self-management programmes compared to other rural regions throughout Australia. The focus group approach may induce conformity of responses. However, the themes were consistent between different focus groups and the two individual interviews. Minor limitations due to unclear relationship between the researcher and participants.

Study	**Rosemann 2006**[112]
Aim	To identify health care needs of patients with OA and to reveal possible obstacles for improvements in primary care management of OA patients.
Population	General practitioners, practice nurses and patients with OA. Practice nurses' characteristics: n=20; 20 females; Age (mean) 29-56 (41.3); Years of working experience (mean) 13-35 (21.7); GP characteristics: n=20; 4 females/16 males; Age (mean) 33-57 (43.5); Years of working experience (mean) 8-19 (11.3); Patient characteristics: n=20; 12 females/8 males; Age (mean) 40-78 (56.2).

Study	**Rosemann 2006[112]**
Setting	Germany. Patients were interviewed at home. GPs and practice nurses were interviewed in their respective practices. Patients were selected at random from the GP's computer files by searching for patients with osteoarthritis.
Study design	Qualitative interview study.
Methods and analysis	Semi-structured interviews were carried out using a guide with open-ended questions. All interview guidelines were as similar as possible to allow comparisons across groups and followed the normal course of a consultation: diagnostic routines, information giving, prescribing, advices for a lifestyle change and referral. Due to the small number of non-surgical evidence based treatment options authors were especially interested what importance evidence based treatments have. In addition, the authors focused on the attitudes of patients, doctors, and assistants towards a larger involvement of the practice nurse in the care of patients suffering from OA. Interviews were transcribed and an initial categorising system was established based on the interview guidelines. The categorising system was consequently modified; subcategories were added after agreement had been reached among all four researchers. Numerous free categories were developed from the text, discussed, and adjusted in an iterative process so that they were as similar as possible in all three interviewed groups, as the objective was to emphasise the different perspectives of the groups regarding individual subject complexes. The codes were clearly defined and linked with representative examples from the original text.
Findings	**Diagnostic aspects – proceedings** GPs felt that diagnosing OA did not pose a major problem to them. Diagnosis is frequently based on an extensive anamnesis and an accurate examination. If there is uncertainty, an x-ray is performed to confirm OA. During OA, the situation is more difficult: it sometimes represents a challenge for GPs to distinguish between complaints resulting from the joint affection and complaints which are mainly related to depressed mood. Satisfaction among patients regarding the diagnostic procedure was high as they felt examination was extensive and accurate. Patients were considered to be well informed due to other sources of information such as print media and TV, which was confirmed by patients. There was no apparent lack or request for more information in terms of the cause and pathomorphology, however in terms of the prognosis, patients were very insecure. Patients were worried about pain and becoming disabled and felt that physicians did not spend time on their fears.
	Diagnostic aspects – problems Many GPs stated that they found it difficult to assess to what extent complaints originate from arthritis and what part of the complaints are due to concomitant depressive symptoms, particularly when there was insufficient radiographic evidence, and the physical examination gave no sign for an acute inflammation of the joint. Depression was also recognized as an important barrier to motivate patients to physical exercise. Patients regarded specialists as an additional source of information, but most of them mentioned that the GP took definitely more time for the anamnesis and was often more accurate than the specialist. GPs also had an ambivalent attitude towards specialist referrals. Referrals were sometimes used to escape from the psychological burden induced by the patient and the absence of treatment options. Most GPs stated to take as much time as possible and patients did not regard time limitation as a main problem.
	Treatment aspects – pharmacological treatment Treatments like massages, physiotherapy and manual therapy were prescribed less frequently. Some GPs complained that in consequence, OA treatment has mainly been reduced to prescribing pain medication. GPs stated that Paracetamol was not accepted

Study	**Rosemann 2006[112]**
	as a real pain reliever because it is known to most patients as medication for "headache" and available without prescription. GPs also argued that most patients have already taken this drug on their own by the time they visit their physician. Thus, NSAIDs are often prescribed as the main treatment. After the withdrawal of most COX-2-inhibitors, patients as well as doctors felt very uncertain what to consider as an appropriate pharmacological treatment, and both patients and GPs had ambivalent attitudes towards analgesics. Patients wait to take pain relief until they cannot take it any longer, rather than in advance. GPs aimed to ensure patients took medication correctly, which involved a balancing act of explanations for anticipated objections regarding treatment, legal requirements, and belittlement. Patients and GPs seem more focussed on side effects rather than possible effects of NSAIDs. GPs felt patients would reject opiates as these are seen as ‘heavy drugs’.
	Treatment aspects – advice giving and counselling GPs give advice and recommendations regarding behaviour interventions such as weight loss, but do not focus on increasing motivation, which was considered to have a low success rate. Patients also reported that their GP had tried to motivate them repeatedly and had explained the general effects of lack of exercise and overweight. However, concrete types of exercise or other possibilities were not mentioned, directions were mostly quite vague. Patients mentioned pain, lack of knowledge regarding respective offers, lack of mobility and a lack of motivation for reasons for not exercising. Indeed, most of the interviewed GPs stated that they did not inform patients about self-help groups or about offers on community level for instance. Reasons for this were a lack of information and frustration about the impact of this information, i.e., those that do give this information find that patients often find excuses for not participating in those services. On the other hand, patients welcomed basic information on self-help groups, but they were often unsure about possible benefits and also expressed their reservations.
	Suggestions concerning improvement of care GPs were convinced that a gate keeper role for GPs as in many other health care systems could reduce patients' pressure to refer to orthopaedics and decrease performed x-rays. Some GPs mentioned that better communication with specialists could increase efficacy of treatment, but no specific suggestions how to achieve this were made. Many GPs stated that the payment system must be changed in order to upgrade conservative treatments and conversation with the patient. Due to the insecurity regarding NSAIDS, some GPs also desired evidence based pharmacological recommendations. Involvement of practice nurses in lifestyle counselling and advising giving is seen as imaginable by GPs, although barriers were time and overload. Nurses agreed they needed better training. To receive information and advices from practices nurses – by printed information or lectures – was acceptable for most patients. But some of them indicated – as some GPs did – that they fear a worsening of the trustful doctor- patient-relationship if the nurse is involved in too many proceedings.
Funding	Study was part of the PRAXARTH project that aims to improve the quality of life of patients suffering from OA. The project is financed by the German Ministry of Education and Research (BMBF), grant-number 01GK0301.
Limitations and applicability of evidence	Minor limitations due to role of researcher not being addressed and ethical issues not being considered. May not be directly applicable as based in Germany where there are a high number of non-surgical orthopaedic physicians (as stated in paper).

