National Institute for Health and Care Excellence

Consultation

Perioperative care in adults

[A] Evidence review for information and support needs

NICE guideline

Qualitative evidence review

November 2019

Draft for Consultation

This evidence review was developed by
the National Guideline Centre

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1 Information and support needs

1.1 Review question: What information and support is useful for adults undergoing surgery, and their families and carers, before, during and after an operation?

1.2 Introduction

Surgery, whether minor or major, is a time of anxiety and concern for patients, family and carers. Patients need reassurance, information and answers to their many questions. While there is undoubtedly a wealth of information available on the internet, it is not easily accessible to those who do not have the IT skills or the means of access. For those who do access internet information it can be confusing, may not relate to practice within the NHS and, most importantly, does not necessarily respond to individual needs and circumstances.

Shared decision making is essential if postoperative pain is to be managed effectively, patient stress and anxiety minimised, emotional wellbeing maximised and strong recovery facilitated. The purpose of this qualitative review is to identify the information and support needs of people in the perioperative period.

1.3 Characteristics table

For full details see the review protocol in appendix A.

Table 1: Characteristics of review question

Objective	To determine what information and support people with undergoing surgery and their families value.
Population and setting	Adults 18 years and over having surgery, and their families and carers.
Context	Information may include, but is not limited to the following: • Decision making (including involvement in discharge planning) • Preferred format of information provision (e.g. plain English, web-based) • Content of information (including ongoing care needs) • Impact of treatment on lifestyle • Information sources other than healthcare professionals (e.g. support groups, online resources) • Psychological support • Financial support • Employment rights
Review strategy	Synthesis of qualitative research. Results are presented in a narrative format. Quality of the evidence is assessed by a GRADE CerQual approach for each review finding.

1.4 Qualitative evidence

1.4.1 Included studies

Thirty three qualitative studies were included in the review;[20, 32, 34, 39, 41, 58, 72, 74, 81, 85, 97, 102, 109, 115, 120, 135, 136, 141, 146, 164, 165, 174, 175, 179, 180, 184, 189, 197, 202, 208, 209, 223, 225] these are summarised in Section 1.4.3 below. Key findings from these studies are summarised in Section 1.4.4 below. See also the study selection flow chart in appendix C, study evidence tables in appendix D, and excluded studies lists in appendix E.

As a large number of papers were identified for this review, inclusion was halted once saturation was reached. Saturation is the point at which no new information emerged from studies that were found to match the review protocol. These studies are listed in Table 20 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
Secondary analyses				
Carrier 2018[41]	Systematic review of qualitative studies	Men of all ages and nationalities who had a radicalized prostatectomy for prostate cancer	To identify men’s perceptions of the impact of the physical consequences of a radicalized prostatectomy on their quality of life	A well-conducted systematic review, using established methods Focused on a specific outcome, but likely to have some wider applicability
Otutaha 2019[164]	Systematic review of qualitative studies	Adults with upper GI cancer	To determine the specific information needs of patients with upper GI cancer	A review with significant methodological limitations Reports some aspects of care that may have limited relevance to the NHS
See 2018[189]	Systematic review of patient education needs, reported in qualitative studies and patient surveys	Adults undergoing total joint arthroplasty	To systematically summarize and synthesize osteoarthritic patients' expectations and experiences in undergoing total joint arthroplasty to identify their educational needs	A review with some methodological limitations, including the use of survey data Results likely to be generalisable
Sibbern 2017[197]	Systematic review of qualitative studies	Adults who had undergone colorectal, cardiac, gynaecological, and orthopaedic surgery in an ERAS program, and were hospitalised equal to or longer than 36 hours	To systematically summarize and synthesize osteoarthritic patients' expectations and experiences in undergoing total joint arthroplasty to identify their educational needs	A review with no significant methodological limitations Results likely to be generalisable
Primary analyses				
Baker 2018[20]	In-depth semi-structured face-to-face interviews with inductive thematic analysis	Patients who had undergone surgery for ulcerative colitis and patients who had	To explore patient information preferences prior to undergoing surgery for	A well-conducted study based in the UK

