National Institute for Health and Care Excellence

Final

Joint replacement (primary): hip, knee and shoulder

[A] Evidence review for information needs

NICE guideline NG157

Qualitative evidence review underpinning recommendations 1.1.1 to 1.1.4 and the research recommendation in the NICE guideline

June 2020

Final

This evidence review was developed by the National Guideline Centre, hosted by the Royal College of Physicians



Disclaimer

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or service users. The recommendations in this guideline are not mandatory and the guideline does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and, where appropriate, their carer or guardian.

Local commissioners and providers have a responsibility to enable the guideline to be applied when individual health professionals and their patients or service users wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with compliance with those duties.

NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the <u>Welsh Government</u>, <u>Scottish Government</u>, and <u>Northern Ireland Executive</u>. All NICE guidance is subject to regular review and may be updated or withdrawn.

Copyright

© NICE 2020. All rights reserved. Subject to Notice of rights.

ISBN 978-1-4731-3722-6

Contents

Infor	mation	needs	5
1.1		question: What information would those having primary elective joint ement surgery like to have prior to surgery?	5
1.2	Introdu	ction	5
1.3	Charac	cteristics table	5
1.4	Qualita	tive evidence	5
	1.4.1	Included studies	5
	1.4.2	Excluded studies	6
	1.4.3	Summary of qualitative studies included in the evidence review	7
	1.4.4	Qualitative evidence synthesis	12
	1.4.5	Qualitative evidence summary	19
1.5	Econoi	nic evidence	26
1.6	Eviden	ce statements	26
	1.6.1	Qualitative evidence statements	26
1.7	The co	mmittee's discussion of the evidence	27
	1.7.1	Interpreting the evidence	27
	1.7.2	Cost effectiveness and resource use	30
	1.7.3	Other considerations	30
Appe	endix A:	Review protocols	35
Appe	endix B:	Literature search strategies	40
	B.1 Cli	nical search literature search strategy	40
	B.2 He	ealth Economics literature search strategy	46
Appe	endix C:	Qualitative evidence selection	50
Appe	endix D:	Qualitative evidence tables	51
Appe	endix E:	Excluded studies	71
	E.1 Ex	cluded qualitative studies	71
Δnne	ndiv F	Research recommendations	72

1 Information needs

1.1 Review question: What information would those having primary elective joint replacement surgery like to have prior to surgery?

1.2 Introduction

It is essential that people undergoing joint replacement surgery receive clear, informative and appropriate communication at all stages throughout the pathway, to assist in the decision-making process. The amount and type of information currently provided varies between hospital Trusts, but is usually delivered by the clinical surgical team and rehabilitation services in combination; often using a "Joint School" approach for hip and knee replacement surgery. The Patient experience in adult NHS services³³ NICE guideline makes recommendations on essential requirements of care, how information should be delivered and how people should be enabled to actively participate in their care. This chapter covers specific needs of people considering hip, knee or shoulder joint replacement and subsequent post-surgical rehabilitation.

The review seeks to establish the type and level of information people undergoing joint replacement surgeries need and would like.

1.3 Characteristics table

For full details see the review protocol in Appendix A:

Table 1: Characteristics of review question

Objective	To find out through qualitative research what information people (and their carers/families) who are having joint replacement would like prior to surgery.
Population and setting	Adults having or have had primary elective joint replacement surgery.
Context	Information needs as described by studies
Review strategy	Synthesis of qualitative research. Results presented in narrative format. Quality of the evidence assessed by a GRADE CerQual approach for each review finding.

1.4 Qualitative evidence

1.4.1 Included studies

We searched for qualitative studies engaging people who were going to have or had already undergone joint replacement surgery and the information they wanted or would have wanted in the preoperative period.

Fifteen studies were included in the review;^{4, 5, 14-16, 19, 20, 23, 25, 26, 30, 40-42, 44} these are summarised in Table 2 below. Key findings from these studies are detailed in Section 1.4.2 below. See also the study selection flow chart in Appendix C: study evidence tables in Appendix D: and excluded studies lists in Appendix E:

1.4.2 Excluded studies

See the excluded studies list in Appendix E:

1.4.3 Summary of qualitative studies included in the evidence review

Table 2: Summary of studies included in the review

Study	Design	Population	Research aim	Comments
Aquilina 2007 ⁴	Semi-structured interviews for up to 45 minutes undertaken 1 day before hospital discharge. Thematic analysis.	30 Maltese people who had hip n=9) or knee (n=21) total joint replacement surgery Mean (range) age: 71 (58 to 85). 13 male and 17 female.	To explore peoples' perceptions relating to preparation for total joint replacement surgery at the pre-admission clinic (PAC) and to identify the perceived value of the information provided and to identify factors that enhance or inhibit preparation.	Malta 4 people had prior joint replacement operations
Bardgett 2016a ⁵	Semi-structured interviews that ranged from 8 to 35 months after surgery and were undertaken by a trained research physiotherapist. Thematic analysis.	Purposive sample of 10 people under 60 years of age who had primary total knee replacement. Age ranged from 40 to 59. 5 men and 5 women. Time until return to work ranged from 2 weeks to 13 weeks.	To identify factors influencing return to work following knee replacement	UK
Conner-Spady 2014 ¹⁴	9 focus groups (4 pre-surgery, 5 post surgery) were conducted. Each focus group lasted approximately 2 hours. Thematic analysis.	Pre-surgery group (n=26): people with osteoarthritis who a) had an orthopaedic surgical consultation and were eligible for primary total joint replacement or b) had been referred to an orthopaedic surgeon for consideration of total joint replacement. Post-surgery group (n=39): people who had primary total	To explore the concept of people readiness and describe the factors people consider when assessing their readiness for total joint replacement.	Canada

Study	Design	Population	Research aim	Comments
		joint replacement approximately 12 months previously 65 people: 66% female, 34% male, and 80% from urban centres with a mean (SD) age of 65 (10) which ranged from 28 to 89.		
Conradsen 2016 ¹⁵	Semi-structured interviews carried out at a rehabilitation centre lasting 25-60 minutes. Phenomenological approach used for analysis.	Purposive sample of 11 people who had been to the preoperational programme in the hospital and had knee (n=3) or hip (n=8) arthroplasty. Mean (SD) age: 71 (7) ranging from 56 to 82.	To investigate how patient education in a surgical department was experienced by patients who had undergone total hip or knee arthroplasty.	Norway
Demierre 2011 ¹⁶	Semi-structured interviews 1 month before hip or knee arthroplasty. Thematic analysis utilised.	Adults under 75 years of age awaiting hip (n=12) or knee (n=12) arthroplasty. Mean (SD) age: 60 (11) 9 men and 15 women.	Longitudinal research project exploring the experience from the moment of deciding to have joint replacement surgery until 12months after surgery.	Switzerland. 8 people had previous arthroplasty
Gillespie 2007 ¹⁹	Semi-structured interviews, 30 to 40 minutes long 1-3 days after surgery. Phenomenological approach to focus on the lived experience of a preoperative assessment clinic.	10 consecutive people who attended the preoperative assessment clinic. 7 private patients and 3 NHS patients. Age ranged from 43 to 78 years old. 4 men and 6 women.	To assess what people felt they gained from the preadmission process that is in place.	UK
Goldsmith 2017 ²⁰	Semi-structured interviews lasting from 45 to 65 minutes Thematic analysis utilised.	45 purposefully selected people 8 months after total knee replacement recruited across 6 sites.	To improve the understanding of a person's experience and their satisfaction following total knee replacement	Canada

Study	Design	Population	Research aim	Comments
Jacobson 2008 ²³	Focus groups in the preoperative group immediately following the hospital's joint replacement class. Individual interviews were conducted in the postoperative group. Thematic analysis utilised.	17 people preoperative and 10 people postoperative. Mean (SD) (range) age: 66 (12) (45-83) 13 male and 14 female. 24 people were white and 3 African American.	To describe the pre- and postoperative experiences of people undergoing total knee replacement surgery	USA
Kendall 2014 ²⁵	Individual interviews approximately one week pre and four weeks post surgery, followed by a group interview. Grounded theory approach to thematic analysis.	Women, 40 to 70 years old, undergoing primary total hip replacement.	An exploration of the lived experience of five active Canadian women from 40-70 years of age, who underwent a primary total hip replacement.	Canada
Kennedy 2017 ²⁶	A mixture of 6 focus groups and 7 telephone interviews with participants. Thematic analysis utilised.	32 purposefully selected people who had undergone hip or knee joint replacement surgery were recruited at their 6 week to one-year follow-up appointment. Mean (SD) age: 68 (8) ranging from 46 to 78. 16 men and 16 women. 16 hip replacements and 16 knee replacements.	Exploring experiences and preferences for education following hip or knee replacement surgery	Canada
Krupic 2012 ³⁰	Interviews 60 to 90 minutes long conducted the day before the planned surgery. Thematic qualitative analysis was undertaken.	20 people with primary or secondary osteoarthritis, admitted for total hip replacement surgery. People born in Sweden (n=10) were aged 40 to 86 years old (median: 63) and immigrants (n=10) 30-87 years old (median: 59). Most of the immigrants came from Europe, one from Africa and	To explore how immigrants and Swedish people described information provided before elective total hip replacement.	Sweden

Study	Design	Population	Research aim	Comments
		one from Asia.		
Smith 2018 ⁴⁰	Interviews 6-12 months after surgery conducted by a trained qualitative methodologist. Thematic analysis used.	People who had undergone total knee arthroplasty (n=4) or total hip arthroplasty (n=7) and attended Kaiser Permanente Northwest (KPNW) preparation. 80 people with high opioid use were selected and 11 people were interviewed. 9 women and two men.	An assessment of barriers and facilitators of effective opioid use for people having orthopaedic surgery.	USA
Soever 2010 ⁴¹	Semi-structured interviews conducted by two investigators, both physiotherapists. A comparative contrast method of analysis was used.	Purposive sample of people who were scheduled for or underwent primary total joint arthroplasty within 3 to 6 months. 15 participants: 13 female and 2 male. 3 were awaiting a TKA, 2 were awaiting a THA, 3 were post-TKA, and 7 were post-THA. Participants ranged in age from 23 to 89 years old.	Answering the question: What do people undergoing total joint arthroplasty want to know?'	Canada
Spalding 2001 ⁴²	2 × 30 minute semi-structured interviews per person. The first within 10 days of surgery and the second 4 weeks after surgery. Data analysed using content analysis.	9 consecutive people who transferred to the orthopaedic rehabilitation unit after total hip replacement and consented to the trial. 2 had received preoperative education classes.	Investigate the justification for preoperative education before admission to people having total hip replacement.	UK
Spooner 2018 ⁴⁴	Semi-structured interviews by telephone.	People who had completed preoperative joint	The primary research question was: How do eight	USA

Study	Design	Population	Research aim	Comments
	Interpretative phenomenological analysis to investigate and make sense of the women's lived experience.	replacement education prior to surgery and underwent TKA less than two months before the interview. 8 women completed the study.	women who experienced total knee replacement make sense of their preoperative education and recovery?	

See Appendix D: for full evidence tables.

1.4.4 Qualitative evidence synthesis

1.4.4.1 Narrative summary of review findings

1.4.4.1.1 Category: Prior to surgery

Review finding 1: Waiting time.

Waiting times can influence a person's decisions prior to surgery. People in 2 studies spoke of concern that there will be what they consider to be overly long waiting times until surgery. This can lead to people agreeing to surgery earlier than is required due to fears that their condition will deteriorate in the waiting period and their pain and reduced function will be difficult to manage. A study showed that some individuals expressed dissatisfaction and regret about having the surgery too soon. Another study included people who wanted information on whether waiting list position can be altered due to circumstances.

The studies using focus groups or semi-structured interviews. The finding was deemed to have moderate limitations as it was unclear how recruitment bias was mitigated. There were moderate concerns about the relevance as a number of people were interviews and focus groups were prior to surgery and it was considered more difficult to ascertain conclusions on information provision for the pre-surgery period while still in the pre-surgery period. Overall there was moderate confidence in the finding.

Review finding 1: Readiness.

This can be subdivided into 2 facets of readiness.

Physical preparation

Information on physical preparation and nutrition was described in 2 studies. This was as readiness in terms of being physically fit and in good shape for surgery to give a better outcome. People wanted to know what the positive effects of readiness are and how to achieve them. Weight loss was emphasized as a factor in 1 study and another study contained people who thought that weight loss might ameliorate the need for joint replacement surgery.

Preparation for hospital and the postoperative period at home

Several details about preoperative education that helped people prepare for surgery and the postoperative changes were provided. People spoke of preparing themselves for the hospital stay and preparing their home environments for their return from the hospital. Specifically, people were interested in knowing what medications, food, clothes, and toiletries they should bring to the hospital; what preparations need to be made to the home environment, including food and equipment, and what blood tests were required prior to surgery.

4 studies with 1 undertaking focus groups and the others were semi-structured interviews. There were moderate concerns on the adequacy of the finding due to richness. Overall there was moderate confidence in the finding.

1.4.4.1.2 During surgery and immediately afterwards

Review finding 1: Clarifying the unknown: risks.

Surgery was associated with uncertainty and specifically the fear of an unknown future. These include risks of anaesthesia, infection, of "being cut", having the wrong joint operated on, mortality, and failure of the operation. Most people in the studies indicated that

information on surgery reduced a "fear of the unknown". A person indicated that knowing exactly what was going to occur was like having a tranquiliser pill. However while most people did want to know about risks, other people wished to minimise discussion of the risks and emphasise the benefits of surgery. Studies reported conflicting knowledge needs. A third of people in 1 study stated apprehension at hearing about potential complications. They thought it might alienate people from having the surgery and the information may be necessary but it leads to thinking "what am I getting into". The delivery of this information might need to be softened and adapted to suit the individual.

These 2 studies were focus groups and semi-structured interviews that in some cases happened in the preoperative period. There were moderate concerns about adequacy due to collection of data preoperatively and often soon after surgery and the richness of the data. Overall there was moderate confidence in the finding.

Review finding 1: Surgery specifics.

7 studies reported the need for specific information prior to the surgery. People wanted to know what to expect, what would happen and what decisions would need to be made. The information they requested information on subjects such as anaesthetics, selection of the implants for use, procedures relating to blood donation and blood transfusion, length of hospital stay, how thromboembolic complications are minimised, details of wound care such as stitch and staple removal and bathing. Some people wanted explicit information about the operation. 2 studies featured people who appreciated being able to touch an implant. "I happen to like to know exactly what is going and what is staying". 2 people stated that they did not want too much lurid detail and felt that they could watch a YouTube video about it if they so wished, while another person, who was a surgeon's daughter, voiced a complete lack of fear.

The 7 studies all utilised semi-structured interviews. There were moderate concerns about methodological limitations due to unclear addressing of selection bias. There were moderate concerns about adequacy due to the interpretation. Overall there was moderate confidence in the finding.

Review finding 1: Shared decision making.

Many participants were informed about the different types of anaesthesia and engaged in a shared decision making process during the preoperative visit. There was a conception that the anaesthetist had already made the decision, the same sentiment was reported with regarding other potential shared decisions regarding the surgical procedure. People described being asked about the operation, but felt unable to make decisions without preparation.

One study found that participants were likely to have a more positive experience, and report improved self-worth, when they felt empowered to make decisions regarding their own care. As empowerment increased, so did self-efficacy. A study concluded that at the most basic level, belief in a patient's capacity to participate in their own care activates their ability to cope with the stressors that come along with illness.

One study included people who thought that maybe experts should make the decisions about some things. An example given was anaesthesia.

There were 4 studies using semi-structured interviews. There were no concerns about the quality of these data and there was high confidence in this theme.

1.4.4.1.3 After the surgery

Review finding 1: Life after surgery.

One study reported that people had little information about life after surgery and wanted to know what the results would be. People sought information that would help them understand the processes involved in surgery and recovery, allay fears, and help them feel less dependent on others. "I have expectations of managing alone; dressing myself, putting on my socks. In Sweden you do not ask for help, that is how it is."

People in the study indicated it was important to emphasise the positive aspects of surgery. The benefits can be best described as recovering lost quality of life through pain relief and increased mobility. Surgery would help them walk, bathe, sleep well, work longer, return to active sports like golfing, cross country skiing, and riding a bike. Regaining mobility also means independence, resuming a social life, improving relationship with spouse and family, and 'leading the life that's appropriate for your age'. One person said: "It won't be the knee of my 20s, I shall experience less pain but I shall not be able to do all I want". They said that it is important for those contemplating TJA to know that there is a responsibility on the part of the patient to exhibit a positive attitude and "work" hard at the recovery process.