Study	**Sanders 2004**[114]
Aim	To explore barriers to health-care utilization in respondents with moderate to severe hip/knee symptoms of pain and disability.
Population	People with moderate to severe pain and disability of the hip and/or knee. Characteristics: n=27; 10 male:17 female; median age: 74 years; 21 worse symptoms in the knee, 6 worse symptoms in the hip; 10 had both knee and hip symptoms; 13 married, 14 unmarried or widowed.
Setting	United Kingdom. People who responded to the Somerset and Avon Survey of Health (SASH) community-based survey.
Study design	Qualitative interviews after questionnaire surveys that identified individuals for the study who responded that they had been told by their doctor that they had either 'osteoarthritis' or 'arthritis' of the hip or knee. Sampling was purposive and theoretically driven.
Methods and analysis	Sampling was purposive and achieved using survey respondents. Sampling was completed in three rounds and after each round data was analysed so later interviews developed these analyses and allowed exploration of new issues arising (constant comparison technique).
Findings	**Perceptions of need and reluctance to seek treatment** Most had experienced the pain and disability of arthritis for one or more decades and tended to perceive their symptoms as being inevitable and associated with normal ageing. The predominance of this view of arthritis as a natural degenerative condition of older age made respondents pessimistic about formal care and this was a major factor in making them reluctant to seek care. Most relied on 'over-the-counter' medications, health food supplements, exercise, and application of heat or cold to treat their symptoms, although most conceded that, at best, these brought limited relief. Respondents were often reluctant to seek care for joint problems, even when their symptoms caused severe disruption to their lives. Several assumed they would not be considered as appropriate candidates for surgery because of their age and so had not even discussed the possibility of treatment with a doctor (four people mentioned how a doctor had discussed this as the reason why they couldn't have surgery). Some reluctance to seek treatment stemmed from perceptions of the risks and personal costs of surgery. Twelve respondents told stories about people they knew who had joint replacements, but because many reported poor outcomes, particularly from knee surgery, they were fearful, or at least uncertain about whether or not they should submit to having surgery themselves.
	Perceptions and experiences of primary care Respondents stated clearly that they did not want to 'bother' GPs with symptoms for which they considered there was no appropriate/acceptable treatment. For some, GPs seemed to reinforce the perception that nothing could be done. People may have been referred for arthroscopy, but neither experienced improvement or received any follow-up, and it would appear that they expected the GP to take the initiative. Several reported that GPs informed them that they were not suitable candidates for surgery.

Study	**Sanders 2004**[114]
	Experiences of secondary care The majority had been referred to a specialist at some stage. Fourteen had been seen by a rheumatologist or orthopaedic surgeon since the baseline study, but less than half had been offered surgery- four had received a total joint replacement, one was on the waiting list, and one had refused it. Two were told that total joint replacement would be inappropriate because they had additional problems with the spine. Two had been seen and then discharged from a specialist clinic several years earlier. Once respondents had actually seen a specialist, the majority seemed satisfied with their treatment. However, there were two who clearly felt that they needed total joint replacement, but believed that they had been stalled from having the surgery because the surgeon considered them to be 'too young' or 'too mobile'. These informants had no clear indication of how they might be reconsidered for surgery.
Funding	Funded by the NHS SW Research and Development Directorate and the MRC HSRC.
Limitations and applicability of evidence	No information about the population which received the survey (and so about the applicants – whether they were from a city/rural area etc.). Minor limitations due to unclear recruitment strategy and relationship between researcher and participants.

Study	**Spitaels 2017**[118]
Aim	To improve guideline adherence by understanding patients' perceived barriers and facilitators in current care.
Population	People with knee osteoarthritis (clinical and/or radiological diagnosis); age 40 years and older; no history of inflammatory arthritis; no previous knee surgery; no cognitive dysfunction that prevents participation in the study. Participant characteristics: n=11; 7 females/4 males; Mean age (range): 66.2 (40-90) years; 8 were retired; the participating patients were registered in 7 general practices in the Flemish-speaking region around the Belgium capital area.
Setting	People were recruited from 3 different settings in Belgium: from the interviewers' general practice population (n=5), the population from other GP practices in the same region (n=5), by an advertisement in the monthly magazine of the national federation for patients with rheumatic diseases (n=1).
Study design	Semi structured face-to-face interviews conducted with the patients. The duration varied from 28 to 88 minutes, with a median range of 52 minutes.
Methods and analysis	All interviews were performed by one investigator. Interviews were conducted until data saturation was reached. Data saturation was defined as the point when no new ideas emerged in 3 consecutive interviews. The questions in the script were based on the national set of quality indicators for knee osteoarthritis, including 21 measurable quality indicators divided over 4 care aspects: diagnosis, lifestyle and education, treatment, and follow-up. For the interview script, every quality indicator from the Belgian set was translated into a specific open-ended question. All interviews were audiotaped and transcribed verbatim. Two researchers independently reviewed all interview transcripts. Words of phrases representing the same concept were clustered into the 6 domains of the framework (characteristics of the guideline, the healthcare professional, the patient, the social environment, the health organization, the financial context). Subnodes were defined for every domain during the coding process, and new codes were defined for information that could