Study	Design	Population	Research aim	Comments
		considered but not undergone surgery	ulcerative colitis	Focused on a specific condition (ulcerative colitis) and included some participants who had not had surgery, but results appear generally applicable.
Brands Appeldoorn 2019[32]	In-depth semi-structured interviews with thematic analysis	Women who had undergone breast conserving treatment	To investigate the information needs of breast cancer patients regarding the long-term cosmetic outcome after breast conserving treatment	A study with some methodological limitations, based in the Netherlands Focused on a specific surgical intervention, but results appear generally applicable, particularly to procedures with substantial cosmetic impact
Brooke 2018[34]	Semi-structured focus groups with iterative thematic analysis	Adults who had undergone surgery for a chronic health condition and caregivers	To understand how patients and caregivers perceived care coordination during transitions of surgical care	A well-conducted study based in the US Focused on care during transition, but results appear generally applicable
Carr 2017[39]	In-depth telephone or face-to-face interviews with phenomenological analysis	Adults awaiting scheduled orthopaedic or cardiac surgery	To understand experiences of wait time among patients awaiting scheduled orthopaedic or cardiac surgery	A well-conducted study based in Canada Focused on waiting for surgery
Dibley 2018[58]	Semi-structured focus groups, using trigger questions, and telephone or face-to-face interviews, using a topic guide, with thematic analysis, guided by a pragmatic analytical hierarchy	Adults who had undergone stoma surgery or who were considering stoma surgery	To explore influences on patients' decision-making and compared preoperative concerns with postoperative outcomes related to stoma surgery	A study with some methodological limitations based in the UK Focused on a specific surgical intervention, but results appear generally applicable, although some participants had not undergone surgery
Fletcher 2019[72]	Brief, structured telephone interviews with descriptive content analysis	Adults who had undergone total knee replacement and who continued to have extreme difficulty kneeling 7 to 10 years after surgery	To explore the long-term impact of difficulty with kneeling and how healthcare services could be improved to help patients kneel after	A well-conducted study based in the UK Focused on one specific outcome

Study	Design	Population	Research aim	Comments
			total knee replacement	
Gainer 2017[74]	Semi-structured focus groups with thematic analysis	Older adults who had undergone Coronary Artery Bypass Graft (CABG) surgery	To investigate the optimal approach to decision making	A well-conducted study based in Canada Focused on CABG surgery, but results appear generally applicable
Gustavell 2017[81]	Semi-structured interviews, face-to-face and by telephone, with inductive content analysis	Adults who had undergone pacreaticoduodenectomy	To explore common symptoms and self-care in the first 6 months after pacreaticoduodenectomy	A study with some methodological limitations based in Sweden Focused on a rare cancer but results appear generally applicable
Halm 2017[85]	Structured interviews, opened with a 'grand tour' question, with constant comparative analysis	Caregivers for adults who had undergone CABG surgery	To describe age and gender-specific concerns, needs, and strategies during the first 3 months after CABG	A well-conducted study based in the US Focused on CABG surgery, but results appear generally applicable
Hewitt 2019[97]	In-depth semi-structured face-to-face interviews with thematic qualitative analysis	Adults diagnosed with soft tissue sarcoma, not currently receiving radiotherapy or chemotherapy treatment	To gain a deeper understanding of patients' perceptions of treatment sequencing (surgery and radiotherapy) for soft tissue sarcoma, to identify concerns throughout treatment, and consider what patients found helpful	A well-conducted study based in the UK Focused on a specific condition (soft tissue sarcoma) and the experience of treatment sequencing, but results appear generally applicable
Høvik 2018[102]	Semi-structured face-to-face focus groups with systematic text condensation	Patients undergoing total knee arthroplasty in a fast-track pathway	To explore the experience of patients undergoing total knee arthroplasty in a fast-track pathway during the first 2 weeks after surgery	A well-conducted study based in Norway Focused on a specific care model, but results appear generally applicable
Ivarsson 2018[109]	In-depth semi-structured face-to-face interviews with critical incident analysis	Adults who had undergone hip fracture surgery	To elucidate perceived situations of significance experienced by people with hip fracture during	A well-conducted study based in Sweden Results appear generally applicable