Only 1 study utilising focus groups spoke about this postoperative aspect. Overall there was low confidence in the finding..

Review finding 1: Planning for aftercare.

One study included people who said they received inadequate information about the process after surgery and were unclear what rehabilitation would entail. One study indicated people wanted to understand the variety of recovery trajectories so when the time came they knew they were on track for recovery, even if it was not the ideal track or an ideal recovery. One study indicated a desire for information such as an expected discharge date that they could make plans around. A study indicated that people linked preoperative education to surgery-related planning and preparations. All participants experienced challenges requiring specific actions or a particular pattern of behaviours; these behaviours were influenced by perceptions of ability and ultimately the level of motivation. A study mentioned some key pointers that could be provided, the move from crutches to stick, when to walk 1 mile, and when it is safe to drive. Also a guide to what to expect during recovery and its "backward-and-forward" nature could be better explained.

1 study utilised focus groups and 5 used semi-structured interviews. There were moderate methodological limitations due to selection of people in the studies and data analysis. Overall there was moderate confidence in the finding.

Review finding 1: postoperative pain.

People stated that it was important to be informed before surgery postoperative challenges such as pain. One person suggested it was best not to 'sugar-coat' the experience as it would be disappointing afterwards. Information on how pain is managed was essential. 1 study found information on pain relief was considered important. Most participants described their pre-operative pain as due to osteoarthritis, but revealed that information on how to relieve it was not delivered prior to surgery.

One study delivered pain management expectations and education in a booklet and video pre-surgery. Interviewees reported that it did not adequately address issues related to pain management. In contrast verbal contact with the surgeon was reported to be clear, helpful and increased the person's confidence. Most people felt concerned going into surgery due to previous surgical pain experiences, fear of pain, or low pain tolerance. 4 others were

concerned about the use of narcotics after surgery in terms of addiction, poor reaction to the medication, or preference for "not taking pills".

5 studies using semi-structured interviews and in 1 case focus groups too. There were moderate concerns about methodological limitations due to selection of people, data analysis and data richness. Overall there was moderate confidence in the finding.

Review finding 1: Age bias and return to work.

People reported that the advice they received from healthcare professionals focused on the needs of the elderly, retired population. Preoperative education reportedly focused on the inpatient stay and immediate postoperative period, but longer-term outcomes, such as return to work, were not routinely discussed. Some reported that it was not appropriate to discuss issues pertinent to them, such as return to work, as it was not relevant to the majority of people. Duration of absence due to sickness, and return to work, was not routinely discussed preoperatively - people were unsure of the processes involved, and described looking to healthcare professionals postoperatively for guidance.

This was taken from 1 study using semi-structured interviews. There were moderate concerns about methodological limitations due to recruitment of people and data richness. In addition there were adequacy concerns due to quantity of data. Overall there was low confidence in this finding.

1.4.4.1.4 Who delivers information and how is it delivered

Review finding 1: verbal communication.

1 study included more people who described the preoperative information as limited; the doctor had no time to explain the operation, there was no time for questions and it was very stressful. This suited 1 person who was not interested in information and wanted to have the surgery as soon as possible. However more often, verbal communication with a surgeon was seen as "humanising". Face-to-face meetings with surgeon were important in establishing trust relationships, allaying fears, and enabling people to feel confident in their decision-making. Most people who had met with a surgeon had a trusting relationship with them. Surgeons who took the time to explain surgery and answer questions were favoured and a direct approach was valued. The benefits of having a relative or partner at the clinic, as stated by 3 studies, included having a source of emotional support and having help remembering and reinforcing what was discussed. Relatives or partners could better appreciate what was going to happen and how to cope. It was also important to communicate with people in a language in which they were fluent, 1 study found people who needed an interpreter were assured that one would be provided to help them but that they did not turn up.

2 studies used focus groups and 4 semi-structured interviews. There were no concerns about the quality of these data and there was high confidence in this theme.

Review finding 1: Written.

One study reported a lack of written material available and the difficulty of remembering oral information. People in 1 study proposed a "step by step" guide to joint replacement. These guides exist in some locations as people in 1 study highlighted that it was useful in the pre and post-surgery period. Where booklets were available people found them useful as a reminder, and as a source of reference and information for preoperative preparations. 3 studies commented on the use of graphics, 2 indicated they were a useful way to provide knowledge and understanding, though one person in the third study had "sleepless nights" after seeing colour pictures of a hip replacement wound. One study indicated the timing of

the information is important as people received it through the post at too late a date to be useful.

This was taken from 1 study using focus groups and 5 using semi-structured interviews. There were adequacy concerns due to data richness. Overall there was moderate confidence in this finding.

Review finding 1: Video.

People in 1 study spoke about a hospital created video 'preparing you for your hip or knee replacement surgery'. This was positively received. A person in another group saw a joint replacement operation on television and found it increased anxiety without positive effect.

There were 2 studies using semi-structures interviews. There were moderate concerns about methodological limitations due to selection of people for the study and analysis of the data. There was little coherence in the data as the 2 studies looked at different uses of video. There were adequacy concerns due to data richness and the conclusions drawn. Overall there was very low confidence in the findings.

Review finding 1: who provides what

Orthopaedic staff

People found that orthopaedic staff had a high degree of knowledge and professionalism and this was reassuring. Knowing the team was important in 1 study as people understood that several health care professionals would be involved in their care. Knowing these individuals, including having an understanding of their roles, was deemed very important. Having one member of the team, aside from the surgeon, whom they could consult at various phases of their TJA was also important. Some people identified the surgeon as their main source of information. While patients felt that surgeons were an important source of knowledgeable information, they often described mixed experiences of how much time they felt surgeons could or did provide. Participants in some studies wanted more information from their surgeon than they received.

Online sources

One study found the majority of people had searched Google for information on the surgery or recovery process. Many did not question the validity or accuracy of this information. For some participants, mostly men, they wanted to actually watch the surgery "to see what goes on in the operating room". Not all people thought that accessing information on the internet was useful and in some instances it reinforced the fear they already felt about the upcoming surgery. In such cases the participants were told to search for information themselves. "My doctor said: You can log on to Hip Register where you will find all the information you need". The process of seeking information included social and other networks, which generated and guided questions that were presented in the preoperative classes.

Other people who have had joint replacement surgery

People deciding to have surgery mostly noticed 'success' stories and noted what factors contributed to successful outcomes, such as a positive attitude and a determination to resume activities following surgery. One patient described it as a process of filtering. Talking to others with successful outcomes gave patients hope, especially if they had the same surgeon. People in 1 study said it was useful to talk to people who had the surgery or with providers to increase confidence and it releases stress as well. A structured peer support group would have been appreciated.

Friends and family

People frequently identified friends and families as an important source of information. Hearing stories from other people that their surgeries had been successful reassured participants. At the same time, they voiced their concern that experiential accounts were not necessarily medically valid. Many voiced a desire to access a bank of patient "testimonials" that the hospital could curate, hence increasing its reliability from a patient perspective. Several noted that they wanted to hear both "good and indifferent" experiences from others. It was also noted that families and other informal support systems require education on TJA. Participants said that such education would enable families to know how they could help, especially in the home environment.

2 studies using focus groups and 6 using semi-structured interviews. There were moderate concerns about coherence as the studies varied widely around sources of information and there were moderate concerns about relevance to this review as many of these information providers are not part of the healthcare team. Overall there was low confidence in the finding.

Review finding 1: Where

Consultation

The consultation Information programme^a made people feel "the process had started". It allowed people to state feelings of anxiety and vulnerability. It was a basis for deciding on surgery. However even after the consultation, questions often remained and some patients desired to meet their surgeon again, to verify the information received and to answer follow-up questions. People felt other treatment options were underemphasised by surgeons and often were not aware of non-surgical treatments. People felt they underwent a thorough assessment and many questions were asked during the screening process. This contributed to a feeling of thoroughness on the part of the nursing staff and people felt comfortable enough to discuss their specific needs.

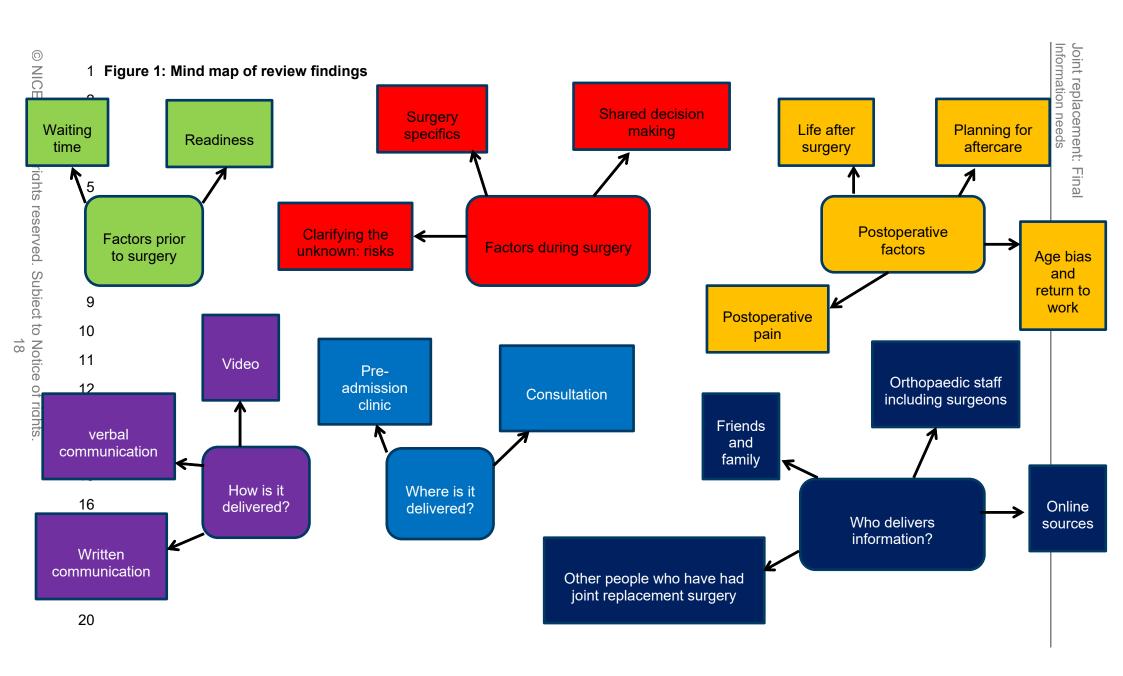
Pre-admission clinic

People were generally encouraged by the pre-admission clinic experience, though a number of people were concerned it would increase anxiety. A study found preoperative education reduced some anxieties while creating new ones, but it also empowered patients to seek information from different sources. Courses held by the clinic were found to be well-organised with clear and detailed instructions on what to expect during the process. People commented on how these courses "built their confidence" as they received individualised attention and reported feeling encouraged after. This confidence building was important given how many people were initially fearful of having surgery.

Positives can be drawn from the process of making shared care choices, as people reported feeling more respected and less infantilised and controlled. Among the useful information provided was what happens during the preadmission visit and how long it should take. One study found that class participants' engagement was especially enhanced by information relating to the preoperative period including activation, self-advocacy, preparing for surgery and rehabilitation stages.

There were 5 studies using semi-structured interviews who spoke about this. There were moderate concerns about methodological limitations due to selection of people and analysis. Overall there was moderate confidence in this finding.

^a 4 hour group intervention undertaken by nurses, orthopaedics and physiotherapists that consisted of information about surgery, mobilisation after surgery, practical details of the hospital stay, pain and other challenges of the postoperative period.



Study design size	and sample		Quality ass	essment	
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessme of confidence
Factors pric					
Waiting times	•				
2 studies	Focus groups and semi-	Waiting times can influence a person's decisions prior to surgery.	Limitations	Moderate concerns about methodological limitations	Moderate confidence ^{1,3}
	structured interviews		Coherence	No or very minor concerns about coherence	
			Relevance	Moderate concerns about relevance	
			Adequacy	No or very minor concerns about adequacy	
Readiness					
4 studies	Focus groups (n=1) and semi- structured	Readiness was described in terms of being in good physical shape for surgery, prepared for hospital, and also having a well organised home environment. People wanted information on the positive effects of readiness and how to achieve them to give a	Limitations	No or very minor concerns about methodological limitations	Moderate confidence
	interviews (n=3)	better surgical outcome.	Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	

Study design size	and sample		Quality asse	essment	
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
			Adequacy	Moderate concerns about adequacy	
Surgery and	immediately	afterwards			
Clarifying the	unknown: risk	s			
2 studies	Focus groups and semi- structured interviews	oups and of an unknown future. These include risks of anaesthesia, infection, of being cut, having the wrong joint operated on, uctured mortality, and failure of the operation. Most people in the studies	Limitations	No or very minor concerns about methodological limitations	Moderate confidence ^{2,4}
			Coherence	Moderate concerns about coherence	
			Relevance	No or very minor concerns about relevance	
			Adequacy	Moderate concerns about adequacy	
Surgery speci	ifics				
7 studies	Semi- structured interviews		Limitations	Moderate concerns about methodological limitations	Moderate confidence ¹
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	
			Adequacy	No concerns about adequacy	

Study design	and cample				
size	and Sample		Quality asse	essment	
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
Shared decisi	ion making				
4 studies Semi- structured	Semi- structured interviews	ructured limitations in how it was run by orthopaedic teams. terviews	Limitations	No or very minor concerns about methodological limitations	High confidence
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	
			Adequacy	No concerns about adequacy	
After surger	у				
Life after surg	gery				
1 study	Focus groups	The study indicated that people had little information provision about the post-surgery experience. However it was seen as a key information requirement in the preoperative period.	Limitations	No or very minor concerns about methodological limitations	Low confidence ⁴
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	
			Adequacy	Moderate concerns about adequacy	

Study design size	and sample		Quality asse	essment	
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
Planning for a	aftercare				
group and so struct	Focus groups (n=1) and semi-) should be provided in the preoperative period. People wanted to understand the variety of recovery trajectories so they could be assured they were on some sort of a track to recovery.	Limitations	Moderate concerns about methodological limitations	Moderate confidence ^{1,3}
	structured interviews (n=5)		Coherence	No or very minor concerns about coherence	
			Relevance	Moderate concerns about relevance	
			Adequacy	No or very minor concerns about adequacy	
postoperative	pain				
5 studies	Semi- structured interviews with focus groups in 1 case	uctured important including how it is treated. erviews th focus oups in 1	Limitations	Moderate concerns about methodological limitations	Moderate confidence ¹
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	
			Adequacy	No or very minor concerns about adequacy	
Age bias and	return to work				
1 study	Semi-	People reported that the advice they received from healthcare	Limitations	Moderate concerns	Low

Study design and sample					
size			Quality asse	Quality assessment	
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
	structured interviews	professionals focused on the needs of the elderly, retired population. Preoperative education focused on the inpatient stay and immediate postoperative period, but longer term outcomes, such as return to work, were not routinely discussed.		about methodological limitations	confidence ^{1,4}
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	
			Adequacy	Moderate concerns about adequacy	
Who delivers	s information	and how is it delivered			
Verbal commi	unication				
6 studies	Focus groups (n=2) and semi- structured interviews (n=4)	Verbal communication built trust with the surgeon but people often did not accurately recall what was said. It can be helpful to have family members in the meeting.	Limitations	No or very minor concerns about methodological limitations	High confidence
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	
			Adequacy	No or very minor concerns about adequacy	
Written communication					
6 studies	Focus	A study indicated people said there was a lack of written material	Limitations	No or very minor	Moderate

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
	groups (n=1) and semi- structured interviews (n=5)	available and it's easy to forget verbal information. A "step by step" guide to joint replacement was proposed and appears to exist in some places.		concerns about methodological limitations	confidence ⁴
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	
			Adequacy	Moderate concerns about adequacy	
Video					
2 studies	Semi- structured interviews	Officially produced videos were positively received in 1 study but viewing operations on television was found to increase anxiety.	Limitations	Moderate concerns about methodological limitations	Very low confidence ^{1,2}
			Coherence	Moderate concerns about coherence	
			Relevance	No or very minor concerns about relevance	
			Adequacy	Moderate concerns about adequacy	
Who provides what					
8 studies	Focus groups (n=2) and semi- structured	Orthopaedic staff have a high degree of knowledge and professionalism and this was reassuring. Surgeons were key sources of information although some people wanted more information than they received.	Limitations	No or very minor concerns about methodological limitations	Low confidence ^{2,3}

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
	interviews (n=6)	Online sources were of mixed usefulness. People deciding to have surgery noticed 'success' stories and noted what factors contributed to successful outcomes of other people who had joint replacement surgery Positive attitude and a determination to resume activities following surgery were noted. People frequently identified friends and families as an important source of information.	Coherence	Moderate concerns about coherence	
			Relevance	Moderate concerns about relevance	
			Adequacy	No or very minor concerns about adequacy	
Where					
5 studies	structured interviews	The consultation Information programme made people feel "the process had started". Allowed people to state feelings of anxiety and vulnerability. Pre-admission clinics were valued in terms of reducing anxiety and increasing confidence and knowledge and facilitated joint decision making.	Limitations	Moderate concerns about methodological limitations	Moderate confidence ¹
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	
			Adequacy	No or very minor concerns about adequacy	

¹ Downgraded if there were concerns about methodological limitations

² Downgraded if there were concerns on the coherence across the studies included in the review

³ Downgraded by if there were concerns on the relevance on the extent to which the body of evidence from the included studies is applicable to the context

⁴Downgraded by if there were concerns on the richness (depth of analysis) and quantity of the evidence supporting a review finding or theme.