Study	**Spitaels 2017[118]**
	not be transcribed into the predetermined domains. Discrepancies were discussed with a third researcher until consensus was reached. Participants were not informed about the study results. Data was analysed using a software package (NVIVO 10).
Findings	38 barriers were identified falling into the six domains: guideline (recommendations not being adapted for practice setting; comorbidity intervenes with treatment options; age intervenes with treatment options), health care professional (poor communication with patient; limited time to provide information of disease process; limited time to inform patients about different treatment options; advice not in accordance with the guidelines; advice not in accordance with patients opinion; no recognition of the medical problem; not supportive in the treatment process; limited time to provide patient-tailored treatment options), patient (limited comprehension of the disease process; negative experiences with drugs; opinion not in accordance with recommendations; limited comprehension of treatment options; not a priority health issue; insist on unnecessary investigations; fear exercise could worsen pain; fear for surgery delays the help seeking process; fear to take medication; not motivated to change habits; lack of time to periodically visit professionals; limited stimulation by professionals in the self-management process; low confidence in health care professional or evidence-based medicine; unrealistic expectations about treatment options; physical complaints interfere with exercise program), social (source of false information about the disease process; fear for stigmatization when using aids and devices; lack of adjustments on the work floor; no tailored sport facilities available; negative influence on treatment options), organisation (limited communication between caretakers; organisation of health care with limited sessions for physical therapy and no obligation for referral; patients lack equipment to sustain treatment in their home setting; difficult to combine work and physical therapy; no transparent information available on the internet) and financial content (high cost for medication, aids and devices; no transparency about refund of care).
	Guideline level Participants noted that specific guidelines were difficult to apply. In particular advice to start or maintain physical activity that was difficult for patients (for example: comorbidity with cardiac or pneumological diseases interfered with sports activities). Several people also experienced their age as a limitation for surgery (for example, specialists being reluctant to perform knee joint replacement surgery for people younger than 50 years).
	Health care professional level Eight barriers were reported. Poor communication with the patient was the most described barrier. People experienced that they did not receive sufficient medical information about their disease process. The term osteoarthritis was not even mentioned by doctors in their medical reports. People were disappointed to learn that their doctors presented knee osteoarthritis as a normal aging phenomenon with limited treatment options. People concluded that healthcare professionals underestimated the physical complaints and were not supportive enough. The limited consultation time was a major concern because it interfered with this process and with providing patient tailored treatment. Older people in particular complained that the limited time was often spent on “more important” comorbidities. Finally, people mentioned they were referred to a physiotherapist to improve their general condition, but they received no specific training for their knee osteoarthritis.
	Patient level Fifteen barriers were reported. Most people had limited comprehension of risk factors for knee osteoarthritis and possible treatments. Therefore, their opinion and expectations were not always in accordance with guideline recommendations. For example, all interviewed patients expected radiological investigations to confirm their diagnosis, or they underestimated the importance of weight control or

Study	Spitaels 2017[118]
	physical activity in the treatment process. They often did not consider knee osteoarthritis a priority health problem but a part of normal aging or inherited process. Therefore, often significant time passed between the onset of symptoms and the first doctors' visit. In case of comorbidity, people even gave priority discussing other health problems with their physician. If the diagnosis was confirmed, medication and/or surgery were the only treatment options from the patients' perspective. Furthermore, they were not inclined to follow advice to engage in more physical activity. For people, it was sometimes difficult to interpret the priority of nonsurgical treatment options such as diet, orthopaedic aids and devices, physical activity, or medication. Negative experience with drugs was an important reason for people to discontinue their medication. Pain during physical therapy and insufficient improvement with physical therapy were other reasons to stop their treatment. All people mentioned fear as an important barrier in some part of their treatment process. Some people were reluctant to use analgesic medication. They were afraid of addiction, side effects, or interaction with other medication. They were afraid of addiction, side effects, or interaction with other medication. Fear of more pain or falling kept patients from starting physical activity. Some had lack of confidence in the health care professional. People sometimes did not have enough faith in evidence-based medicine: proven or not by science, they wanted to experience themselves if medication worked or not. Thus, patients indicated "not providing alternative treatment options" as a reason to stop their treatment and seek alternative medical care. Lack of support by health care professionals to keep them motivated was repeatedly mentioned as a reason to discontinue physical activities.
	Social environment Patients reported 5 barriers. People attached great importance to information from their social environment although this information was not always based on scientific evidence. Fear for surgical experience or influence from people in the patients' environment. Moreover, orthopaedic aids and devices were seen as a form of stigmatization by almost all people. People active in the labour market specifically mentioned lack of acknowledgement. They complained that employers were not inclined to provide alternative work, or a workload adapted to their physical conditions.
	Organisation level Patients reported 5 barriers. Lack of communication between healthcare professionals could delay the treatment process and confused people in choosing their follow-up. In Belgium, people have the opportunity to make an appointment with their specialist without referral from their GP. They often did not know whom to consult and whether to choose for an orthopaedist or rheumatologist. Second, the number of reimbursed sessions of physical therapy is limited in Belgium. This was a barrier to continue physical therapy. People also reported it was difficult to persevere the exercise program, prescribed by their physiotherapist, because they did not have the same equipment at home to insist these exercises. Perseverance of their exercise program was especially difficult for people who combine work with physical therapy after working hours. For some, this was the reason to stop physical therapy. Finally, people indicated that they searched the internet for reliable information about diagnostic and therapeutic options for knee osteoarthritis, but were not able to find clear and transparent information.
	Financial level Patients reported 2 barriers. High cost was a common problem from: certain medication not being refunded, physical therapy and orthopaedic aids being expensive, modifications in people's homes (such as a stair lift) came at their own expenses. Moreover, many people discovered too late in their treatment process whether certain costs were refunded or not. This lack of transparency led to interruption of the treatment process.