Study	Design	Population	Research aim	Comments
			prehospital and in-hospital care	
Kennedy 2017[115]	Semi-structured face-to-face focus groups and interviews with inductive analysis	Adults attending follow-up visits for hip or knee replacement surgery	To determine the informational needs and delivery preferences for education of families and patients undergoing hip or knee replacement	A well-conducted study based in Canada Results appear generally applicable
Kyte 2018[120]	Semi-structured face-to-face interviews with qualitative content analysis	Adults who had surgery for primary lung cancer	To describe surgically treated lung cancer patients' experiences of coming home after discharge from hospital to expand the knowledge about their supportive care needs	A well-conducted study based in Norway Focused on a specific condition (lung cancer), but results appear generally applicable
Malley 2017[136]	Semi-structured interviews with thematic analysis	Adults in the preoperative phase of surgical care	To explore the issues and challenges of care transitions in the preoperative environment	A well-conducted study based in the US Results appear generally applicable
Malley 2018[135]	Semi-structured telephone interviews with qualitative content analysis	Older adults hospitalised for an elective hip or knee joint replacement	To explore how older patients with multiple chronic conditions and their family caregivers perceive their engagement and overall care experience throughout the preoperative phase of elective orthopaedic hip or knee joint replacement	A well-conducted study based in the US Results appear generally applicable, although this is a population of older adults
McMullen 2019[141]	Qualitative focus groups and interviews, using a modified grounded theory approach for analysis, complemented by analytic memos and comparative analysis	Adults who received a cystectomy with urinary diversion (ileal conduit, neobladder, or continent pouch) for the treatment of bladder cancer	To identify patients' needs and challenges from pretreatment to approximately 2 years after surgery, and to identify how these needs were addressed across 2 different delivery	A study with some methodological limitations, based in the US May be limited in some aspects around applicability to the NHS

Study	Design	Population	Research aim	Comments
			systems	
Meleo-Erwin 2019[146]	Qualitative, thematic analysis of selected online comments, using web-based software	People who posted on two online weight-loss surgery forums	To describe the post-operative experience of bariatric surgery from the perspective of patients themselves	A study with significant methodological limitations, focused on US-specific issues May be limited in some aspects around applicability to the NHS
Owers 2017[165]	In-depth interviews, with a general inductive analysis	Adults who had undergone bariatric surgery	To explore issues missing from preoperative education for bariatric surgery	A well-conducted study based in the UK Results appear generally applicable
Rattray 2019[174]	In-depth semi-structured face-to-face interviews with thematic qualitative analysis	Adults admitted for a lower GI surgical procedure	To explore patients' perceptions of recommencing feeding after colorectal surgery to determine areas of improvement to meet their needs and expectations	A well-conducted study based in Australia May have some limited applicability as focused on a specific intervention (post-surgical nutrition)
Recio-Saucedo 2018[175]	Semi-structured face-to-face interviews with qualitative framework analysis	Women diagnosed with breast cancer aged 40 years or younger who had undergone surgery	To investigate the information requirements of young women to support their treatment decision making at diagnosis	A well-conducted study based in the UK Results appear generally applicable, although this is a population of younger women
Rosaasen 2017[179]	Semi-structured interviews with thematic analysis	Adults who had a kidney transplant	To identify pretransplant education topics from the posttransplant patient perspective	A study with some methodological limitations, based in Canada Results appear generally applicable, although the time from surgery is long, participants were asked about what they wish they had known at the time of surgery
Rosenberg 2018[180]	Focus groups, using a semi-structured approach with thematic content analysis	Women aged 40 years or younger with stage 0 to III breast cancer, who had undergone breast cancer surgery	To explore the process of surgical decision-making in young women, including how issues particular to younger women affected their	A well-conducted study based in the US Results appear generally applicable, although this is a population of younger women

Study	Design	Population	Research aim	Comments
			decision and the post-surgical experience	
Samuelsson 2018[184]	Semi-structured face-to-face interviews with inductive content analysis	Older adults who had undergone elective colorectal cancer surgery with curative intent	To describe how older patients experience the healthcare chain and information given before, during and after colorectal cancer surgery	A well-conducted study based in the US Results appear generally applicable, although this is a population of older people
Smith 2018[202]	Semi-structured face-to-face interviews with content analysis	Adults who had undergone hip or knee arthroplasty and who used high doses of opioids after surgery	To understand patients educational needs on pain management when undergoing hip or knee arthroplasty	A well-conducted study based in the US Results may be less applicable to countries other than the US, because of the differences in opioid prescribing and use
Strickland 2018[208]	Semi-structured face-to-face interviews with thematic analysis	Adults undergoing lower limb (hip or knee) arthroplasty	To explore patients' perspective of surgery and early recovery when undergoing lower limb (hip or knee) arthroplasty	A well-conducted study based in the UK Results appear generally applicable
Stutzman 2017[209]	Semi-structured face-to-face interviews with hermeneutic cycling, and thematic analysis	Patients and family members experiencing a perioperative event that would result in a transfer to the ICU	To identify important patient and family perspectives regarding the transition from the operating room to the ICU	A study with some methodological limitations, based in the US Results appear generally applicable
Webb 2018[223]	Semi-structured face-to-face interviews with thematic analysis	Women undergoing breast reconstruction	To discover missed opportunities for providing information to women undergoing breast reconstruction in an effort to decrease regret and improve patient education, teaching modalities, and satisfaction	A well-conducted study based in Canada Results appear generally applicable
Wickwar 2018[225]	Semi-structured face-to-face interviews with thematic analysis	Adults undergoing orbital decompression surgery for thyroid eye disease	To explore patients' expectations of orbital decompression surgery for	A study with some methodological limitations, based in the UK Results appear generally