1.5 Economic evidence

The committee agreed that due to the qualitative nature of the review question health economic studies would not be relevant, and so were not sought.

1.6 Evidence statements

1.6.1 Qualitative evidence statements

14 qualitative studies utilising either semi-structured interviews and/or focus groups suggested 6 areas important in information provision. These encompassed information needs and delivery of information.

Information needs specific to 3 key time points were discussed:

Information on the period prior to surgery:

- Waiting times (2 studies, moderate confidence): An unclear waiting period prior to surgery can unduly influence a person's decision when to have surgery.
- Readiness (4 studies, moderate confidence): Readiness was described in terms of being in good physical shape for surgery, prepared for hospital, and also having a well organised home environment. The hope was to give a better surgical outcome people wanted information on the positive effects of readiness are and how to achieve them.

Information on the surgery itself and immediately afterwards:

- Clarifying the unknown: risks (2 studies, moderate confidence): Surgery was
 associated with uncertainty and specifically the fear of an unknown future. Fears
 include risks of anaesthesia, infection, of being cut, having the wrong joint operated
 on, mortality, and failure of the operation. Most people in the studies indicated that
 information on surgery reduced a "fear of the unknown".
- Surgery specifics (7 studies, moderate confidence): 7 studies involved people saying
 it was important to be receive specific information prior to the surgery. They wanted to
 know what to expect, what would happen and what decisions would need to be
 made
- Shared decision making (4 studies, moderate confidence): People were positive
 about shared decision making but indicated that there were limitations to how it was
 done by orthopaedic teams.

Information about the postoperative period:

- Life after surgery (1 study, low confidence): The study indicated that people had little information provision about the post-surgery experience. However it was seen as a key information provision in the preoperative period.
- Planning for aftercare (6 studies, moderate confidence): People believed that more comprehensive aftercare information should be provided in the preoperative period.
 Knowing the various possible postoperative trajectories is important.
- Postoperative pain (5 studies, moderate confidence): Information about postoperative pain was seen to be very important including how it is treated.

Age bias and return to work (1 study, low confidence): People reported that the
advice they received from healthcare professionals focused on the needs of the
elderly, retired population. Preoperative education reportedly focused on the inpatient
stay and immediate postoperative period, but longer term outcomes, such as return to
work, were not routinely discussed.

3 areas were summaries of people's views and experience on the delivery of the information.

How information is delivered:

- Verbal communication (6 studies, high confidence): Verbal communication built trust
 with the surgeon but people often did not accurately recall what was said. It can be
 helpful to have family members in the meeting.
- Written communication (6 studies, moderate confidence): A study indicated a lack of written material available and the difficulty in remembering information provided verbally. A "step by step" guide to joint replacement was proposed and was referenced in some studies.
- Video (2 studies, very low confidence): Officially produced videos were positively received in 1 study but utilising operations on television was found to increase anxiety.

Who provides the information (8 studies, low confidence):

- Orthopaedic staff: people found they had a high degree of knowledge and professionalism and this was reassuring. More face to face time with surgeons would have been appreciated.
- Online sources: were found to be of mixed usefulness.
- Other people who have had joint replacement surgery: People deciding to have surgery mostly noticed 'success' stories and noted what factors contributed to successful outcomes, such as a positive attitude and a determination to resume activities following surgery.
- Friends and family: People frequently identified friends and families as an important source of information.

Where is it delivered (5 studies, moderate confidence):

- The consultation Information programme made people feel "the process had started". Allowed people to state feelings of anxiety and vulnerability.
- Pre-admission clinic: these clinics received very positive feedback in terms of reducing anxiety and increasing confidence and knowledge and facilitated joint decision making.

1.7 The committee's discussion of the evidence

1.7.1 Interpreting the evidence

1.7.1.1 The quality of the evidence

The studies were of good quality utilising either semi-structured interviews and/or focus groups to explore people's views on information provision prior to surgery. The studies

tended to explore pre-surgery education and readiness/preparation of people undergoing joint replacement surgery. The methodological limitations were related to the populations included which were narrower than the wide variety of people requiring replacement surgery e.g. studies were of people preparing for knee and hip replacement only and most studies were coded by a single researcher only. Low ratings for adequacy were related to insufficient richness and limited interpretation of findings, and/or the quantity of data found. Where there were limitations around richness it was considered that further analysis highlighting diversity of perspective would have been helpful. The limitations around interpretation tended to be around inadequate discussion for and against the researcher's arguments. There was some concern about the predominance of studies prior to surgery. There was moderate confidence in most of the themes though they ranged from very low confidence to high confidence.

1.7.1.2 Findings identified in the evidence synthesis

15 studies were included in this evidence review and 12 of them studied people who had primary hip or primary knee replacement surgery. 3 studies included a more generic group of people who had or were due to have joint replacement surgery. None of these studies specifically mentioned people having shoulder joint replacement surgery.

The themes found in the evidence were:

- Factors prior to surgery: waiting times and readiness
- Management of people in surgery and immediately afterwards: clarifying the unknown: risks, specifics of surgery, and shared decision making
- Management of people after surgery: life after surgery, planning for aftercare, postoperative pain, age bias, and return to work
- Who delivers information: orthopaedic staff, online sources, people who have had joint replacement surgery, or friends and family
- How is information delivered: verbal, written, or video
- Where is information delivered

The committee discussed all of the themes observed in the evidence review and used the evidence review and their experience to develop recommendations. The first recommendation lists specific areas of information that should be given on prior to surgery. The committee agreed it is important to list specific areas of information - this is helpful for healthcare professionals but also provides a helpful checklist for people considering surgery both of areas to consider and as an aide memoire when attending a consultation. Information should also be offered in a format people can easily understand.

The committee noted shared decision making where the person scheduled for joint replacement and their families and carers discuss options with the surgeon was very important, and that certain topics should definitely be discussed. These included the alternatives to joint replacement, the potential benefits and risks of the procedures including the possibility for more surgery in the future and the options for anaesthesia and their associated risks.

The committee discussed information around selection of the implant. People have varying desires as to the level of information around the implant that is being used and the choice a person gets vis-a-vis the implant is limited by local availability of particular implants. The committee indicated that discussion with people undergoing the surgery tended to be more about the type of surgery TSA, RSA or hemiarthroplasty rather than specific choice of implant brand.

The committee agreed through consensus that people can require assessment or management by orthopaedic services at any time before or after surgery for a variety of

reasons. Therefore, the committee recommended people should know who to contact if they have questions or concerns in the pre or post-surgical period.

There was discussion of the provision of information detailing what to expect in the post-surgery period. This includes an understanding of length of hospital stay, post-operative pain and recovery and the upcoming rehabilitation. The committee considered it important people understand the length of recovery period and the reality of pain that may continue for several months. The committee noted that people begin to wonder if the pain will ever end 5 weeks after surgery and may need to be prepared for it not to improve for up to 3 months. Honest information is important as there is a lot of anxiety about pain and engagement with reality of recovery period help to build trust.

The committee considered that up to 20% of people having hip or knee replacement in England plan to return to work. The committee believe people who wish to return to work would ideally be offered a meeting with an occupational therapist at 'joint school' or a comparable setting who can give individualised information and answer queries on return to work after surgery. There are additional requirements linked to return to work around fit notes that are provided, on request, by the hospital team on discharge.

The committee discussed returning to driving after surgery. It was stated that information is insufficient in many cases. "Whenever you feel you're able to" was stated as the usual advice and the requirement from the DVLA is that if people have not stopped for 3 months the DVLA do not need to be informed.. Insurance companies have more varying requirements but these were seen to be arbitrary and not evidence-based. The committee also spoke about the importance of other usual activities such as having sex and return to sports after joint replacement surgery. This led the committee to recommend preoperative discussion of returning to usual activities, such as driving, playing sports, and sexual activity in the postoperative period.

The committee discussed how information could be delivered. There are benefits to written and verbal communication. It was noted that these principles are not unique to joint replacement and recommendations are included in 'Patient experience in adult NHS services: improving the experience of care for people using adult NHS services' guideline. Principles include the use of a tailored approach for each person, involvement of family members and carers, and encouraging the people to express their personal needs and preferences. The committee decided to make a recommendation to follow the principles on communication, information and shared decision making in patient experience in adult NHS services guideline.

The committee discussed the role of the surgeon in information-giving. The committee noted the value of discussion with the surgeon in the evidence reviews.in establishing trust and allaying fears. The surgeon is commonly conceptualised as the person with knowledge of all aspects of surgery and recovery. However, there are questions more suited to other health professionals, for example, an occupational therapist answering questions about return to work or physiotherapists on physical recovery. Some areas run 'Joint school' or other educational sessions where a series of presentations are given by members of the orthopaedic team on the specific stages of care. The committee noted that not all places have a system of 'joint school'. Pre-operative assessment clinics can also provide individualised information.

The committee discussed the efficiency of group provision of information but also the importance of individualised content where required. There is a danger of orthopaedic teams trying to shoehorn people into a one size fits all pathway and this standardisation isn't always effective.

The committee agreed that it was the quality of the time spent with the health professional rather than the quantity and this could be maximised by effective information-giving prior to the face-to-face meeting with the surgeon. For example, if a person were better informed for

the initial clinical consultation appointment then they can ask the questions that require surgical expertise on that occasion. Therefore, committee decided that the recommendations would not specify who gives the information and this would be organised using a flexible, pragmatic approach by the orthopaedic teams based on local service specification and pathways in local areas.

One complex area was the timing of provision of information prior to surgery. The committee were certain that this should begin at the time of listing for surgery and be ongoing throughout the whole care pathway.

It's important not to deliver the information too late for practical use as was done in the postal provision of written information in one study. However, the committee that there is a further layer of complexity which are people's changing needs for information in the period running up to surgery. A committee member stressed this by saying "different people need different information at different time points." The committee were aware that this means it is not possible to give standardised timings on when information should be delivered and did not include specifics in the recommendations. It should be left to the local orthopaedic team to use their knowledge and expertise to deliver the information at a time that suits the person having surgery in keeping with local care pathways.

The committee discussed that different members of the multidisciplinary team have experience and expertise in different areas. Discussions could be with any suitably qualified member of the multidisciplinary team. Should a person have specific needs or a specific query then the multidisciplinary team member with the appropriate experience will be consulted and involved in discussions.

1.7.2 Cost effectiveness and resource use

No economic evidence was searched for or presented regarding information needs for people undergoing a joint replacement.

The committee agreed that return to work information should be given. It was suggested this could be done towards the end of the day at joint school when people could be offered a meeting with an occupational therapist (OT). The OT can give individualised information and answer queries on return to work after surgery. As the OT would already be present during joint school this is not likely to represent additional resource use.

Verbal information dissemination may be required at times. There may be a resource impact depending on which member of staff does this, and when they do it. The committee agreed that supporting surgeons to provide information was correct but some aspects of information provision are better done by others and a team approach is required. The committee decided that the recommendations would not specify who gives the information and this would need to be organised using a flexible, pragmatic approach by the orthopaedic teams based on local service specification.

The recommendation cross refers to the Patient experience in adult NHS services: improving the experience of care for people using adult NHS services guideline.³³.

1.7.3 Other considerations

The committee were aware that some people who have had a joint replacement will require a fit note for their employer. It is anticipated that clinicians will follow the Department of Work & Pensions guidance for this (Statement of Fitness for Work, A guide for hospital doctors', https://www.gov.uk/government/publications/fit-note-guidance-for-hospital-doctors).

References

- 1. Abu Al-Rub Z, Hussaini M, Gerrand CH. What do patients know about their joint replacement implants? Scottish Medical Journal. 2014; 59(3):158-61
- 2. Al-Taiar A, Al-Sabah R, Elsalawy E, Shehab D, Al-Mahmoud S. Attitudes to knee osteoarthritis and total knee replacement in Arab women: A qualitative study. BMC Research Notes. 2013; 6:406
- 3. Andersson V, Otterstrom-Rydberg E, Karlsson AK. The importance of written and verbal information on pain treatment for patients undergoing surgical interventions. Pain Management Nursing. 2015; 16(5):634-41
- Aquilina R, Baldacchino D. An exploratory study of Maltese patients' perceptions of their preparation for total joint replacement at the pre-admission clinic. Journal of Orthopaedic Nursing. 2007; 11(3-4):194-203
- Bardgett M, Lally J, Malviya A, Deehan D. Return to work after knee replacement: A qualitative study of patient experiences. BMJ Open. 2016; 6(2):e007912
- 6. Bardgett M, Lally J, Malviya A, Kleim B, Deehan D. Patient-reported factors influencing return to work after joint replacement. Occupational Medicine (Oxford). 2016; 66(3):215-21
- 7. Barlow T, Griffin D, Barlow D, Realpe A. Patients' decision making in total knee arthroplasty: A systematic review of qualitative research. Bone & Joint Research. 2015; 4(10):163-9
- 8. Barlow T, Scott P, Griffin D, Realpe A. How outcome prediction could affect patient decision making in knee replacements: A qualitative study. BMC Musculoskeletal Disorders. 2016; 17:304
- 9. Barlow T, Scott P, Thomson L, Griffin D, Realpe A. The decision-making threshold and the factors that affect it: A qualitative study of patients' decision-making in knee replacement surgery. Musculoskeletal Care. 2018; 16(1):3-12
- Billon L, Decaudin B, Pasquier G, Lons A, Deken-Delannoy V, Germe AF et al. Prospective assessment of patients' knowledge and informational needs and of surgeon-to-patient information transfer before and after knee or hip arthroplasty. Orthopaedics & Traumatology, Surgery & Research. 2017; 103(8):1161-1167
- 11. Cano-Plans S, Lacueva-Perez L, Cabrera E, Zabalegui A. Knowledge expectations of orthopaedic patients. International Journal of Nursing Practice. 2018; 24(3):e12639
- 12. Chabaud A, Eschalier B, Zullian M, Plan-Paquet A, Aubreton S, Saragaglia D et al. Mixed qualitative and quantitative approach for validating an information booklet before total hip arthroplasty. Annals of Physical and Rehabilitation Medicine. 2018; 61(3):140-143
- 13. Cheung KW, Chung SL, Chung KY, Chiu KH. Patient perception and knowledge on total joint replacement surgery. Hong Kong Medical Journal. 2013; 19(1):33-7
- 14. Conner-Spady BL, Marshall DA, Hawker GA, Bohm E, Dunbar MJ, Frank C et al. You'll know when you're ready: A qualitative study exploring how patients decide when the time is right for joint replacement surgery. BMC Health Services Research. 2014; 14:454