Study	**Spitaels 2017[118]**
	20 facilitators were also identified within five of the six domains: guideline (tailored treatment options available in case of comorbidity), health care professional (good communication with patients; patient-tailored information; confidence in health care professional; supportive for patients in the treatment process; continuity of care), patient (self-management capacities; motivated and positive attitude; realistic expectations about treatment options; confidence in professional; positive experience with treatment; sufficient knowledge about disease process; hope for improvement (after operation); agreement with professional about treatment modalities), social (source of reliable information; positive empowerment from environment; practical support in case of disability), social (source of reliable information, positive empowerment from environment, practical support in case of disability) and organisation (organisation of collective treatment opportunities like sports clubs; accessible health care and good information about aids and devices; providing correct information through public channels, like the internet)
Funding	Not reported. It says the data were part of the coauthors' master's thesis and the authors report no conflict of interest.
Limitations and applicability of evidence	The study notes that there were limitations in the recruitment of patients and the potential bias by using semi structured interviews. People were recruited from 7 general practices and not all eligible patients were able or willing to participate. Therefore, answers could be biased. Interpretation bias may be present, but interviews were completed until data saturation and transcripts were analysed by 2 reviewers. The study is small and does not represent statistical generalisability. Specifically looks at applicability to a Belgium guideline. However, does have information about information availability. Some participants were the interviewers' general practice patients (the interviewer was a medical student in postgraduate training for general practitioner) and so this could have influenced the answers being given. Minor limitations due to relationship between researcher and participants.

Study	**Stone 2017[119]**
Aim	To investigate the potential facilitators and barriers to physical activity for adults with osteoarthritis.
Population	People diagnosed with osteoarthritis who were: currently diagnosed with arthritis by a rheumatologist; able to speak and understand English; at least 30 years of age; actively seeking medical treatment for their arthritis; not currently enrolled in a regular physiotherapy/physical activity program. Participant characteristics: n=15; 9 females/6 males; mean age (SD): 54.6 (13.6) years; mean length of osteoarthritis diagnosis (SD): 5.0 (3.5) years.
Setting	People from the office of a general practitioner-primary care physician in Toronto, Canada. The physician's office was utilized due to their focus on mid-older adults. Advertisement was achieved through posters placed in the medical office of the physician. Snowball sampling was utilized (participants recommending other people for participation). Interviews were conducted in a person's home.
Study design	Semi-structured interviews.
Methods and analysis	Interviews were conducted over 60-90 minutes by the primary researcher and focussed on three topics: life experience with physical activity and exercise; managing osteoarthritis within physical, psychological, and social contexts; and experiences with osteoarthritis

Study	**Stone 2017**[119]
	related recommendations, prescriptions, and management strategies. Interviews were digitally recorded and transcribed verbatim. The interview process was repeated until saturation was met. The interviews were examined using interpretational analysis. This involved coding and categorization of recurring concepts and forming overarching themes of pertaining to verbal trends in the data. Codes were reviewed and refined three times using the constant comparative method between transcripts. Analysis also followed a deductive thematic constructionist approach for identifying, analysing, and reporting patterns from the participants' experiences that reflect discourses commonly operating within society.
Findings	**Barriers**
	Pain All people discussed experiencing intense physical pain on a daily basis, and that it negatively affected their desire to be active. Multiple people experienced a constant state of pain, in which any movement, let alone "stressful" exercise, was overwhelming. Other functional difficulties included pain during walking, showering, and bending (described as "chores"). In addition, people reported fatiguing rapidly, which made considering physical activity more of a challenge. Some people explained how this caused them to feel "broken" and often motivated them in avoiding social interactions that involved some sort of physical activity. Low levels of self-efficacy demotivated people from physical activity as they did not believe they could successfully perform a task without exacerbating their current pain levels. In addition, people expressed fear of experiencing pain after exercise that they were determined to avoid (which provided a logical rationale for avoiding activity).
	Psychological distress People expressed depressing thoughts, referring to osteoarthritis as "mentally agonizing". Many felt betrayed by their bodies and felt helpless regarding their functional limitations. Experiences showed that osteoarthritis-related pain can lead to disabling thoughts, which can be the precursors for adopting passive coping and learned helplessness. Participants became visibly uncomfortable and hesitant toward discussing osteoarthritis-related psychological distress, which could lead to a maladaptive suppression of psychiatric distress which increases the general distress level and demotivates physical activity.
	Lack of medical support People were knowledgeable of the benefits that physical activity can have for the general population; however, many were unaware of specific osteoarthritis-related benefits and unsure of what activities would provide optimal self-management. Furthermore, people noted that physicians often provided them with counter advice or did not offer any recommendations. This created further confusion about physical activity and the potential benefits for osteoarthritis. Many people held the perspective of being inadequately education about exercise by their health care providers, and rarely having an open dialogue regarding prescribing exercise and/or physiotherapies. This lack of communication regarding exercise and physical activity was compounded with a participant perspective of having inadequate knowledge and communication regarding their osteoarthritis diagnosis in general. This increased confusion often related to their disease and alternative treatment options.
	Facilitators
	Pain relief

Study	**Stone 2017[119]**
	When people were able to effectively moderate their pain, they were motivated toward contemplating physical activity adoption. People commonly found heat and hydrotherapy helpful for pain management. People also noted positive experiences with physiotherapy inspired them toward physical activity.
	Medical support All people spoke about the instrumental role of health care providers in influencing and encouraging physical activity. People expressed that if their physician advocated exercise, they would be eager to adopt it. In addition, people desired more knowledge and specific guidance relating to physical activity indicating that if they were told what to do and how to do it by their doctor then they would do it.
	Social support People expressed feeling facilitated towards physical activity adoption with high levels of social support stemming from their family and friends. People explained that seemingly "radical" treatments became viable options within the presence of unconditional support. Spouses and children were cited as being the most important family members in facilitating physical activity adoption. People also mentioned that community-based support facilitated the adoption of physical activity.
Funding	The Authors received no financial support for the research, authorship, and/or publication of the study.
Limitations and applicability of evidence	The methods used could not control for potential "interviewer effect" and/or "demand characteristics" in which participants' willingness to divulge may be based upon how their personally perceive the interviewer and provide answers perceived to be desirable based on the interviews' line of questioning. All researchers involved came from the aging- and kinesiology-focused research domains and so could have been influenced by previous research in the field. Generalisability may be limited due to the use of a convenience sample from a private medical office that only comprised of people with osteoarthritis with a relatively shorter mean during of osteoarthritis (due to the inclusion of an under-researched "younger adult" population with osteoarthritis). Moderate limitations due to unclear relationship between researcher and participants and inappropriate requitement strategy.