Study	Design	Population	Research aim	Comments
			thyroid eye disease (TED) and whether these were met	applicable, particularly to procedures with substantial cosmetic impact

See appendix D for full evidence tables.

1.4.4 Qualitative evidence synthesis

Table 3: Review findings

Main findings	Statement of finding
Content of information	
Treatment planning and process of care[34, 97, 109, 136, 184, 189, 208, 209, 223]	Patients and families value information on the treatment plan and process of care throughout the surgical journey, through to care after discharge. Information can help to reduce anxiety both before, during, and after the surgical procedure.
Outcomes of surgery[32, 41, 72, 74, 97, 102, 109, 120, 135, 141, 164, 165, 179, 180, 184, 189, 197, 202, 223, 223]	Patients want to know what outcomes of surgery, both positive and negative, they should expect and what a 'normal' recovery looks like.
Care immediately after surgery[174, 184]	Patients want information on what to expect in the period immediately after surgery, both in terms of negative and positive outcomes and what kind of care they might expect.
Self-care after surgery[20, 81, 85, 102, 115, 120, 135, 141, 146, 164, 179, 184, 189, 202]	Patients and families or caregivers want more information about self-care after surgery, in order for them to manage the self-care as effectively as possible.
Coordination of care[120, 136, 141, 189]	Patients and families or caregivers want information on how care would be coordinated, particularly on discharge from hospital. Specifically, people want to know who to contact in case of problems, and how to contact them.
Financial issues[164]	Patients want information on how to cope with financial and insurance issues.
Information provision and information seeking	
Level of detail[20, 97, 120, 141, 189, 223]	Patients are generally satisfied with the amount and level of information, but this may vary with individual's needs and preferences.
Balance and consistency [41, 58, 85, 102, 115, 141, 197, 202, 208, 223]	Patients want information that is accurate, balanced and consistent from sources they can trust.
Information sources and mode of communication[20, 32, 41, 58, 74, 102, 109, 115, 135, 164, 174, 175, 179, 180, 184, 197, 202, 208, 209, 223, 223]	Patients value simple and direct information, often in a written format, that they can use throughout their care pathway. Members of the surgical team are also seen as key sources of information, before, during, and after surgery.
Support needs	
Social relationships[39, 41, 74, 81, 85, 97, 109, 120, 164, 165, 179, 180, 223]	Patients value social relationships from a range of sources, to provide practical and emotional support through the process of care.
Support groups[20, 41, 58, 97, 102, 180, 223]	Support groups, either in person or online, are seen as a valuable resource for people undergoing surgery.
Home care[135]	Patients want to be asked about what home care they might need before discharge from hospital.

1.4.4.1 Narrative summary of review findings

1.4.4.1.1 Content of information

Review Finding 1: Treatment planning and process of care

Patients wanted their treatment options and the process of care throughout the surgical journey explained to them in advance, this included care after discharge. Patients valued learning about the different benefits and harms of different surgical approaches and how this might impact on their future outcomes. This helped allow for informed decision making and helped to reduce uncertainty during the process, including reducing pre-surgical anxiety.

Families and caregivers also wanted information during the surgical procedure, including how long the operation might take, and how the surgery was proceeding.

Whilst most patients reported receiving enough information, some patients wanted more information and often patients could not recall information from the pre-surgical consultations after surgery.

Overall, patients and families value information on the treatment plan and process of care throughout the surgical journey, through to care after discharge. Information helped to reduce anxiety before, during, and after the surgical procedure.