- 15. Conradsen S, Gjerseth MM, Kvangarsnes M. Patients' experiences from an education programme ahead of orthopaedic surgery a qualitative study. Journal of Clinical Nursing. 2016; 25(19-20):2798-806
- 16. Demierre M, Castelao E, Piot-Ziegler C. The long and painful path towards arthroplasty: A qualitative study. Journal of Health Psychology. 2011; 16(4):549-60
- 17. Doust JA, Morgan TN, Weller BJ, Yuill BJ. Patient desire for information before a total hip-replacement operation. Medical Journal of Australia. 1989; 151(4):201
- 18. Fujita K, Makimoto K, Hotokebuchi T. Qualitative study of osteoarthritis patients' experience before and after total hip arthroplasty in Japan. Nursing & Health Sciences. 2006; 8(2):81-7
- 19. Gillespie B, Spalding NJ. A phenomenological study of patients' experiences of an orthopaedic preadmission clinic. International Journal of Therapy & Rehabilitation. 2007; 14(1):16-23
- Goldsmith LJ, Suryaprakash N, Randall E, Shum J, MacDonald V, Sawatzky R et al. The importance of informational, clinical and personal support in patient experience with total knee replacement: A qualitative investigation. BMC Musculoskeletal Disorders. 2017; 18(1):127
- 21. Hovik LH, Aglen B, Husby VS. Patient experience with early discharge after total knee arthroplasty: A focus group study. Scandinavian Journal of Caring Sciences. 2018; 32(2):833-842
- 22. Hsu KY, Tsai YF, Yeh WL, Chen DW, Chen CY, Wang YW. Triggers and decision-making patterns for receiving total knee arthroplasty among older adults with knee osteoarthritis: A qualitative descriptive study. Journal of Clinical Nursing. 2018; 27(23-24):4373-4380
- 23. Jacobson AF, Myerscough RP, Delambo K, Fleming E, Huddleston AM, Bright N et al. Patients' perspectives on total knee replacement. American Journal of Nursing. 2008; 108(5):54-63
- 24. Kazmierski D, Truszczynska-Baszak A, Malgorzata K, Jerzy B. The knowledge of patients after total hip arthroplasty regarding postsurgical recommendations and physiotherapy. Postepy Rehabilitacji. 2018; 32(1):21-30
- 25. Kendall VEM. The lived experience of younger, active women in recovery from a total hip replacement. Saybrook University. 2014. Ph.D.
- Kennedy D, Wainwright A, Pereira L, Robarts S, Dickson P, Christian J et al. A qualitative study of patient education needs for hip and knee replacement. BMC Musculoskeletal Disorders. 2017; 18:413
- 27. Kirsi J, Tuij L, Helena L-K. Finnish pilot study of empowering patient education from the point of view of orthopaedic patients and their significant others. Journal of Orthopaedic Nursing. 2009; 13(4):212-212
- 28. Ko Y-L, Wu H-F, Lin P-C. A survey of patients' quality of life and health-care needs prior to undergoing total joint replacement surgery. International Journal of Nursing Practice. 2013; 19(4):415-422
- 29. Koekenbier K, Leino-Kilpi H, Cabrera E, Istomina N, Stark ÅJ, Katajisto J et al. Empowering knowledge and its connection to health-related quality of A life: A cross-cultural study: A concise and informative title: Empowering knowledge and its connection to health-related quality of life. Applied Nursing Research. 2016; 29(1):211-216

- 30. Krupic F, Maatta S, Garellick G, Lyckhage ED, Karrholm J. Preoperative information provided to Swedish and immigrant patients before total hip replacement. Medicinski Arhiv. 2012; 66(6):399-404
- 31. Lane JV, Hamilton DF, MacDonald DJ, Ellis C, Howie CR. Factors that shape the patient's hospital experience and satisfaction with lower limb arthroplasty: An exploratory thematic analysis. BMJ Open. 2016; 6:e010871
- 32. Mota RE, Tarricone R, Ciani O, Bridges JF, Drummond M. Determinants of demand for total hip and knee arthroplasty: A systematic literature review. BMC Health Services Research. 2012; 12:225
- 33. National Clinical Guideline Centre. Patient experience in adult NHS services: improving the experience of care for people using adult NHS services. NICE clinical guideline 138. London. National Clinical Guideline Centre, 2012. Available from: http://www.nice.org.uk/CG138
- 34. National Institute for Health and Care Excellence. Developing NICE guidelines: the manual [updated 2018]. London. National Institute for Health and Care Excellence, 2014. Available from: http://www.nice.org.uk/article/PMG20/chapter/1%20Introduction%20and%20overview
- 35. Parks ML, Hebert-Beirne J, Rojas M, Tuzzio L, Nelson CL, Boutin-Foster C. A qualitative study of factors underlying decision making for joint replacement among African Americans and Latinos with osteoarthritis. Journal of Long-Term Effects of Medical Implants. 2014; 24(2-3):205-12
- 36. Parsons GE, Godfrey H, Jester RF. Living with severe osteoarthritis while awaiting hip and knee joint replacement surgery. Musculoskeletal Care. 2009; 7(2):121-35
- 37. Prouty A, Cooper M, Thomas P, Christensen J, Strong C, Bowie L et al. Multidisciplinary patient education for total joint replacement surgery patients. Orthopaedic Nursing. 2006; 25(4):257-61; quiz 262-3
- 38. See MTA, Kowitlawakul Y, Tan AJQ, Liaw SY. Expectations and experiences of patients with osteoarthritis undergoing total joint arthroplasty: An integrative review. International Journal of Nursing Practice. 2018; 24(2):e12621
- Sharrock C, Kennedy D, Spencer S. Patients' expectations, experiences and the determinants of satisfaction related to metacarpophalangeal arthroplasty. Musculoskeletal Care. 2014; 12(3):132-40
- 40. Smith DH, Kuntz J, DeBar L, Mesa J, Yang X, Boardman D et al. A qualitative study to develop materials educating patients about opioid use before and after total hip or total knee arthroplasty. Journal of Opioid Management. 2018; 14(3):183-190
- 41. Soever LJ, Mackay C, Saryeddine T, Davis AM, Flannery JF, Jaglal SB et al. Educational needs of patients undergoing total joint arthroplasty. Physiotherapy Canada. 2010; 62(3):206-14
- 42. Spalding NJ. Clients' views of preoperative education before hip replacement...symposium on patient education. British Journal of Therapy & Rehabilitation. 2001; 8(4):130-135
- 43. Specht K, Kjaersgaard-Andersen P, Pedersen BD. Patient experience in fast-track hip and knee arthroplasty--a qualitative study. Journal of Clinical Nursing. 2016; 25(5-6):836-45

44. Spooner MT. The experience of preoperative patient education for women preparing for and recovering from total knee replacement. Boston, MA. Northeastern University. 2018. Ph.D.

Appendices

Appendix A: Review protocols

Table 4: Review protocol: Information needs

Table 4: Review protocol: Information needs		
ID	Field	Content
0.	PROSPERO registration number	Not registered
1.	Review title	Information needs prior to joint replacement surgery
2.	Review question	What information would those having primary elective joint replacement surgery like to have prior to surgery?
3.	Objective	To find out through qualitative research what information people (and their carers/families) who are having joint replacement would like prior to surgery.
4.	Searches	The following databases will be searched: Embase MEDLINE CINAHL, Current Nursing and Allied Health Literature PsycINFO 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 committee meeting and further studies retrieved for inclusion if relevant. The full search strategies will be published in the final review.
5.	Condition or domain being studied	Primary elective joint replacement surgery

ID	Field	Content
6.	Population	Inclusion: Adults having primary elective joint replacement.
		Exclude data from people meeting any of the following criteria: Adults having joint replacement as immediate treatment following fracture. Adults having revision joint replacement.
		Adults having joint replacement as treatment for primary or secondary cancer affecting the bones.
7.	Intervention/Exposure/T est	Participants' views, accounts and interpretations of the information they received on surgical risks and benefits before undergoing joint replacement surgery.
8.	Comparator/Reference standard/Confounding factors	Not applicable
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 articles.
11.	Context	N/A
12.	Primary outcomes (critical outcomes)	Themes will be derived from the evidence identified for this review and not pre-specified.
13.	Secondary outcomes (important outcomes)	Not applicable
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 information 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

ID	Field	Content			
		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 this review the CASP qualitative checklist will be used to assess risk of bias of individual studies. A sample of 10% of the critical appraisals will be quality assured by a second reviewer. 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	If suggested by the evidence, themes may be reported separately for patients, families and carers.			
18.	Type and method of review		Intervention		
			Diagnostic		
			Prognostic Qualitative		
		\boxtimes			
			Epidemiologic		
			Service Delivery	/	
			Other (please sp	pecify)	
19.	Language	English			
20.	Country	England			
21.	Anticipated or actual start date	26/04/19			
22.	Anticipated completion date	20/03/20			
23.	Stage of review at time	Review stage		Started	Completed
	of this submission	Preliminary searches			▽

ID	Field	Content		
		Piloting of the study selection process		V
		Formal screening of search results against eligibility criteria		▼
		Data extraction		
		Risk of bias (quality) assessment		
		Data analysis		
24.	Named contact	5a. Named contact [Give development centre name] 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 G	uideline Centre	
25.	Review team members	From the National Guideline Centre: Carlos Sharpin [Guideline lead] Alex Allen [Senior Systematic Reviewer] Rafina Yarde [Systematic reviewer] Robert King [Health economist] Agnès Cuyàs [Information specialist] Eleanor Priestnall [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		

ID	Field	Content	
		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: [NICE guideline webpage].	
29.	Other registration details	N/A	
30.	Reference/URL for published protocol	[Give the citation and link for the published protocol, if there is one.]	
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	Patients experience, information, diverticular disease	
33.	Details of existing review of same topic by same authors	N/A	
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

The literature searches for this review are detailed below and complied with the methodology outlined in Developing NICE guidelines: the manual.³⁴

For more detailed information, please see the Methodology Review.

B.1 Clinical search literature search strategy

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

Table 5: Database date parameters and filters used

Database	Dates searched	Search filter used
Medline (OVID)	1946 – 01 May 2019	Exclusions Qualitative studies
Embase (OVID)	1974 – 01 May 2019	Exclusions Qualitative studies
CINAHL, Current Nursing and Allied Health Literature (EBSCO)	Inception – 01 May 2019	Exclusions Qualitative studies
PsycINFO (ProQuest)	Inception – 01 May 2019	Exclusions Qualitative studies

Medline (Ovid) search terms

1.	arthroplasty/ or arthroplasty, replacement/ or arthroplasty, replacement, hip/ or arthroplasty, replacement, knee/ or arthroplasty, replacement, shoulder/ or hemiarthroplasty/
2.	joint prosthesis/ or hip prosthesis/ or knee prosthesis/ or shoulder prosthesis/
3.	((joint* or knee* or shoulder* or hip*) adj5 (surger* or replace* or prosthe* or endoprosthe* or implant* or artificial or arthroplast* or hemiarthroplast*)).ti,ab.
4.	or/1-3
5.	letter/
6.	editorial/
7.	news/
8.	exp historical article/
9.	Anecdotes as Topic/
10.	comment/
11.	case report/
12.	(letter or comment*).ti.
13.	or/5-12
14.	randomized controlled trial/ or random*.ti,ab.
15.	13 not 14
16.	animals/ not humans/
17.	exp Animals, Laboratory/
18.	exp Animal Experimentation/

19.	exp Models, Animal/
20.	exp Rodentia/
21.	(rat or rats or mouse or mice).ti.
22.	or/15-21
23.	4 not 22
24.	limit 23 to English language
25.	Patients/ or Inpatients/ or Outpatients/
26.	Caregivers/ or exp Family/ or exp Parents/ or exp Legal-Guardians/
27.	(patient* or carer* or caregiver* or famil*).ti,ab.
28.	or/25-27
29.	Patient Education Handout/ or exp Information-Services/ or Publications/ or Books/ or Pamphlets/ or Counseling/ or Directive-Counseling/
30.	28 and 29
31.	(patient* adj3 (education or educate or educating or literature or leaflet* or booklet* or pamphlet* or information*)).ti,ab.
32.	Patient Education as Topic/
33.	Consumer Health Information/
34.	(information* adj3 (patient* or need* or requirement* or support* or seek* or access* or disseminat* or barrier*)).ti,ab.
35.	(discharge* adj3 (information* or advice)).ti,ab.
36.	or/31-35
37.	exp Consumer Behavior/ or Personal-Satisfaction/ or exp Patient-Acceptance-Of-Health-Care/
38.	((patient* or user* or carer* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or significant other* or partner*) adj3 (attitud* or priorit* or perception* or preferen* or expectation* or choice* or perspective* or view* or satisfact* or inform*)).ti,ab.
39.	((patient* or user* or carer* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or significant other* or partner*) adj3 (knowledge or awareness or misconception* or understanding or misunderstanding)).ti,ab.
40.	((patient* or user* or carer* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or significant other* or partner*) adj3 (experience or experiences or opinion* or concern* or belief* or feeling* or idea* or satisfaction or anxiet* or fear* or acceptance or denial or stigma* or label* or behaviour* or behavior*)).ti,ab.
41.	((patient* or user* or carer* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or significant other* or partner*) adj3 (need* or requirement* or support* or communication* or involve*)).ti,ab.
42.	or/37-41
43.	30 or 36 or 42
44.	24 and 43
45.	Qualitative research/ or Narration/ or exp Interviews as Topic/ or exp "Surveys and Questionnaires"/ or Health care surveys/
46.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
47.	(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.
48.	or/45-47
49.	44 and 48

Embase (Ovid) search terms

1.	*arthroplasty/ or *replacement arthroplasty/ or *hip replacement/ or *knee replacement/ or *shoulder replacement/ or *hemiarthroplasty/
2.	*joint prosthesis/ or *hip prosthesis/ or *knee prosthesis/ or *shoulder prosthesis/
3.	((joint* or knee* or shoulder* or hip*) adj5 (surger* or replace* or prosthe* or endoprosthe* or implant* or artificial or arthroplast* or hemiarthroplast*)).ti,ab.
4.	or/1-3
5.	letter.pt. or letter/
6.	note.pt.
7.	editorial.pt.
8.	case report/ or case study/
9.	(letter or comment*).ti.
10.	or/5-9
11.	randomized controlled trial/ or random*.ti,ab.
12.	10 not 11
13.	animal/ not human/
14.	nonhuman/
15.	exp Animal Experiment/
16.	exp Experimental Animal/
17.	animal model/
18.	exp Rodent/
19.	(rat or rats or mouse or mice).ti.
20.	or/12-19
21.	4 not 20
22.	limit 21 to English language
23.	*patient/ or *hospital patient/ or *outpatient/
24.	*caregiver/ or *family/ or adult child/ or family relation/ or grandparent/ or military family/ or nuclear family/ or single-parent family/ or *parent/ or father/ or mother/ or single parent/ or legal guardian/
25.	(patient* or carer* or caregiver* or famil*).ti,ab.
26.	or/23-25
27.	information service/ or documentation/ or publication/ or book/ or counseling/ or directive counseling/
28.	26 and 27
29.	(patient* adj3 (education or educate or educating or literature or leaflet* or booklet* or pamphlet* or information*)).ti,ab.
30.	patient education/
31.	consumer health information/
32.	(information* adj3 (patient* or need* or requirement* or support* or seek* or access* or disseminat* or barrier*)).ti,ab.
33.	(discharge* adj3 (information* or advice)).ti,ab.
34.	or/29-33
35.	*consumer attitude/ or *satisfaction/ or patient attitude/ or patient compliance/ or patient dropout/ or patient participation/ or patient preference/ or patient satisfaction/
36.	((patient* or user* or carer* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or significant other* or partner*) adj3 (attitud* or priorit* or perception* or preferen* or expectation* or choice* or perspective* or view* or satisfact* or inform*)).ti,ab.