Study	**Suarez-Almazor 2010[120]**
Aim	To conduct a qualitative analysis of decision-making factors influencing preferences for total knee arthroplasty in patients with knee osteoarthritis.
Population	A physician diagnosis of knee osteoarthritis; no previous knee replacement; race (African American and non-Hispanic, Hispanic, or white and non-Hispanic); age (55 to 80 years); adequate cognitive status as determined by the interviewer; and English language proficiency. Participant characteristics: n=37; 23 females/14 males; 13 white, 15 African-American, 9 Hispanic; Mean age: 64 years; mean disease duration: 7 years.
Setting	Six focus groups across a range of diverse ethnic backgrounds from people attending primary care clinics at the same outpatient institution, Kelsey-Seybold, Houston, TX. Two groups were conducted with African-Americans, two groups with Hispanics, and two groups with whites.

Study	Suarez-Almazor 2010[120]
Study design	Focus groups with semi-structured group discussions.
Methods and analysis	Focus groups were conducted and transcripts were recorded from each group. Thematic analysis was conducted, using a grounded theory approach. The transcripts were reviewed for accuracy by the research team and subsequently entered into Atlas.ti, a qualitative software program that facilitates the investigators' ability to organise, code and soft patients' verbatim responses. A team of at least two coders was assigned to independently review each transcript. Each coding team discussed their assigned transcripts on a line-by-line basis. The research team as a whole agreed upon definitions of emergent themes, which were refined as each subsequent transcript was reviewed. Themes were then clustered in order to recognize patterns within the data.
Findings	**Sources of information** (how or from whom patients receive their information about knee osteoarthritis; includes physicians, others, media, and Internet) Primary care physicians were the most common source of professional medical information.
	Expectations (refers to patients' anticipated outcomes and their importance in making the decision to undergo surgery) Including those gained from previous experiences of surgery.
	Readiness (patients' subjective perception about how ready they may be for surgery; perception that they reach a state where the best option might be).
	Fears (unpleasant emotions and apprehensions that patients have regarding knee surgery) Several fears were identified: fear of a lengthy recovery, fear from complications and from anaesthesia, concerns about longevity of prosthesis, and worries about how the surgery may affect their other health problems.
	Expenses/Willingness to Pay (refers to what patients would/could spend on knee surgery) Financial issues were a concern for most participants.
	Good Experiences (positive experiences that may impact patient expectations for knee surgery. Can personal experiences, such as previous surgeries, or knowledge of surgical experiences in others)
	Trust in Doctors (perception that the doctor is qualified and will act in their best interest; includes physician's judgement and experience)
	Bad experiences (negative experiences that may affect patient expectations for knee surgery. Can be personal experiences, such as previous surgeries or knowledge of surgical experiences in others)
	Concern, Longevity of Prosthesis (length of time the prosthesis will last)
	New technology (patients' comments about expectations for new technology for the treatment of knee arthritis; improved procedures)
	Scepticism (attitude of doubt, or a disposition to incredulity toward healthcare in general or toward knee surgery specifically)
	Surgery as last resort (patients' expressed desire for other options instead of knee surgery; surgery as last option after other treatments)

Study	**Suarez-Almazor 2010**[120]
	Concern, General health (concerns about other medical conditions, which may have an impact on the patients' outcomes during and/or after surgery)
	Desire for surgery information (desire for information relating to treatment and surgery procedures) Many people expressed additional information about the surgery and what to expect, with a lack of knowledge hindering their decision making.
	Second opinion (advice from another physician; includes patients' struggles with different information)
	Decision conflict (patient and relative or family disagree about the need or readiness for surgery)
Funding	Based on work supported by the Agency for Healthcare Research and Quality (AHRQ) and the NIH Office of Research on Minority Health through the EXCEED program (PO1HS10876).
Limitations and applicability of evidence	The study notes that this may be limited in its generalisability. Findings relating to paying is specific to USA, not relevant to the UK. All the people participating in focus groups were drawn from a single outpatient institution and the sample size was relatively small. It is not possible to assume that the decision-making factors identified by the patients in this study can be generalized to the population of people with osteoarthritis who are considering total knee arthroplasty at large. Minor limitations due to unclear relationship between researcher and participants and unclear if ethical issues considered.

Study	**Thomas 2013**[126]
Aim	To examine the experiences of primary care consultation among older adults with symptomatic foot osteoarthritis.
Population	Older adults with symptomatic foot osteoarthritis. Symptomatic foot OA was defined as having foot pain in the preceding 4 weeks, shaded on a foot manikin. Characteristics: n=11; 6 females/5 males; Age 56-80 years.
Setting	The interviews were conducted in the participants' homes. Participants were purposively sampled from 3 general practices in North Staffordshire. Participants had taken part in a previous cohort study (Clinical Assessment Study of the Foot).
Study design	Qualitative study.
Methods and analysis	Semi-structured interviews were undertaken using a topic guide structured around key questions and possible prompts concerning the nature of the problem in the context of the individuals' broader health, the decision to seek help for the foot problem and the pattern of help seeking, and their health care experiences. The topic guide was developed and refined during 4 pre-study pilot interviews. The interviews lasted between 30 and 59 minutes. For data analysis, the interviews were audio recorded, transcribed verbatim into written format, and anonymized with pseudonyms. The transcripts were analysed using an interpretative phenomenological analysis, broadly set within the framework detailed by Smith et al.

Study	Thomas 2013[126]
Findings	**Day-to-day impact and managing symptoms** Mobility is restricted or affected in all participants, which impacted work, social lives, and everyday responsibilities. It also impacted self-image and self-confidence for those who found footwear and appearance important. Attempts to self-manage painful foot symptoms were often described in conjunction with other health concerns such as pain at other joint sites and comorbid conditions, with patients seeing them as connected. These other health concerns may take precedence in terms of the decisions made to consult a GP.
	Searching for explanations Participants wanted an explanation for increasing pain and reassurance regarding the cause of pain, especially when there was increased intensity or frequency of abnormal symptoms. Participants predominately saw their GP, despite additional health care options being available. There was a lack of knowledge regarding other options, and some perceived the view of the GP to be final.
	Consulting and meeting needs Although they consulted their GPs to enable better management of symptoms and their consequences, the participants often perceived being given limited information and brief assessments as not being taken seriously. A lack of visual change in appearance, the perceived brevity of the GP's assessment, and the lack of post examination advice left some participants feeling at times that their concerns were invalid. There also appeared to be a predominant emphasis on symptom management with analgesics, which was unwelcome. Although the majority of participants described negative consultation experiences, 5 participants talked about re-consulting their GP in the future. A fear of deterioration, hope for the advent of new ideas and treatment, and lack of perceived options other than the GP for intervention emerged as triggers to re-consultation.
Funding	Supported by Arthritis Research UK (grant 18174).
Limitations and applicability of evidence	Moderate limitations due relationship of researcher being unclear, and data analysis methods (performed by main author and audited by a second). Relevant to UK practice, specifically for OA of the foot.

Study	Thorstensson 2006[127]
Aim	To describe conceptions, as registered by a semi-structured interview, of exercise as treatment among sixteen middle-aged people with moderate to severe knee osteoarthritis.
Population	People giving informed consent with symptomatic and radiographic knee osteoarthritis (Kellgren and Lawrence grade 3 or more, i.e., definitive osteophytes and joint space narrowing), were interviewed. The interviewer was familiar with the research method and interview technique.

Study	**Thorstensson 2006**[127]
	Participant characteristics: n=16; 6 females/10 males; Mean age (range): 53 (36-64) years; mean disease duration (range): 9 (0.25-30) years.
Setting	Individual interviews conducted in Sweden at a place chosen by the informants, either in their homes (n=9), at their workplace (n=1), at the interviewers' home (n=2) or at Spenshult hospital (n=4).
Study design	Descriptive qualitative study with a phenomenographic approach.
Methods and analysis	Individual interviews were taken place. The interview was based on six questions, but were left open-ended to allow the individual to elaborate. The transcripts were approached using a phenomenographic approach conducted in four steps: the transcribed interviews were carefully read while listening to the tape recording; statements were identified, which corresponded to the aim of the study; statements were assigned to content-related categories (conceptions); similarities and differences between conceptions were observed, and conceptions that had the same theme were grouped together and further assigned to a more general category (a descriptive category). The final descriptive categories consisted of 2-5 conceptions, which were illustrated with carefully selected quotations from the interview statements. Saturation was achieved after 6 interviews. During the process, an experienced researcher, who possess extensive knowledge of the research method, served as a co-assessor in all steps to assure reliability of the results.
Findings	**To gain health** All informants were well aware of the positive effects of exercise on health. The thoughts about benefits from exercise on knee osteoarthritis were, however, divergent. Some reported increased pain.
	To experience coherence Statements about connecting knowledge about osteoarthritis with knowledge and experiences of exercise. The informants expressed satisfaction and were convinced of the effectiveness of exercise.
	To experience well-being In this conception he informants described experiences of mental and physical relaxation, satisfaction and wellbeing connected to the moments immediately following the exercise sessions.
	To be in control This conception described the informants' experiences of how exercise could improve their ability to handle their situation, and cope with the problems related to knee osteoarthritis.
	To experience improved physical functioning This conception described thoughts about regaining functional performance or performing daily recreational activities more easily after the exercise intervention.
	To experience symptom relief This conception contained experiences of the effects of exercise on pain and other symptoms. Statements ranged from total pain relief to a worsening of symptoms.
	To become motivated

Study	Thorstensson 2006[127]
	Some people felt no need to exercise, others were planning to start but experienced several obstacles and some were exercising at present.
	To experience inspiration This conception was about the wish to be active. The statements ranged from a desire to exercise regularly to having no motivation to exercise at all.
	To be prepared to persevere This conception described the experience of exercising despite pain and discomfort, because of the known benefits.
	To experience the need to exercise In this conception, the informants described their need to exercise. The statements ranged from conceptions about the importance of exercise in order to maintain physical functioning, to the fact that daily living demands movement.
	To experience the need for support All people expressed a desire for advice and guidance, but in different ways, to exercise.
	To have structure This conception contained statements about accessibility as a prerequisite for exercise, and the importance of quality of exercise, concerning both purpose with and type of exercise.
	To receive guidance This conception concerned the perceived need for moral support, encouragement, and instructions on how to exercise. The statements were about compliance and the anxiety of doing something wrong.
	To devote time This conception including different aspects of time as essential for the effectiveness of the exercise. The statements concerned time as the most appropriate time point during disease course when first starting to exercise, and having adequate time to exercise.
	To experience resistance The participants had many doubts and concerns about exercise as a source of treatment, even though they all believe that exercise is good for one's health. All people in the study experienced deprecation and/or hesitation about the benefits versus harm from exercise on knee osteoarthritis.
	To hesitate This conception contained doubts about the benefits of exercise. Experiencing pain while exercising made it difficult to decide whether it was beneficial or counterproductive.
	To deprecate This conception described the belief that exercise could cause harm or be unnecessary in that the informants considered other treatments to be more effective.