37.	((patient* or user* or carer* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or significant other* or partner*) adj3 (knowledge or awareness or misconception* or understanding or misunderstanding)).ti,ab.
38.	((patient* or user* or carer* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or significant other* or partner*) adj3 (experience or experiences or opinion* or concern* or belief* or feeling* or idea* or satisfaction or anxiet* or fear* or acceptance or denial or stigma* or label* or behaviour* or behavior*)).ti,ab.
39.	((patient* or user* or carer* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or significant other* or partner*) adj3 (need* or requirement* or support* or communication* or involve*)).ti,ab.
40.	or/35-39
41.	28 or 34 or 40
42.	22 and 41
43.	health survey/ or exp questionnaire/ or exp interview/ or qualitative research/ or narrative/
44.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
45.	(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.
46.	or/43-45
47.	42 and 46

CINAHL (EBSCO) search terms

S1.	(MH "Arthroplasty") OR (MH "Arthroplasty, Replacement") OR (MH "Arthroplasty, Replacement, Hip") OR (MH "Arthroplasty, Replacement, Knee") OR (MH "Arthroplasty, Replacement, Shoulder") OR (MH "Hemiarthroplasty")
S2.	(MH "Joint Prosthesis") OR (MH "Shoulder Prosthesis")
S3.	TI ((joint* or knee* or shoulder* or hip*) n5 (surger* or replace* or prosthe* or endoprosthe* or implant* or artificial or arthroplast* or hemiarthroplast*))
S4.	AB ((joint* or knee* or shoulder* or hip*) n5 (surger* or replace* or prosthe* orendoprosthe* or implant* or artificial or arthroplast* or hemiarthroplast*))
S5.	S1 OR S2 OR S3 OR S4
S6.	PT anecdote or PT audiovisual or PT bibliography or PT biography or PT book or PT book review or PT brief item or PT cartoon or PT commentary or PT computer program or PT editorial or PT games or PT glossary or PT historical material or PT interview or PT letter or PT listservs or PT masters thesis or PT obituary or PT pamphlet or PT pamphlet chapter or PT pictorial or PT poetry or PT proceedings or PT "questions and answers" or PT response or PT software or PT teaching materials or PT website
S7.	S5 NOT S6
S8.	(MH "Patients") OR (MH "Inpatients") OR (MH "Outpatients")
S9.	(MH "Caregivers") OR (MH "Family+") OR (MH "Parents+") OR (MH "Guardianship, Legal+")
S10.	TI (patient* or carer* or caregiver* or famil*)
S11.	AB (patient* or carer* or caregiver* or famil*)
S12.	S8 OR S9 OR S10 OR S11
S13.	(MH "Information Services+") OR (MH "Books") OR (MH "Pamphlets") OR (MH "Counseling")
S14.	S12 AND S13

S15.	TI (patient* n3 (education or educate or educating or literature or leaflet* or booklet* or pamphlet* or information*))
S16.	AB (patient* n3 (education or educate or educating or literature or leaflet* or booklet* or pamphlet* or information*))
S17.	(MH "Patient Education")
S18.	(MH "Consumer Health Information")
S19.	TI (information* n3 (patient* or need* or requirement* or support* or seek* or access* or disseminat* or barrier*))
S20.	AB (information* n3 (patient* or need* or requirement* or support* or seek* or access* or disseminat* or barrier*))
S21.	TI (discharge* n3 (information* or advice))
S22.	AB (discharge* n3 (information* or advice))
S23.	S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22
S24.	(MH "Consumer Attitudes") OR (MH "Personal Satisfaction") OR (MH "Patient Attitudes") OR (MH "Patient Compliance") OR (MH "Patient Dropouts") OR (MH "Patient Preference") OR (MH "Patient Satisfaction")
S25.	TI ((patient* or user* or carer* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or significant other* or partner*) n3 (attitud* or priorit* or perception* or preferen* or expectation* or choice* or perspective* or view* or satisfact* or inform*))
S26.	AB ((patient* or user* or carer* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or significant other* or partner*) n3 (attitud* or priorit* or perception* or preferen* or expectation* or choice* or perspective* or view* or satisfact* or inform*))
S27.	TI ((patient* or user* or carer* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or significant other* or partner*) n3 (knowledge or awareness or misconception* or understanding or misunderstanding))
S28.	AB ((patient* or user* or carer* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or significant other* or partner*) n3 (knowledge or awareness or misconception* or understanding or misunderstanding))
S29.	TI ((patient* or user* or carer* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or significant other* or partner*) n3 (experience or experiences or opinion* or concern* or belief* or feeling* or idea* or satisfaction or anxiet* or fear* or acceptance or denial or stigma* or label* or behaviour* or behavior*))
S30.	AB ((patient* or user* or carer* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or significant other* or partner*) n3 (experience or experiences or opinion* or concern* or belief* or feeling* or idea* or satisfaction or anxiet* or fear* or acceptance or denial or stigma* or label* or behaviour* or behavior*))
S31.	TI ((patient* or user* or carer* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or significant other* or partner*) n3 (need* or requirement* or support* or communication* or involve*))
S32.	AB ((patient* or user* or carer* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or significant other* or partner*) n3 (need* or requirement* or support* or communication* or involve*))
S33.	S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32
S34.	S14 OR S23 OR S33
S35.	S7 AND S34
S36.	(MH "Qualitative Studies+")
S37.	(MH "Qualitative Validity+")
S38.	(MH "Interviews+") OR (MH "Focus Groups") OR (MH "Surveys") OR (MH "Questionnaires+")
S39.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*)
S40.	(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*)
S41.	S36 OR S37 OR S38 OR S39 OR S40
S42.	S35 AND S41

PsycINFO) (ProQuest) search terms
1.	(((joint* OR knee* OR shoulder* OR hip*) NEAR/5 (surger* OR replace* OR prosthe* OR endoprosthe* OR implant* OR artificial OR arthroplast* OR hemiarthroplast*)) NOT (su.exact.explode("rodents") OR su.exact.explode("mice") OR (su.exact("animals")
	NOT (su.exact("human males") OR su.exact("human females"))) OR ti(rat OR rats OR mouse OR mice)) AND ((MAINSUBJECT.EXACT("Patients")) OR
	MAINSUBJECT.EXACT("Outpatients")) OR (MAINSUBJECT.EXACT.EXPLODE("Parents") OR
	MAINSUBJECT.EXACT("Caregivers") OR MAINSUBJECT.EXACT.EXPLODE("Family") OR
	MAINSUBJECT.EXACT("Guardianship")) ÓR (patient* OR carer* OR caregiver* OR famil*) AND (MAINSUBJECT.EXACT("Books") OR
	MAINSUBJECT.EXACT.EXPLODE("Information Services") OR
	MAINSUBJECT.EXACT("Counseling")) OR ((patient* NEAR3 (education OR educate OR educating OR literature OR leaflet* OR booklet* OR pamphlet* OR information*)) OR MAINSUBJECT.EXACT("Patient education") OR (information* NEAR3 (patient* OR need* OR requirement* OR support* OR seek* OR access* OR disseminat* OR
	barrier*)) OR (discharge* NEAR3 (information* OR advice)))) OR
	(MAINSUBJECT.EXACT("Satisfaction") OR MAINSUBJECT.EXACT.EXPLODE("Consumer Attitudes") OR
	MAINSUBJECT.EXACT("Client Attitudes") OR MAINSUBJECT.EXACT("Treatment Dropouts") OR MAINSUBJECT.EXACT("Client Satisfaction") OR
	MAINSUBJECT.EXACT("Client Participation") OR ((patient* OR user* OR carer* OR
	famil* OR parent* OR father* OR mother* OR spouse* OR wife OR wives OR husband* OR significant other* OR partner*) NEAR3 (attitud* OR priorit* OR
	perception* OR preferen* OR expectation* OR choice* OR perspective* OR view* OR
	satisfact* OR inform*)) OR ((patient* OR user* OR carer* OR famil* OR parent* OR father* OR mother* OR spouse* OR wife OR wives OR husband* OR significant other*
	OR partner*) NEAR3 (knowledge OR awareness OR misconception* OR understanding OR misunderstanding)) OR ((patient* OR user* OR carer* OR famil* OR
	parent* OR father* OR mother* OR spouse* OR wife OR wives OR husband* OR
	significant other* OR partner*) NEAR3 (experience OR experiences OR opinion* OR concern* OR belief* OR feeling* OR idea* OR satisfaction OR anxiet* OR fear* OR
	acceptance OR denial OR stigma* OR label* OR behaviour* OR behavior*)) OR
	((patient* OR user* OR carer* OR famil* OR parent* OR father* OR mother* OR spouse* OR wife OR wives OR husband* OR significant other* OR partner*) NEAR3
	(need* OR requirement* OR support* OR communication* OR involve*))) AND ((joint*
	OR knee* OR shoulder* OR hip*) NEAR/5 (surger* OR replace* OR prosthe* OR endoprosthe* OR implant* OR artificial OR arthroplast* OR hemiarthroplast*)) NOT
	(su.exact.explode("rodents") OR su.exact.explode("mice") OR (su.exact("animals")
	NOT (su.exact("human males") OR su.exact("human females"))) OR ti(rat OR rats OR mouse OR mice)) AND ((MAINSUBJECT.EXACT("Patients") OR
	MAINSUBJECT.EXACT("Outpatients")) OR
	(MAINSUBJECT.EXACT.EXPLODE("Parents") OR MAINSUBJECT.EXACT("Caregivers") OR
	MAINSUBJECT.EXACT.EXPLODE("Family") OR
	MAINSUBJECT.EXACT("Guardianship")) OR (patient* OR carer* OR caregiver* OR famil*) AND (MAINSUBJECT.EXACT("Books") OR
	MAINSUBJECT.EXACT.EXPLODE("Information Services") OR
	MAINSUBJECT.EXACT("Counseling")) AND ((patient* NEAR3 (education OR educate OR educating OR literature OR leaflet* OR booklet* OR pamphlet* OR information*))
	OR MAINSUBJECT.EXACT("Patient education") OR (information* NEAR3 (patient* OR need* OR requirement* OR support* OR seek* OR access* OR disseminat* OR

barrier*)) OR (discharge* NEAR3 (information* OR advice)))) OR (MAINSUBJECT.EXACT("Satisfaction") OR MAINSUBJECT.EXACT.EXPLODE("Consumer Attitudes") OR MAINSUBJECT.EXACT("Client Attitudes") OR MAINSUBJECT.EXACT("Treatment Dropouts") OR MAINSUBJECT.EXACT("Client Satisfaction") OR MAINSUBJECT.EXACT("Client Participation") OR ((patient* OR user* OR carer* OR famil* OR parent* OR father* OR mother* OR spouse* OR wife OR wives OR husband* OR significant other* OR partner*) NEAR3 (attitud* OR priorit* OR perception* OR preferen* OR expectation* OR choice* OR perspective* OR view* OR satisfact* OR inform*)) OR ((patient* OR user* OR carer* OR famil* OR parent* OR father* OR mother* OR spouse* OR wife OR wives OR husband* OR significant other* OR partner*) NEAR3 (knowledge OR awareness OR misconception* OR understanding OR misunderstanding)) OR ((patient* OR user* OR carer* OR famil* OR parent* OR father* OR mother* OR spouse* OR wife OR wives OR husband* OR significant other* OR partner*) NEAR3 (experience OR experiences OR opinion* OR concern* OR belief* OR feeling* OR idea* OR satisfaction OR anxiet* OR fear* OR acceptance OR denial OR stigma* OR label* OR behaviour* OR behavior*)) OR ((patient* OR user* OR carer* OR famil* OR parent* OR father* OR mother* OR spouse* OR wife OR wives OR husband* OR significant other* OR partner*) NEAR3 (need* OR requirement* OR support* OR communication* OR involve*))) 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 metasynthes* 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 theoreticalsampl* 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*)))) AND la.exact("English")

B.2 Health Economics literature search strategy

Health economic evidence was identified by conducting a broad search relating to the joint replacement population in the NHS Economic Evaluation Database (NHS EED – this ceased to be updated after March 2015) and the Health Technology Assessment database (HTA), with no date restrictions. NHS EED and HTA databases are hosted by the Centre for Research and Dissemination (CRD). Additional health economics searches were run in Medline and Embase.

Table 6: Database date parameters and filters used

Database	Dates searched	Search filter used
Medline	2014 – 01 May 2019	Exclusions Health economics studies
Embase	2014 – 01 May 2019	Exclusions Health economics studies
Centre for Research and Dissemination (CRD)	HTA - Inception – 01 May 2019 NHSEED - Inception to March 2015	None

Medline (Ovid) search terms

1.	arthroplasty/ or arthroplasty, replacement/ or arthroplasty, replacement, hip/ or arthroplasty, replacement, knee/ or arthroplasty, replacement, shoulder/ or hemiarthroplasty/
2.	joint prosthesis/ or hip prosthesis/ or knee prosthesis/ or shoulder prosthesis/

3.	((joint* or knee* or shoulder* or hip*) adj5 (surger* or replace* or prosthe* or endoprosthe* or implant* or artificial or arthroplast* or hemiarthroplast*)).ti,ab.
4.	or/1-3
5.	letter/
6.	editorial/
7.	news/
8.	exp historical article/
9.	Anecdotes as Topic/
10.	comment/
11.	case report/
12.	(letter or comment*).ti.
13.	or/5-12
14.	randomized controlled trial/ or random*.ti,ab.
15.	13 not 14
16.	animals/ not humans/
17.	exp Animals, Laboratory/
18.	exp Animal Experimentation/
19.	exp Models, Animal/
20.	exp Rodentia/
21.	(rat or rats or mouse or mice).ti.
22.	or/15-21
23.	4 not 22
24.	limit 23 to English language
25.	Economics/
26.	Value of life/
27.	exp "Costs and Cost Analysis"/
28.	exp Economics, Hospital/
29.	exp Economics, Medical/
30.	Economics, Nursing/
31.	Economics, Pharmaceutical/
32.	exp "Fees and Charges"/
33.	exp Budgets/
34.	budget*.ti,ab.
35.	cost*.ti.
36.	(economic* or pharmaco?economic*).ti.
37.	(price* or pricing*).ti,ab.
38.	(cost* adj2 (effective* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
39.	(financ* or fee or fees).ti,ab.
40.	(value adj2 (money or monetary)).ti,ab.
41.	or/25-40
42.	24 and 41

Embase (Ovid) search terms

1. *arthroplasty/ or *replacement arthroplasty/ or *hip replacement/ or *knee replacement/ or *shoulder replacement/ or *hemiarthroplasty/

2.	*joint prosthesis/ or *hip prosthesis/ or *knee prosthesis/ or *shoulder prosthesis/
3.	((joint* or knee* or shoulder* or hip*) adj5 (surger* or replace* or prosthe* or endoprosthe* or implant* or artificial or arthroplast* or hemiarthroplast*)).ti,ab.
4.	or/1-3
5.	letter.pt. or letter/
6.	note.pt.
7.	editorial.pt.
8.	case report/ or case study/
9.	(letter or comment*).ti.
10.	or/5-9
11.	randomized controlled trial/ or random*.ti,ab.
12.	10 not 11
13.	animal/ not human/
14.	nonhuman/
15.	exp Animal Experiment/
16.	exp Experimental Animal/
17.	animal model/
18.	exp Rodent/
19.	(rat or rats or mouse or mice).ti.
20.	or/12-19
21.	4 not 20
22.	limit 21 to English language
23.	health economics/
24.	exp economic evaluation/
25.	exp health care cost/
26.	exp fee/
27.	budget/
28.	funding/
29.	budget*.ti,ab.
30.	cost*.ti.
31.	(economic* or pharmaco?economic*).ti.
32.	(price* or pricing*).ti,ab.
33.	(cost* adj2 (effective* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
34.	(financ* or fee or fees).ti,ab.
35.	(value adj2 (money or monetary)).ti,ab.
36.	or/23-35
37.	22 and 36

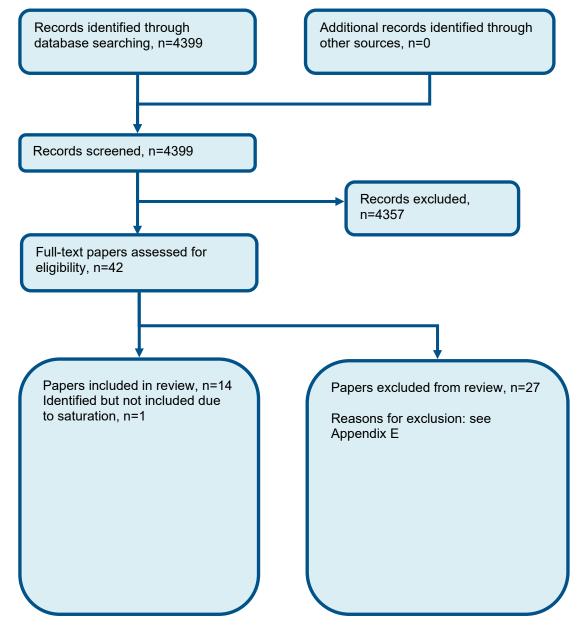
NHS EED and HTA (CRD) search terms

#1.	MeSH DESCRIPTOR arthroplasty
#2.	MeSH DESCRIPTOR arthroplasty, replacement

#3.	MeSH DESCRIPTOR arthroplasty, replacement, hip
#4.	MeSH DESCRIPTOR arthroplasty, replacement, knee
#5.	MeSH DESCRIPTOR arthroplasty, replacement, shoulder
#6.	MeSH DESCRIPTOR hemiarthroplasty
#7.	MeSH DESCRIPTOR joint prosthesis
#8.	MeSH DESCRIPTOR hip prosthesis
#9.	MeSH DESCRIPTOR knee prosthesis
#10.	MeSH DESCRIPTOR shoulder prosthesis
#11.	(((joint* or knee* or shoulder* or hip*) adj5 (surger* or replace* or prosthe* or endoprosthe* or implant* or artificial or arthroplast* or hemiarthroplast*)))
#12.	(#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11) IN NHSEED
#13.	(#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11) IN HTA

Appendix C: Qualitative evidence selection

Figure 2: Flow chart of qualitative study selection for the review of information needs



Appendix D: Qualitative evidence tables

Study	Aquilina 2007 ⁴
Aim	To explore peoples' perceptions relating to preparation for total joint replacement surgery at the pre-admission clinic (PAC). To identify the perceived value of the information provided and to identify factors that enhance or inhibit preparation.
Population	31 consecutive Maltese people scheduled to undergo hip (n=9) or knee (n=21) total joint replacement surgery were invited to join the study. All but 1 accepted. 4 people had previous joint replacement operations. Mean (range) age: 71 (58 to 85). 13 male and 17 female.
Setting	Maltese General Hospital
Study design	Qualitative study
Methods and analysis	In-depth semi-structured interviews of up to 45 minutes. The interviews took place 1 day before hospital discharge and the statements and observations were written by the interviewer. Seven open ended questions and probing questions to generate in-depth data. The data was analysed thematically through extracting significant statements, formulating meaning, and identifying themes and categories.
Findings	Managing a complex situation: information giving is a complex affair that entails skilled intervention by the healthcare professional since the reflections of some people reflected an internal struggle between the need to know and the apprehension of knowing too much.
	Clarifying the unknown: most people indicated that information on surgery reduced a "fear of the unknown". A person indicated that knowing exactly what was going to occur was like having a tranquiliser pill. This reduction in anxiety positively affected a relative who was present for an interview. Reducing anxiety of the unknown such having seen pictures of a space blanket and home modifications for the post surgery period.
	Conflicting knowledge needs: 8 people stated apprehension at hearing about potential complications. It might alienate people from having the surgery. The information is necessary but "what am I getting into". Maybe it could be cushioned. Maybe experts should make the decisions about some things themselves such as anaesthesia. Watching the operation on TV made a person very anxious without positive benefit. Also the lived experience is unique for the person and information will not explain how your own experience will be.
	Experiencing the clinic: this is around the organisation of the pre-admission clinic.
	Complementary educational strategies: Combined approach of verbal and written information. Verbal was seen as "humanising" while booklets are a reminder and source of reference. Both appear to be useful. The pictures in the booklet are a useful way to provide knowledge and understanding. Useful to have a relative who might recall specifics better.
	Organisation of care: Structure and organisation of the pre-admission clinic. Somewhere organised with clear and detailed instructions. A much faster experience than expected. Individualised attention and feelings of encouragement. Made a person feel respected as an intelligent individual and a human being not paternalistic and controlling. There are some shared care choices to be made and that is positive.

Study	Aquilina 2007 ⁴
Limitations and applicability of evidence	Minor limitations. The assessment of pre-admission clinics was direct and applicable to this evidence review.

Study	Bardgett 2016a ⁵
Study	
Aim	To identify factors influencing return to work following knee replacement
Population	10 participants selected from a cohort of 50 people undergoing primary total knee replacement who were recruited into a population-based postal questionnaire study investigating barriers and facilitators to return to work after joint replacement carried out at the same institution. All were under the age of 60 years at the time of primary knee replacement surgery for OA. People were excluded from interview if they were unemployed in the 3 months prior to surgery. From the cohort of 50 people, 37 people were in employment preoperatively, and consented to be approached for interview. From these, purposive sampling was used to select patients with a range of characteristics known to influence rates of return to work such as age, gender and type of employment. Age ranged from 40 to 59. 5 men and 5 women. Time until return to work ranged from 2 weeks to 13 weeks.
Setting	Musculoskeletal Outpatient Department of a large teaching hospital in UK from December 2013 to March 2014.
Study design	Qualitative study
Methods and analysis	The interviews ranged from 8 to 35 months after surgery and were undertaken by a trained research physiotherapist. Thematic analysis utilised. People were asked to discuss the impact of their knee symptoms and surgery on work participation incorporating both preoperative and postoperative experiences during the interview. A semi-structured topic guide was used to allow the patients to talk freely about their experiences and expand on any aspects they felt were relevant (figure 1). There was large variation in the length of interviews (30–100 minutes). Interviews were audio recorded and transcribed verbatim. Local R&D approval was obtained and ethical approvals were granted by the Proportionate Review Sub-committee of the NRES Committee London. This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.
	Limited and inconsistent advice between healthcare providers to optimise return to work
	Patients reported that the advice they received from healthcare professionals focused on the needs of the elderly, retired population. Preoperative education reportedly focused on the inpatient stay and immediate postoperative period, but longer term outcomes, such as return to work, were not routinely discussed.
	Patients stated that the content of preoperative education they received reinforced the perception of joint replacement surgery as a procedure for the older retired population. Patients described themselves as the minority, and some reported that it was not appropriate to discuss issues pertinent to them, such as return to work, as it was not relevant to the majority of patients. As duration of absence due to sickness, and return to work, was not routinely discussed preoperatively, patients were unsure of the processes involved, and described looking to healthcare professionals postoperatively for guidance. Patients described waiting until their routine postoperative hospital review or GP appointment for the reassurance and guidance on when they were fit enough to resume activity or permission to

Study	Bardgett 2016a ⁵
	return to work.
	Although most patients stated that it was they who made the decision when to return to work, they also described how this decision was influenced by the advice from healthcare professionals. The advice given at this time did not appear to be tailored to the individual but directly impacted patient's experience, on occasion delaying return to work even when patients felt able to return earlier. Some patients reportedly believed that they should not return to work until the clinician gives permission for insurance or health and safety reasons.
	The majority of patients discussed the potential benefits of more tailored work-related advice, or the involvement of an occupational health worker to discuss the individual's requirements and facilitate the process of return to work. Those patients who did have occupational health involvement described their role in facilitating how they returned to work, but they did not advise on when to return.
Limitations and applicability of evidence	Moderate limitations due to selection of people for the study and data richness. The advice to optimise return to work was direct and applicable to this evidence review.

Study	Conner-Spady 2014 ¹⁴
Aim	To explore the concept of people readiness and describe the factors people consider when assessing their readiness for total joint replacement.
Population	Eligibility criteria for the pre-surgery group were people with osteoarthritis who a) had an orthopaedic surgical consultation and were eligible for primary total joint replacement or b) had been referred to an orthopaedic surgeon for consideration of total joint replacement. The post-surgery group had to have had a primary total joint replacement approximately 12 months previously. In 3 centres consecutive eligible patients were identified through the surgical registry and patient lists in the orthopaedic clinics and were contacted by a clinic nurse or research personnel at each site. In the fourth centre flyers were posted in the orthopaedic hospital clinic and interested people contacted the research manager. For both pre- and postsurgery groups the recruiter attempted to obtain representation from males and females, hip and knee patients, and urban and rural locations. There were 65 participants, 66% female, 34% male, and 80% from urban centres with a mean (SD) age of 65 (10) which ranged from 28 to 89. 26 participants were pre-surgery and 39 were post-surgery. Of the pre-surgery group, 5 participants were waiting to see a surgeon (pre-consult) and 21 had seen the surgeon (post-consult). Of these 21, 14 had decided to have surgery and 7 were undecided or deferring the decision.
Setting	4 cities across Canada: Halifax, Toronto, Winnipeg, and Calgary.
Study design	Qualitative study
Methods and analysis	9 focus groups (4 pre-surgery, 5 postsurgery) were conducted. The purpose was to collect data in a social context in which participants can consider their own views in context with the views of others through a process of sharing perspectives and experiences. Semi-structured interview style questions were used by the moderator. Each focus group lasted approximately 2 hours. People were initially asked to remember when they first considered having joint replacement: what was important, how they made their decision

Study	Conner-Spady 2014 ¹⁴
	regarding having surgery, what factors did they consider and what information sources did they use to help them? Two researchers observed each focus group and took notes. All focus groups were audio- and video-taped and transcribed verbatim. The data were analysed by qualitative thematic analysis
	Ethics approval was obtained from the research ethics boards of the Universities of Dalhousie, Toronto, Manitoba, and Calgary.
Findings	Mental preparation: People weighed the expected benefits of surgery against the perceived risks. Much of the expected benefit centred around pain relief and the activities that this relief enabled. Surgery would let them walk, have a bath, sleep well, work longer, return to active sports like golfing, cross country skiing, and riding a bike. Regaining their mobility also meant independence, resuming a social life, improving their relationships with spouse and family, and 'leading the life that's appropriate for your age'.
	Surgery was associated with uncertainty and the fears of facing an unknown and uncertain future, of anaesthesia, of infections, of being cut, having the wrong joint operated on, of dying, and of failure—that it might not work and you would be worse off.
	People living alone worried about who would help them after surgery, their need to rely on others, and about being alone.
	Patients described their decision whether to undergo surgery as 'weighing the odds', 'taking a gamble', 'taking a chance', and 'a calculated risk'. For many patients this decision process was lengthy. Individuals going ahead with surgery concluded that the benefits outweighed the risks. Undecided individuals still weighed the pros and cons. Some thought they might have surgery sometime, but now they wanted to try alternative therapies. Some on the waiting list remained ambivalent about having surgery. For others it was an easy decision.
	Readiness for surgery included mental preparation to deal with their fears and to gain a sense of control. Patients who had decided on surgery described various strategies to help them prepare and conquer their fears. These included information seeking, planning for aftercare, emphasizing the positive aspects of surgery, minimizing the risks, and putting their trust in the surgeon. One person described readiness as 'being totally informed what to expect'. Typically, patients received information booklets from their surgeon's office before their surgeon consultation. But even after the consultation, questions often remained and some patients desired to meet their surgeon again, to verify the information received and to answer follow-up questions.
	In addition to information provided by the surgeon, patients sought information from reading, from other patients who had similar surgery, from information sessions, and by looking online. Patients wanted to know about the procedure, its risks, aftercare, and what outcomes to expect. These activities gave patients a sense of control and helped them plan for aftercare and anticipate a better quality of life. Other patients minimized the risks, tried to avoid stress, and emphasized the benefits of surgery.
	Patients weighed the situation and experiences of others when making their own decision. They observed their outcomes, their hospital experience, and their post-surgery and recovery experiences. People deciding to have surgery mostly noticed 'success' stories and noted what factors contributed to successful outcomes, such as a positive attitude and a determination to resume activities following surgery. One patient described it as a process of filtering. Talking to others with successful outcomes gave patients hope, especially if they had the same surgeon. For individuals who knew patients who had poorer outcomes, they would rationalize that other factors played a part, for example, the individual didn't exercise before or after surgery.
	The face-to-face meeting with the surgeon was important in establishing a trust relationship, allaying fears, and enabling the patient to feel confident in their decision. Most patients who had met with a surgeon had a trusting relationship with their surgeon.

Study	Conner-Spady 2014 ¹⁴
	Physical preparation: Patients also described readiness in terms of being physically fit and in good shape for surgery. They took steps, such as weight loss and physical exercise, to make their rehabilitation less strenuous and improve their chances of a good surgical outcome. Some felt that if they lost weight, maybe they wouldn't need surgery.
	Optimal timing for surgery: Readiness involved determining the optimal time for surgery. Patients considered their age, their rate of joint deterioration, the lifespan of the prosthesis, and the anticipated wait time. Age was considered primarily in terms of the lifespan of the prosthesis and how many revisions a patient might have. Some patients were told they were too young for surgery or had received conflicting information as to the minimum age for surgery. Others worried about what they would do in ten to fifteen years when they might need a revision. People also considered the years of living with a poor quality of life if nothing was done. Some patients in their 40s or 50s wanted surgery so they could enjoy 20 or 30 years of improved quality of life, while others wanted to wait in case something went wrong. Patients also weighed the consequences of waiting - fears of being in a wheelchair, or deterioration in their condition, and their ability to deal with the pain if their condition worsened.
	The knowledge of long waiting times influenced the decision of some patients as to when to go on the wait list for surgery. Once patients agreed to have surgery, they knew the wait time was long. Because they expected a lengthy wait, some patients agreed to surgery before they were ready and were worried that their condition would deteriorate. Some individuals on the waiting list expressed ambivalence about their decision regarding surgery while others, who went on the list preemptively, expressed dissatisfaction and regret that they had had the surgery.
Limitations and applicability of evidence	Minor limitations. The analysis or readiness for surgery was direct and applicable to this evidence review.

Study	Conradsen 2016 ¹⁵
Aim	To investigate how patient education in a surgical department was experienced by patients who had undergone total hip or knee arthroplasty.
Population	A purposive sample of 11 people were selected who had been to the preoperational programme in the hospital and had knee (n=3) or hip (n=8) arthroplasty. The preoperational programme was a 4 hour group intervention undertaken by nurses, orthopaedics and physiotherapists that consisted of information about surgery, mobilisation after surgery, practical detailed of the hospital stay, pain and other challenges of the postoperative period. Mean (SD) age: 71 (7) ranging from 56 to 82. 3: informal qualifications, 5 practical professional training, 3 higher education degree.
Setting	Town in a rural area on the west coast of Norway in 2011.
Study design	Qualitative study
Methods and analysis	Individual semi-structured interviews carried out at a rehabilitation centre. There were 12 questions and lasted 25-60 minutes. It was audiotaped and transcribed. People were asked about the adequacy of their coping abilities, and around the cognitive, emotional and

Study	Conradsen 2016 ¹⁵
	social aspects of the training programme. Also they were asked about what information would have been useful that was not given. Phenomenological approach used for analysis.
	Application sent to the Regional Committee for Research Ethics to carry out the study.
Findings	Realistic information preparing for surgery
	Some people wanted concrete explicit operative detailed. Also seeing and holding a prosthesis. Several commented positively about this.
	Also appreciated hearing about postoperative challenges such as pain. One person indicated best not to sugarcoat the experience as it would be disappointing afterwards.
	Lack of written material available. Easy to forget oral information. Written information on expected order of events, a "step by step" guide would be beneficial.
	Involvement and sense of control
	Information programme made people feel "the process had started". Allowed people to state feelings of anxiety and vulnerability. It was a basis for deciding on surgery.
	Some seemed to appreciate the responsibility about making decisions while others had mixed feelings. People felt their decision making in hospital around diet, sleeping hours and other practical matters was more limited than expected. You have to "buy" what they offer. However people also expressed satisfaction with daily routines.
	Other treatment options underemphasised by surgeons. People were not aware of non-surgical treatments.
	In general there was an opinion that good information makes the process safer and no information means no safety.
	Trust in staff
	Trustful relationship with hospital, rehabilitation centre and the staff involved makes the experience much more comfortable. Important for the person to feel respected. Lack of information or misleading information may damage this trust, especially as regards pain involved. It also important to give an accurate account of postoperative procedure such as rehabilitation as discrepancies can damage trust in the process.
Limitations and applicability of evidence	Moderate limitations due to selection of people for the study. The analysis of education in the surgical department was carried out preoperatively and this is a moderate concern in terms of relevance for this evidence review.

Study	Demierre 2011 ¹⁶
Aim	Longitudinal research project exploring the patient experience from the moment of deciding to have joint replacement surgery until

Study	Demierre 2011 ¹⁶
	12months post surgery.
Population	24 adults under 75 years of age Mean (SD) age: 60 (11) 12 people awaiting hip arthroplasty and 12 people awaiting knee arthroplasty. 9 men and 15 women. 8 people had previous arthroplasty
Setting	People experiencing hip or knee arthroplasty in 1 hospital.
Study design	Qualitative study
Methods and analysis	Semi-structured interviews 1 month before hip or knee arthroplasty. Interview schedule used to explore common themes such as course of illness, representations of prosthesis, people's experiences of medical support and treatment, and postoperative expectations. Interviews lasted mean 18 minutes and were recorded and transcribed. Thematic analysis utilised. Approved by the University Hospital Ethical Board: Universite de Lausanne, Switzerland.
Findings	Expectations about arthroplasty : Expectations are about recovering lost quality of life. "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".
	Postoperative life: people have imprecise idea of what rehabilitation will entail. Functional difficulties and for example finding a suitable position when sleeping on ones back. Many physiotherapy sessions and necessity of intense walking.
Limitations and applicability of evidence	Severe limitations as it was unclear how people were selected for the study and the interviews were short. Longitudinal research project exploring the patient experience from the moment of deciding to have joint replacement surgery until 12months post surgery. preadmission clinics is direct and applicable to this evidence review.