Study	**Thorstensson 2006**[127]
Funding	Grants were received from the Swedish Rheumatism Association in Stockholm, the Swedish Rheumatism Association in Gothenburg, the Department of Research and Development at Spenshut Hospital for Rheumatic Diseases, Halmstad, Sweden.
Limitations and applicability of evidence	The number of participants could be considered to be small. It can be argued that the researcher could have influenced both the informants’ statements and the interpretation of the answers with people being less likely to reveal negative opinions. The study states that all people gave at least some sort of negative opinion (but this bias may still have an effect). Moderate limitations due to unclear statement of findings and recruitment strategies.

Appendix E – Excluded studies

Table 17: Studies excluded from the qualitative review

Reference	Reason for exclusion
Agrawal 2012[1]	Incorrect population: not osteoarthritis
Al-Khlaifat 2020[2]	Not relevant: knowledge of management options to relieve symptoms in patients in the middle east
Anthierens 2017[6]	Not relevant: talks about information provision but in the context of academic detailers providing GPs with information
Arslan 2021[7]	Incorrect study design: systematic review of quality indicators
Baird 2000[9]	Not relevant: about the experience of living and dealing with OA
Barker 2014[10]	Incorrect population: not specifically osteoarthritis, and not all had been diagnosed
Bayliss 2008[13]	Incorrect population and not relevant: not necessarily specific to OA, only one relevant theme
Berkovic 2019[14]	Not relevant: about the experience of young people with OA in the workplace
Booker 2021[15]	Incorrect study design: survey and interviews, which were not reported separately
Booker 2021[16]	Incorrect study design: review of qualitative and quantitative studies
Bowden 2021[17]	Incorrect study design
Brembo 2020[19]	Not relevant: themes not relevant to the review
Bunzli 2021[21]	Incorrect study design
Carpenter 2015[24]	Incorrect study design
Carr 2017[25]	Not relevant: only to do with designing of a 'user interface'
Chabaud 2018[26]	Not relevant: semi-structured interviews were uninformative, does not report themes.
Che Hasan 2020[28]	Not relevant: specific to one programme
Christiansen 2020[30]	Not relevant: about facilitators and barriers to physical therapy
Christiansen 2020[31]	Not relevant: themes not relevant to the review
Chou 2018[29]	Incorrect study design
Cuperus 2013[34]	Not relevant: talks about information, but only in relation to the booklet
Darlow 2018[36]	Not relevant: themes not relevant to review
Darlow 2020[35]	Not relevant: themes not relevant to review
Dragoi 2013[39]	Incorrect study design: survey
du Long 2016[40]	Incorrect study design: survey
Egerton 2021[41]	Incorrect study design: survey and interviews, which were not reported separately
Fedutes 2004[44]	Incorrect study design: survey
Frankel 2016[45]	Not relevant: Surgeons' decision-making for giving patient total joint arthroplasty
French 2015[46]	Incorrect study design: Delphi survey
Fujita 2006[47]	Not relevant: Experiences before and after hip arthroplasty
Gignac 2006[48]	Not relevant: is about signs and symptoms of OA rather than information
Grime 2014[50]	Incorrect study design: summary of qualitative research

Reference	Reason for exclusion
Gustaffson 2007[51]	Not relevant: experiences in perioperative period in replacement surgery
Hall 2005[52]	Incorrect study design: abstract only, does not seem to be a qualitative study
Hampson 1993[54]	Not relevant: personal models of OA
Hehl 2014[55]	Not relevant: reports strategies of communication accommodation rather than themes
Hofstede 2016[58]	Incorrect study design: Rather than themes, the study has a list of survey items and ratings from participants regarding importance rather than themes.
Holden 2019[59]	Not relevant: approaches to analgesic use
Hurley 2018[61]	Not relevant and incorrect study design- about exercise interventions rather than general OA treatment/diagnosis process. Mixed methods study design.
Jeon 2019[63]	Not relevant: specific to the website rather than general experience
Jinks 2007[64]	Incorrect population: unclear if participants have OA
Johansson 2014[65]	Incorrect study design - no themes reported, quantitative data only from survey responses
Kanavaki 2017[67]	Review which only briefly mentions information
Kanavaki 2016[68]	Incorrect study design: systematic review protocol
Larsson 2019[71]	Not relevant: only relates to the specific patient education intervention
Lavender 2021[72]	Not relevant: challenges of living with OA and explore how a peer mentorship intervention can support these challenges
Lawford 2021[73]	Not relevant: themes not relevant to the review
Lawford 2020[75]	Not relevant: themes not relevant to the review
Lawford 2019[74]	Not relevant: only relates to specific intervention
Ledingham 2020[76]	Not relevant: exercise adherence and participants beliefs
Lenhard 2020[77]	Not relevant: only one theme relating to patient specific factors regarding intra-articular injections
Lin 2019[78]	Not relevant: talks about info but only in relation to the specific intervention
Liu 2007[80]	Incorrect study design: survey
Lopez-Olivo 2022[81]	Incorrect population: Includes people with OA, osteoarthritis and rheumatoid arthritis
MacFarlane 2020[82]	Not relevant: physician-perceived benefits and drawbacks of offering intra-articular injections.
Maly 2009[84]	Not relevant: about how participants interpret their symptoms to recognise knee OA
Manias 2007[86]	Incorrect population and not relevant: includes people who may not have had osteoarthritis and talks about information but only with regards to medication.
Milder 2011[92]	Not relevant: no relevant themes. Study is about how patients make decisions about analgesics.
Miller 2020[93]	Not relevant: barriers and facilitators to OA care
Moe 2011[94]	Focus on programme design. No further information regarding themes
Mora 2012[95]	Incorrect study design: not qualitative
Morden 2014[96]	Not relevant: most themes talk about information but only in terms of the specific intervention that had been developed as part of the study
Mrklas 2020[97]	Not relevant: themes not relevant to the review