Study	Gillespie 2007 ¹⁹
Aim	To assess what people felt they gained from the preadmission process that is in place.
Population	10 consecutive people referred to the preoperative assessment clinic who consented and fit the inclusion criteria. The criteria were adults, first attendance of the pre-assessment clinic and first total hip replacement or resurfacing arthroplasty. Exclusion criteria were English as a second language or communication difficulties, cognitive or learning difficulties, and having revision arthroplasty. 7 private patients and 3 NHS patients. Age range 43 to 78 years old. 4 men and 6 women.
Setting	UK hospital.
Study design	Qualitative study

Study	Gillespie 2007 ¹⁹
Methods and analysis	Semi-structured interviews were used. These took 30-40 minutes and happened 1-3 days after surgery. They were conducted, recorded and transcribed by the same researcher.
	Phenomenological approach to focus on the lived experience of a preoperative assessment clinic.
	The interviews were taped and transcribed.
	Permission for the study was gained from both the Chairman of the Independent Hospital Medical Council and the Local NHS Research Ethics Committee.
Findings	Being with a relative: having a partner at the clinic is beneficial for emotional support and helping to remember and reinforce what was discussed. Relatives or partners could better appreciate what was going to happen and how to cope.
	Written information: Written information was valued because of its clarity and use it at home and during preoperative preparations.
	Thorough assessment: Many questions asked during the screening process. This contributed to a feeling of thoroughness on the part of the nursing staff. Also people could discuss their own specific situations.
	Attitudes of staff: High degree of knowledge and professionalism was commented on and was reassuring. Positive attitude was appreciated. Named nurse contact was important too. Staff offered advice rather than instruction and this was positive: "not too didactic, not too pedantic". Shared decision making very much appreciated.
	Educational content: Structured chronological information such as expected discharge date that they could make plans around. Also things like the move from crutches to stick, when to walk 1 mile, when it is safe to drive. The perception was of much more limited postoperative function. Also things like stopping some medications preoperatively or postoperatively.
	Negative experiences: subjects related to areas outside the person's control. Aspects of the clinic as "frightening" and one person had "sleepless nights" after seeing colour pictures of a hip replacement wound. This always related to medical procedures such as electrocardiograph testing, discussing aspects of surgery, phlebotomy, and two people with needle phobia.
Limitations and applicability of evidence	Minor limitations. The assessment of preadmission clinics is direct and applicable to this evidence review.

Study	Goldsmith 2017 ²⁰
Aim	To improve the understanding of a person's experience and their satisfaction following total knee replacement
Population	People aged 19 years or older with a primary or secondary diagnosis of osteoarthritis scheduled to undergo primary total knee replacement in Canada between April 2012 and August 2013.
Setting	Varied: participant's homes and medical clinics
Study design	Qualitative study
Methods and	Semi-structured, in-depth interviews with 45 people 8 months after surgery. Interviews lasted from 45 to 65 minutes

Study	Goldsmith 2017 ²⁰
analysis	The interviews and debriefs were digitally recorded and transcribed.
	The interviews were independently coded by 2 reviewers.
	Ethics approval and consent to participate Ethics approval for this study was obtained from relevant universities and health regions: University of British Columbia, Simon Fraser University, Trinity Western University, Fraser Health Authority, Vancouver Coastal Health Authority, Vancouver Island Health Authority, Interior Health Authority, Northern Health Authority.
Findings	People received information through formal clinical sources, such as pre-surgical education sessions and health care providers, and informal personal sources, such as friends and family, the internet, and, when applicable, their experience with having already received TKA on their other knee. Talking to other TKA patients was another form of informational support.
	Some participants further said that their education session information was not meaningful as it was difficult to understand or remember the instructions or it was difficult to reconcile the different messages they received from different presenters.
	Surgeons were key clinical sources of information about TKA preparation and recovery, although many participants wanted more information from their surgeon than they received.
	The most frequent type of informational support identified as needing improvement was information on pain expectations. People expressed concern about inadequate information regarding pain management.
	People wanted to understand the variety of TKA recovery trajectories so they could be assured they were on some sort of a track to recovery, even if it was not the ideal track or an ideal recovery
Limitations and applicability of evidence	Minor limitations. The assessment of people who have had TKA is direct and applicable to this evidence review.

Study	Jacobson 2008 ²³
Aim	To describe the pre- and postoperative experiences of people undergoing total knee replacement surgery
Population	17 people in the preoperative period and 10 people in the postoperative period. Mean (SD) (range) age: 66 (12) (45-83) 13 male and 14 female. 24 people were white and 3 African American.
Setting	St Thomas Hospital, USA.
Study design	Qualitative descriptive design
Methods and	Focus groups in the preoperative group immediately following the hospital's joint replacement class. Individual interviews were

Study	Jacobson 2008 ²³
analysis	conducted in the postoperative group.
	Thematic analysis utilised.
	Approved by the Institutional Review Board at Kent State University, USA
Findings	Waiting and worrying : One factor that contributed to worry was having too little information about the operation. How long it will take, general ambiguity, they wanted to know what was going to be done.
	Also, what to expect during recovery. The "backward-and-forward" nature of recovery could be better explained.
	Detailed and graphic information on the surgery and recovery was appreciated. For example touching an implant.
	Letting go and letting in: it was useful to talk to people who had the surgery or with providers to increase confidence. Releases stress as well. Structured peer support group would be been appreciated.
	Physicians who took the time to explain surgery and answer questions were favourable. Valued a direct approach.
Limitations and applicability of evidence	Moderate limitations and it was unclear how representable the convenience sample was. The analysis of preoperative experiences was direct and applicable to this evidence review.

Study	Kendall 2014 ²⁵
Aim	An exploration of the lived experience of five active Canadian women from 40-70 years of age, who underwent a primary total hip replacement (THP).
Population	Women, 40 to 70 years old, undergoing primary total hip replacement.
Setting	People on a waiting list in Alberta, Canada, for THR
Study design	Qualitative
Methods and analysis	Individual interviews approximately one week pre and four weeks post surgery, followed by a group interview. The researcher did not have a roll in treating the people. Grounded theory approach. Analysis utilised coding, categorising, and thematic conceptualisation. Ethics approval with the University of Calgary Health Research Ethics Board (CHREB)
Findings	Lack of information to patients was more apparent in the older hospitals. It raised anxiety. There also appeared to be a need to decide what information and how much depth of information should be given to patients. All the participants prepared questions to address to their doctors. However, it was generally two weeks after the surgery before they were able to speak with their surgeons and in some cases six weeks.
	Surgeons personal support: All the participants reported being happy with their surgeons, the only proviso being that they wished they

Study	Kendall 2014 ²⁵
	could have more time and more information from them. Participants' impressions of medical staff were coloured by previous experiences, whether negative or positive. The patients in this research were treated in three different hospitals and experiences in some were better than experiences in others.
	Nurse personal support: Nursing care had the most negative comments from all participants but one, even though three different hospitals were used. Reports indicated variability in nursing presence, a term used in the literature to mean a nurse-patient relationship, which engenders the possibility of the nurse meeting the patient's health needs (Miner- Williams, 2007). There were instances where patient health needs were not met because nurses lacked empathy or responsiveness (e.g., Debbie experienced a fall because of lack of supervision, Vivian asked for spiritual assistance three times, but received none, and Ronnie experienced pressure from a nurse to administer self-injections regardless of expressing fear of needles and preferring pills instead).
	Participant comments about the pre-operation education classes were mostly positive. The notion of how much detail to give about the nature of the operation again came into play. It appeared to be an individual one. Debbie and Vivian did not want too much lurid detail and felt that they could watch a YouTube video about it if they so wished, while Kate, being a surgeon's daughter voiced complete lack of fear and knowing what questions to ask. Karen and Ronnie had done a lot of research and seemed very well informed and positive about their three-hour pre-hip operation educational class, which was offered as part of a comprehensive, conjoint, updated, medical plan. Apart from people and equipment support, participants were also mindful of nutrition and the newest hospital included this in its education component. Over half the participants were intent on losing weight before their operation, as a health measure, to be better fit for the operation.
Limitations and applicability of evidence	Severe methodological limitations as it was unclear how representable the convenience sample was and data analysis. The analysis of preoperative information experiences was direct and applicable to this evidence review.

Study	Kennedy 2017 ²⁶
Aim	Exploring experiences and preferences for education following hip or knee replacement surgery
Population	32 purposefully selected people who had undergone hip or knee joint replacement surgery were recruited from outpatient clinics at their 6 week to one-year follow-up visits post joint replacement. Mean (SD) age: 68 (8) ranging from 46 to 78. 16 men and 16 women. 16 hip replacements and 16 knee replacements.
Setting	Canadian orthopaedic centre specialized in joint replacement surgery.
Study design	Qualitative
Methods and analysis	A mixture of 6 focus groups and 7 telephone interviews with 32 participants. Saturation was reached at that point. 4 specific aspects of the patient's experience with educational material. It began with open, broader questions about the patient's educational needs and experiences leading up to surgery and then questions were asked about each stage of the hospital and recovery process. Finally, a series of questions were asked in relation to the patient's preferences for future educational materials,

Study	Kennedy 2017 ²⁶
	including videos and internet resources. Focus groups or interviews were run by a trained qualitative interviewer or an experienced Research Associate. All interviews and focus groups were audio-taped and professionally transcribed verbatim.
	Thematic analysis utilised. Local Research Ethics Board approval was obtained for this study.
Findings	Educational gaps around pain management
	More education required around pain management post-operatively. In particular, participants expressed an interest in education related to expected levels of post-operative pain, the purpose of the prescribed medications, information on how to take the medications, their side effects and how to "wean off" pain medications.
	Another participant describes his perception of other people's negative experiences of medication side effects. People are both afraid to ask about medication and are without recourse regarding pain medication once they leave the hospital.
	Participants suggested that nobody provided them with information about how to "wean" themselves off their pain medication once they were back at home.
	While participants did acknowledge they received information that they would need to reduce their pain medication, they frequently felt that these instructions lacked crucial information about how they would accomplish this in terms of practical steps. As one participant shared,
	Participants' validation of existing materials
	Guide for patients having hip or knee replacement: The following participant highlights that the Guide is useful across various stages of the pre to post surgery process and was something she referred to throughout her recovery.
	Preoperative education class: Participants commented on the benefits of attending the Preoperative Education class. They commented on how appropriate preparation "built their confidence". This confidence building was important given how many people were initially fearful of having surgery. In the following account, the participant stresses the importance of hearing from another patient and described how valuable it was to have the expertise of the rehabilitation staff.
	Dr Mike Evans' 'preparing you for your hip or knee replacement surgery': Participants who had viewed the Dr Mike Evans' video expressed that they had found it helpful, especially as it emphasized and was consistent with
	Favoured sources of patient information
	Family and friends: Patients frequently identified friends and families as an important source of information. Hearing stories from other people that their surgeries had been successful seemed to go a long way toward reassuring participants. At the same time, they voiced their concern that experiential accounts were not necessarily medically valid. Many voiced a desire to access a bank of patient "testimonials" that the hospital could curate, hence increasing its reliability from a patient perspective. Several noted that they
	wanted to hear both "good and indifferent" experiences from others.

Dr Google: The majority of participants had searched Google for information on the surgery or recovery process. Many did not question the validity or accuracy of this information. For some participants, mostly men, they wanted to actually watch the surgery "to see what

Study	Kennedy 2017 ²⁶
	goes on in the operating room". Not all people thought that accessing information on the internet was useful and in some instances it reinforced the fear they already felt about the upcoming surgery.
	Surgeons as a source of education: Some participants identified the surgeon as their main source of information. While patients felt that surgeons were an important source of knowledgeable information, they often described mixed experiences of how much time they felt surgeons could or did provide.
	Interest in new delivery modes for education, such as social media
	Several participants were interested in accessing information from newer technologies including mobile health applications and social media. A small number of people said that they would in the future use an app. Other participants, however, were uncertain as to how social media would be useful for them. Some noted that they were comfortable with the computer but did not own smartphones or other technology that would enable them to use newer forms of social media/mobile apps.
Limitations and applicability of evidence	Moderate limitations and it was unclear how representable the sample of 32 people was. The analysis of preoperative education was direct and applicable to this evidence review.

Study	Krupic 2012 ³⁰
Aim	To explore how immigrants and Swedish people described information provided before elective total hip replacement.
Population	Inclusion criteria were patients with primary or secondary osteoarthritis, admitted for surgery from their own homes in the surrounding area. An exclusion criterion was patients unable to participate in an interview. Twenty patients were invited to participate and all agreed. They were recruited consecutively until 10 immigrants and 10 Swedish patients had been enrolled.
	Participants born in Sweden were aged 40 to 86 (median age 63) and immigrants 30-87 years (median age 59). Most of the immigrants came from Europe, one from Africa and one from Asia. Immigrants had a high educational level and three had academic degrees. Participants born in Sweden had a minimum of elementary school level education.
Setting	People were recruited two weeks prior to total hip replacement surgery at the Sahlgrenska University Hospital, Mölndal, Sweden.
Study design	Qualitative study
Methods and analysis	Face-to-face interviews using open-ended questions interview were conducted the day before the planned surgery. They lasted 60 to 90 minutes, were audiotaped and transcribed. Qualitative analysis was undertaken using a published technique. The Regional Ethical Board, University of Gothenburg, Sweden, approved the study (No: 275-10).
Findings	Getting information about surgery
	Some patients stated that it was important to be informed before surgery. They wanted information about pain management, the surgical procedure, anaesthetics and the selection of implant for surgical insertion into their bodies. Most of the patients described the preoperative information as limited; the doctor had no time to explain the operation, there was no time for questions and it was very stressful. One participant was not interested in information and wanted to have the surgery as soon as possible.

Study

Krupic 2012³⁰

To handle hip pain

Information on pain relief was considered important. Most participants described their pain as due to osteoarthritis, but revealed that information on how to relieve it was not part of pre-operative information

Limited information from orthopaedic staff

Most participants wanted both oral and written information from orthopaedic staff before surgery, but many felt that the information was inadequate and lacked details about the operation. "The doctor informed me that I would get a new hip, but not how it would happen, neither the type of prosthesis nor the surgical process." Much of the written information was sent by post from the hospital several days before surgery. However, it was considered limited by most participants. They had no knowledge of what would happen before or during surgery. "I did not know anything about my surgery just that it ends." The participants who spoke no Swedish were assured that an interpreter would be provided to help them. However, sometimes the interpreter never showed up.

Finding information themselves

Participants lacking information on their upcoming operation found different ways of searching for it. Some searched on their own. Those who could understand Swedish searched the Internet, read books about hip replacement surgery or asked friends or relatives who had undergone THR. "I read about my operation on the Internet, in books and asked friends who had already undergone this surgery and feel ready for the operation tomorrow. Sometimes the time allotted to inform patients was too short. In such cases the participants were told to search for information themselves. "My doctor said: You can log on to Hip Register where you will find all the information you need". Some immigrants only received meagre information concerning their operation. For those who could not speak Swedish, had no friends or relatives to ask and had never visited a hospital before, the situation was complicated.

To choose anaesthesia

Many participants were informed about the different types of anaesthesia. They described that during the preoperative visit they had been given the impression that they would be asked which type of anaesthesia they would prefer during surgery. However, when they spoke to the anaesthesiologist the day before surgery, they felt that she/he had already made a decision. "I said to my anaesthesiologist that I needed a general anaesthetic and wanted to sleep during the operation, but he said: an epidural is sufficient". Details concerning the surgery and the surgical procedure were also decided quickly. Participants described being asked about the operation, but felt unable to make decisions without preparation. The rapid pace caused them considerable stress.

Getting a new hip

The participants also received inadequate information about the process after surgery. However, they had many thoughts and ideas regarding what would happen. A new hip implant meant new opportunities and they considered that life would be better after the operation. However, all participants focused on their pain and looked forward to pain relief immediately after surgery.

Being pain free

The participants were informed about pain after surgery from different sources. Some were informed by health care professionals, others by relatives and friends who had previously undergone surgery. They expressed many different thoughts about life after surgery. All participants expected that the pain would decrease or disappear. "Undergoing surgery feels fantastic even if I'm free from pain for

Study	Krupic 2012 ³⁰
	just an hour or two. I would be glad if I could move without pain." All participants had great expectations of a pain-free life after surgery.
	Being independent
	The participants had little information about life after surgery. They expressed hopes of being more mobile and less dependent on others. They wanted to fend for themselves at all costs. "I have expectations of managing alone; dressing myself, putting on my socks. In Sweden you do not ask for help, that is how it is." The participants expressed hopes of becoming active again and enriching their lives by walking, housework, hobbies and other activities. However, the expectations of life after surgery were not only positive, as some participants had concerns about dislocation of the prosthesis or falling after the operation, which could damage the implant.
Limitations and applicability of evidence	Minor methodological limitations. The analysis of preoperative education was assessed preoperatively and it would be more applicable to this direct and applicable to this evidence review.