Reference	Reason for exclusion
Nelligan 2020[98]	Not relevant: themes not relevant to the review. Study about self-directed eHealth intervention
Nilsing Strid 2020[99]	Not relevant: varying needs for communication about sexual health
Ozkan 2021[102]	Incorrect study design: survey
Panter 2021[103]	Incorrect study design: survey
Park 2020[105]	Not relevant: barriers and facilitators to physical activity
Pellinen 2016[106]	Incorrect study design: not qualitative
Porcheret 2013[108]	Incorrect study design
Power 2008[109]	Not relevant: not about information
Radwin 2005[110]	Incorrect study design and incorrect population: abstract only and does not specify OA, just arthritis.
Rao 1998[111]	Incorrect population: people with osteoarthritis and rheumatoid arthritis. The majority of groups had RA and OA results generally not reported separately.
Ryan 2013[113]	Incorrect population: only 5 of the 13 patients have osteoarthritis, the other 8 have RA
Saroop 2001[115]	Incorrect study design: no qualitative data
Swardh 2021[121]	Not relevant: themes not relevant to the review
Tallon 2000 [122]	Not relevant: not about information
Tanimura 2011[123]	Study not available
Teo 2020[125]	Not relevant: experiences of physiotherapists
Teo 2021[124]	Not relevant: experiences of people having physiotherapy
Tiffany 2018[79]	Not relevant: specifically about patient reported outcome measures
Traumer 2018[128]	Not relevant: motives of undergoing total knee replacement
Turner 2007[130]	About knowledge of OA (and diagnosis) rather than information
Van de Velde 2018[129]	Not relevant: only related to a specific intervention
Veale 2008[130]	Incorrect study design and incorrect population - no qualitative themes and does not specify OA
Victor 2004[131]	Incorrect study design: mixed methods but mostly quantitative, no themes
Vina 2019[132]	Incorrect study design and not relevant: survey of ethnic differences in the use of exercise
Wallis 2019[135]	Incorrect study design: systematic review with no relevant themes
Wallis 2020[133]	Not relevant: barriers and facilitators for referral to a specific programme in Denmark
Wallis 2021[134]	Not relevant: themes not relevant to the review
Washington 2015[136]	Incorrect study design and not relevant: survey about decision aids
Webber 2019[137]	Not relevant: knowledge gap but in relation to physical activity and sedentary lifestyle
Willis 2013[140]	Incorrect population: unclear if the population is OA specifically.
Yilmaz 2005[139]	Incorrect study design: no themes reported
Zornow 1973[143]	Incorrect study design: survey

Table 18: Studies identified but not extracted due to saturation

Reference	Topic
Zaidi 2013[142]	Information sources for deciding on surgery

Reference	Topic
O'Brien 2019[100]	Patient factors for deciding on surgery
Smith 2019[116]	Information for deciding on surgery

Appendix F – Research recommendations – full details

F.1.1 What information on osteoarthritis, including the management of flare-ups, do people with osteoarthritis, their family and carers need after diagnosis?

F.1.2 What information do people with osteoarthritis from different ethnic and socio-economic groups and those with learning disability, health literacy issues and severe mental illness (and their family and carers) need?

Why this is important

There was little evidence on what information patients wanted after diagnosis, in particular information on managing flare-ups. Therefore more research is required regarding what to inform the patient in order that they can self-manage. Furthermore, there was no evidence which looked at the needs for information provision from different ethnic and socio-economic groups and those with learning disability, health literacy issues and severe mental illness and so this needs further exploration.

F.1.3 Rationale for research recommendations

Importance to 'patients' or the population	Ensuring patients get reliable information would help them to come to terms with the diagnosis and know more about osteoarthritis and how to self-manage it.
Relevance to NICE guidance	There was some evidence of the information patients needed but there was not a lot of evidence specifically after diagnosis; or what information was required for managing flare-ups.
Relevance to the NHS	Evidence on information required by families and carers could significantly reduce the support that patients require from NHS healthcare practitioners, reducing the burden on service delivery.
National priorities	None
Current evidence base	The evidence base found that patients wanted more reliable sources of information, so that they can adequately self-manage.
Equality considerations	Special consideration should be given to people with osteoarthritis from different ethnic and socio-economic groups; those with learning disabilities; health literacy issues; and severe mental illness.

F.1.4 Modified PICO table: What information on osteoarthritis, including the management of flare-ups, do people with osteoarthritis, their family and carers need after diagnosis?

Population	Adults (age ≥16 years) with osteoarthritis affecting any joint and their family and carers.
Intervention	This would be a qualitative review, therefore there would not be any specific interventions. However, information would be sort relating to people's experience of flares.
Comparator	N/A

Outcome	Qualitative in-depth interviews or focus groups with thematic analysis.
Study design	Qualitative study design
Timeframe	Any
Additional information	None

F.1.5 Modified PICO table: What information do people with osteoarthritis from different ethnic and socio-economic groups and those with learning disability, health literacy issues and severe mental illness (and their family and carers) need?

Population	Adults (age ≥16 years) with osteoarthritis affecting any joint and their family and carers. Strata: • People from different ethnic groups • People from different socio-economic groups • People with a learning disability • People with health literacy issues • People with severe mental illness
Intervention	This would be a qualitative review, therefore there would not be any specific interventions. However, information needs would be sorted by people with the characteristics described in the strata.
Comparator	N/A
Outcome	Qualitative in-depth interviews or focus groups with thematic analysis.
Study design	Qualitative study design
Timeframe	Any
Additional information	None