Study	Smith 2018 ⁴⁰
Aim	An assessment of barriers and facilitators of effective opioid use for people having orthopaedic surgery.
Population	People who have undergone total knee arthroplasty or total hip arthroplasty and undergone Kaiser Permanente Northwest (KPNW) preparation. This includes preoperative assessment of opioid use, and setting expectations for post-surgery pain management. After discharge people prescribe 12 weeks of opioid pain medication before care transfers to primary care. People were selected using purposeful sampling method. People were interviewed 6-12 months after surgery. 80 people with high opioid use were selected and 11 people were interviewed. 9 women and two men. 4 total knee replacements and 7 total hip replacements.
Setting	Kaiser Permanente Northwest (KPNW) integrated care delivery system.
Study design	Qualitative study
Methods and analysis	Interviews were undertaken based on an interview guide created through expertise, literature search, and clinical input. A trained qualitative methodologist conducted the interviews, the interviews were audio recorded and transcribed. Thematic analysis used to analyse the results. The study was funded by the Federal Food and Drug Administration. Kaiser Permanente Northwest (KPNW) Institutional Review Board approved the study
Findings	Presurgery pain management expectations and education: education booklet and video. It did not adequately address issues related to pain management. Verbal contact with the surgeon was reported to be clear, helpful and increased the person's confidence. Most people felt concerned going into surgery due to previous surgical pain experiences, fear of pain, or low pain tolerance. 4 others were concerned about the use of narcotics after surgery in terms of addiction, poor reaction to the medication, or preference for "not

Study	Smith 2018 ⁴⁰
	taking pills".
Limitations and applicability of evidence	Severe limitations as it was unclear how selection bias was addressed and the data was not rich. The assessment of advice prior to surgery on pain management is direct and applicable to this evidence review.

Study	Soever 2010 ⁴¹
Aim	Answering the question: What do people undergoing total joint arthroplasty want to know?'
Population	People scheduled to undergo primary total joint arthroplasty or 3 to 6 months post primary total joint arthroplasty and able to understand and converse in English and participate in an interview lasting approximately 1 hour. Potential participants with cognitive impairments were excluded from the study though potential participants with other medical comorbidities were not excluded. Purposive sampling technique was used. 15 participants: 13 were female, and 2 male. 3 were awaiting a TKA, 2 were awaiting a THA, 3 were post-TKA, and 7 were post-THA. Participants ranged in age from 23 to 89 years.
Setting	Potential participants were identified by orthopaedic surgeons located at the two participating hospitals in Canada, one an academic hospital and the other a community hospital
Study design	Qualitative study
Methods and analysis	A semi-structured interview method following an interview guide. Questions ranged from general to more specific in nature; probes were used to encourage the elaboration of responses. The interviews were conducted by two investigators, both physiotherapists who had qualitative research experience. The initial interview guide was modified to include new questions addressing new and developing themes. The interviews were tape recorded and were transcribed verbatim. A comparative contrast method of analysis was used.
	The research protocol was approved by the Research Ethics Boards of the two participating hospitals, and informed consent was obtained from all participants.
Findings	Educational Needs
	Access: Participants specifically indicated a need for information related to how waiting lists are prioritised and whether one's position on the waiting list can change depending on circumstances. Participants often reported deciding to proceed with surgery sooner rather than later after consultation with others who had been through the experience.
	Knowing the team: Participants understood that several health care professionals would be involved in their care. Knowing these individuals, including having an understanding of their roles, was deemed very important. Having one member of the team, aside from the surgeon, whom they could consult at various phases of their TJA was also important.

NICE

Study

Soever 2010⁴¹

Arthritis: Participants also expressed a need for information about types of arthritis, causes, and management of symptoms. The following comments from two participants, relatively young and old and diagnosed with rheumatoid arthritis and osteoarthritis respectively, illustrate the desire for arthritis-related information.

Preoperative phase: Participants expressed a need to know details of what happens during the preadmission visit, including how long it will take. Participants provided several details about important information that helped them prepare for surgery. They spoke of preparing themselves for the hospital stay and preparing their home environments for their return from the hospital. Specifically, participants were interested in knowing what medications, food, clothes, and toiletries they should bring to the hospital; what preparations need to be made to the home environment, including food and equipment; what exercises, if any, and blood tests need to be done prior to surgery; details about employability in the perioperative period; risks, benefits, and procedures related to blood donation and blood transfusion; and hospital length of stay and discharge destination following the acute-care stay. Participants also expressed a need for education on pain management.

Surgery and medical recovery: Participants expressed interest in details of the surgical procedure, including specifics of the prosthesis: I happen to like to know exactly what is going to happen and what is going and what is staying. Education on options available for anaesthesia was identified as important. Participants spoke about their experiences with thromboses and expressed a desire for education on medications for anticoagulation, anti-embolic stockings, and prevention of thromboses. Details of surgical wound care, including stitch/staple removal and bathing, were also identified as important.

Rehabilitation process and functional recovery: Participants wanted education about positioning to provide comfort and prevent complications. How long do I have to live with a pillow between the knees? Details of therapy and exercises, including type, location, protocols, frequency, and duration, were important information for participants: In addition, participants stated that information on precautions related to achieving positive outcomes, avoiding complications, and avoiding revision surgery; equipment; bathing, pedicures, and personal care; and transportation, driving, and transferring into vehicles would facilitate the rehabilitation process and functional recovery.

Follow-up: Participants were interested in details relating to the period required for recovery. Most frequently, they expressed a need for information about time frames.

Factors Affecting Educational Needs

Knowledge about TJA: Participants awaiting TJA admitted to a lack of knowledge about the surgery and rehabilitation process:

Fears: Some fears expressed by participants related to overall outcome, while others related to specifics of the surgery and rehabilitation. Participants proposed that education related to their specific area of concern would help to alleviate some of their fears.

Family information needs: Participants noted that their families and other informal support systems require education on TJA. Participants said that such education would enable families to know how they could help, especially in the home environment.

Expectations counterbalanced with responsibility: Participants discussed expectations from two main perspectives: the actual process they would undergo for a TJA, including preparation, surgery, rehabilitation, and recovery; and the impact on their well-being or quality of life. Participants were most definite about expecting an improved quality of life after TJA and less certain about what to expect with the process and the continuum of care: They said that it is important for those contemplating TJA to know that there is responsibility

Study	Soever 2010 ⁴¹
	involved on the part of the patient, which was described as involving a positive attitude and expecting to have to "work" at the recovery process.
Limitations and applicability of evidence	Moderate limitations as it was unclear how representable the sample of 15 was of the overall population. The question of what people undergoing total joint arthroplasty want to know? is direct and applicable to this evidence review.

Study	Spalding 2001 ⁴²
Aim	Investigate the justification for preoperative education before admission to people having total hip replacement.
Population	Consecutive people who transferred to the orthopaedic rehabilitation unit after total hip replacement and consented to the trial. 2 people received preoperative education classes.
Setting	1 NHS trust in the UK
Study design	Qualitative study
Methods and analysis	A pilot interview was conducted to assess the suitability of the questions and the next 9 interviews used in the study analysis. Each person had 2 30 minute semi-structured interviews. The first within 10 days of surgery and the second 4 weeks after surgery. All were tape recorded and transcribed. Data analysed using content analysis. Ethical approval granted by the NHS trust's local research ethics committee.
Findings	Preoperative education: mixed points of view. Most wanted it but some indicated it would increase anxiety or it indicated a lack of trust in staff. However the more prevalent thought was that it would reduce anxiety. Also there was some evidence that preoperative education would allow people to prepare better for postoperative changes required with a joint replacement.
Limitations and applicability of evidence	Severe limitations due to limited data analysis, richness and overall conclusions. The question of whether preadmission education is useful is direct and applicable to this evidence review.

Study	Spooner 2018 ⁴⁴
Aim	The primary research question was: How do eight women who experienced total knee replacement make sense of their preoperative education and recovery?
Population	People who had completed preoperative joint replacement education prior to surgery and underwent TKA less than two months before the interview. Inclusion criteria:

Ottorale	0
Study	Spooner 2018 ⁴⁴
	 not employed by the operative hospital or educational provider, affiliated physicians, or Northeastern University
	not directly related to the researcher or affiliated with the operative hospital or the educational provider
	not had a previous joint replacement surgery within five years
	no previous experience with knee replacement education classes
	the joint replacement was unilateral, not bilateral
	the preoperative joint replacement education was completed no more than six weeks prior to surgery
	the surgery was within two months before the participant interview;
	the person could read, write, and speak English
	the person did not have a current diagnosis of dementia or any other self-identified neurological deficits. The person did not have a current diagnosis of dementia or any other self-identified neurological deficits.
	Recruitment began following Institutional Review Board (IRB) approval from Northeastern University. Access to research participants was achieved through affiliations with New England Baptist Hospital and MyKnee Guru, a social media platform for knee replacement patients operated by Dr Axyl Sylvan. 8 women completed the study.
0 "	·
Setting	Access to research participants was achieved through affiliations with New England Baptist Hospital and MyKnee Guru, a social media platform.
Study design	Qualitative section of a thesis
Methods and analysis	Semi-structured interviews by telephone. Interviews were recorded and transcribed. The eight women who participated were interviewed to explore how experiences in preoperative education classes were evaluated and translated into empowerment. Qualitative research approach
	This study utilised interpretative phenomenological analysis to investigate and make sense of the women's lived experience in class and while preparing for and recovering from knee replacement surgery.
Findings	Uncertainty and Sense-making
	Uncertainty experienced before surgery motivated each of the eight women participants to seek information about surgery and recovery. Each participant experienced uncertainty or doubt before her knee replacement surgery, which was characterized by the use of the phrase "to know." Each wanted to know what to expect, to know what would happen, to know about decisions that needed to be made, and to understand what the results would be. The prospect of surgery introduced uncertainty and anxiety related to the surgery itself and its implications for daily life. The feeling of uncertainty yielded questions designed to build knowledge about surgery, the process, and recovery. Participants sought information that would enhance understanding, allay fears, and help them know the process of surgery and recovery. The process of seeking information included social and other networks, which generated and guided questions that were presented in the preoperative classes.
	Situational Scanning and Evaluation of Expectations
	This study found that preoperative education reduced some anxieties while creating new ones, but it also empowered patients to seek

NICE

Study Spooner 2018⁴⁴

information both inside and outside the class. Participants actively reasoned about their experience using information gathered and vetted in the preoperative classes. The knowledge compiled through a participant's engagement in class was balanced against developing personal expectations and hopes for surgery and recovery. A concept of self-view was formed and projected towards the future, which influenced the decision making process especially with regard to preparing the home and recovering from surgery. This development was more pronounced as participants became increasingly comfortable with their expectations and as they began preparations for surgery, including focusing on anesthesia as a point of engagement. Multiple sources, including physicians, family, friends, and educational materials delivered during the class, became points of reference against which participants evaluated their roles.

Application of Knowledge Before and After Surgery

The study showed that participants linked preoperative education to surgery-related planning and preparations. All participants experienced challenges requiring specific actions or a particular pattern of behaviours; these behaviours were influenced by perceptions of ability and ultimately the level of motivation.

Enhanced Engagement

The study found that class participants' engagement was enhanced at several points. It was influenced by information related to the preoperative class, including activation, self-advocacy, preparing for surgery, and adherence to rehabilitation. The participants all elaborated on when their motivation and their ability to act aligned with a specific trigger, which resulted in actions related to surgery.

Becoming Empowered Patients

The study found that participants were likely to have a link between their perceptions, their self-view, and their ability make decisions about their care. As empowerment increased, so did self-efficacy, which participants experienced through their beliefs about their skills and abilities to engage in their care. Furthermore, the participants described emotional connections between their perception of ability and engagement in recovery. At the most basic level, belief in our capacity activates our ability to cope with stressors that come along with illness.

Limitations and applicability of evidence

Moderate limitations as it was unclear how representable the convenience sample of 8 people was of the overall population and data analysis. The question of how 8 women who experienced total knee replacement makes sense of their preoperative education and recovery is direct and applicable to this evidence review.

Appendix E: Excluded studies

E.1 Excluded qualitative studies

Table 7: Studies excluded from the qualitative review

Reference	Reason for exclusion
Abu Al-Rub 2014 ¹	Not a qualitative study on specific information needs
Al-Taiar 2013 ²	Limited relevant qualitative data for this clinical question
Andersson 2015 ³	Incorrect population
Bardgett 2016 ⁶	A number of people in this postal survey utilised in interviews in an included study
Barlow 2015 ⁷	Systematic review with different inclusion criteria however included studies were checked for this review
Barlow 2016 ⁸	Not a qualitative study on specific information needs
Barlow 2018 ⁹	Study not related to information needs prior to surgery
Billon 2017 ¹⁰	Semi-quantitative study
Cano-Plans 2018 ¹¹	Outcomes mainly analysed quantitatively
Chabaud 2018 ¹²	Development of an information booklet
Cheung 2013 ¹³	Semi-quantitative study
Doust 1989 ¹⁷	Not a qualitative study on specific information needs
Fujita 2006 ¹⁸	Study does not address information needs
Hovik 2018 ²¹	Study does not address information needs
Hsu 2018 ²²	Analysis of triggers in deciding to have knee replacement surgery
Kazmierski 2018 ²⁴	Semi-quantitative study
Kirsi 2009 ²⁷	Conference abstract
Ko 2013 ²⁸	Study does not address information needs
Koekenbier 2016 ²⁹	Quantitative study
Lucas 2013	
Lucas 2013	
Lane 2016 ³¹	No relevant data on information needs prior to surgery
Mota 2012 ³²	Systematic review of quantitative studies
Parks 2014 ³⁵	Limited relevant qualitative data for this clinical question
Parsons 2009 ³⁶	Study on the experience living with severe osteoarthritis
Prouty 2006 ³⁷	Description of a pre-operative education program
See 2018 ³⁸	Systematic review with different inclusion criteria however included studies were checked for this review
Sharrock 2014 ³⁹	Incorrect population
Specht 2016 ⁴³	Study does not address information needs

Appendix F:Research recommendations

F.1 Information needs

Research question: How should information for people having joint replacement surgery be delivered?

Why this is important:

The provision of information to people prior to surgery is known to be very helpful for not only their well-being in the pre and post-surgery periods but also their engagement with the shared decision-making process with the orthopaedic team. It is an effective way for people to both make an informed choice with regard to having surgery but also to assist in their individual preparation for surgery and to aid in their recovery after surgery, as well as to reduce uncertainty with regard to what is unknown. However there is uncertainty around how the information is delivered which includes whom delivers it, where it is delivered, and the mode of delivery, be that group discussions, online courses, individual conversations or combinations of these.

Criteria for selecting high-priority research recommendations:

PICO question	Population: Focus groups of people referred for joint replacement surgery and those up to 2 years post-surgery, focus groups of surgeons who perform joint replacement surgery, focus groups of healthcare professionals involved in patient care before and after surgery for example nurses and therapists. Interventions/context: Questions designed to elicit the how information should be delivered, particularly with regard to who should provide which information and when, to those considering undergoing / intending to undergo joint replacement surgery and whether aspects of this information could be provided in a group format and with further reference material such as links to website / NHS site. Comparison: Standard/ usual care Outcome(s): Development of a protocol, through thematic analysis from the focus groups, for who should provide what information and when, for people undergoing joint replacement surgery, and which could then be measured for effectiveness against standard/ usual care in a further study.
Importance to patients or the population	Providing information to people, with regard to joint replacement surgery, in the most effective way possible should assist in allowing them to make a more informed choice with regard to whether to have surgery and what to expect before, during and after surgery.
Relevance to NICE guidance	This is in keeping with the NICE patient experience guideline with respect to patient information.
Relevance to the NHS	It would allow for a much more consistent service across orthopaedic services across the NHS.
National priorities	No linked national priority area identified.
Current evidence base	The evidence base has qualitatively explored information prior to surgery and it touches on some of the factors here such as timing, person delivering the information, and mode of delivery. However there is a space in the evidence base for a formal study of who, when and how information is delivered.
Equality	It is important to address people with cognitive impairments and their family or carers in the design of this trial. There may be differing effectiveness of the interventions in this group of people and their family or carers.
Study design	A 2 stage study with the first stage being a qualitative study re the development of a possible protocol for who should provide what

	information, and what back up information should be available, for those considering/ intending to undergo joint replacement surgery. The second stage would then involve a quantitative study testing this protocol for information giving against standard/ usual care to evaluate whether this is more effective or not in conveying information to people
Feasibility	Information is currently delivered to people prior to surgery and this should not increase that commitment. There are no ethical issues if the information is correctly delivered and people are able to engage with the team if is not successful for the. Methods of information delivery should provide an achievable technical challenge.
Other comments	
Importance	 Medium: the research is relevant to the recommendations in the guideline, but the research recommendations are not key to future updates.