This review finding was based on primary research, and one systematic review addressing the experiences of people undergoing a range of different types of surgery and their families, mostly in the UK and the US. There was a judgement of high confidence in this review finding, as there were no significant methodological limitations or concerns.

Review Finding 2: Outcomes of surgery

Patients wanted to know what would be the likely benefits and harms of surgery. If patients were aware of the likely consequences of surgery, particularly in terms of the harms and longer-term effects, they reported being more able to cope with the process of surgery and recovery. Patients also wanted to know about the impact of surgery on their quality of life, their ability to return to activities of normal daily life, how to manage pain (see evidence review N1 on management of pain), and how to identify and respond to complications.

Patients often reported a lack of information about the early stages of recovery, both in the perioperative period and on discharge from hospital.

Overall, patients wanted to know about the outcomes, both positive and negative, to be expected and what a ‘normal’ recovery looked like so they had realistic expectations.

This review finding was based on primary and secondary research addressing the experiences of people undergoing a range of different types of surgery and their families. There was a judgement of high confidence in this review finding, as there were no significant methodological limitations or concerns.

Review Finding 3: Care immediately after surgery

Patients valued information on what to expect in the period immediately after surgery, both in terms of negative and positive outcomes and the care they might receive. Some patients reported this period as being valuable in learning about self-care that would continue after discharge, and potentially through the longer-term.

This review finding was based on primary research addressing the experiences of people undergoing colorectal surgery. There was a judgement of low confidence in this review finding, because of concerns about relevance and coherence.

Review Finding 4: Self-care after surgery

Most patients reported a lack of information being given on how to manage their care on discharge from hospital. Patients wanted to be able to manage their own care, but faced challenges around pain management (see evidence review N1 on management of pain), identifying complications, using equipment, and ordering new supplies. Patients also wanted to know about changes in diet and exercise, and when they could return to usual routines.

Overall, patients and families or caregivers did not feel they received enough information about self-care after surgery, and this prevented them from managing self-care as effectively as possible.

This review finding was based on primary and secondary research addressing the experiences of people undergoing a range of different types of surgery and their families. There was a judgement of high confidence in this review finding, as there were no significant methodological limitations or concerns.

Review Finding 5: Coordination of care

Patients and families or caregivers wanted information on how care would be coordinated, particularly on discharge from hospital. Specifically, people wanted to know who to contact in case of problems, and how to contact them.

This review finding was based on primary and secondary research addressing the experiences of people undergoing a range of different types of surgery and their families. There was a judgement of high confidence in this review finding, as there were no significant methodological limitations or concerns.

Review Finding 6: Financial issues

Patients wanted information on how to cope with financial and insurance issues.

This review finding was based on secondary research addressing the experiences of people undergoing surgery. There was a judgement of very low confidence in this review finding, because of concerns about methodological limitations, relevance and adequacy.

1.4.4.1.2 Information provision and information seeking

Review Finding 1: Level of detail

Most patients felt they received enough information from the health care team. However, some people felt they needed more information, whilst others felt overwhelmed by the amount of information they were given.

People also reported that their needs changed over the course of treatment. Information needs also differ depending on the individual’s preferences; for example, some patients were happy to follow the recommendation from the health care professional, whilst others wanted a more active role in the decision-making process.

Overall, patients were satisfied with the amount and level of information, but this may vary with individual’s needs and preferences.

This review finding was based on primary and secondary research addressing the experiences of people undergoing a range of different types of surgery and their families. There was a judgement of high confidence in this review finding, as there were no significant methodological limitations or concerns.

Review Finding 2: Balance and consistency

Patients wanted information that was accurate, balanced and that reflected the true experience of surgery and aftercare. Where information was repeated, patients valued consistency in the information being provided, as contradictory or inconsistent information increased uncertainty and insecurity in some patients. Patients also reported information that they trusted. Trust was based both on the consistency of information from different sources, and the source itself. For example, the surgeon was often seen as a trusted source of information.

Overall, patients wanted information that was accurate, balanced and consistent from sources they could trust.

This review finding was based on primary and secondary research addressing the experiences of people undergoing a range of different types of surgery and their families. There was a judgement of high confidence in this review finding, as there were no significant methodological limitations or concerns.

Review Finding 3: Information sources and mode of communication

Patients used a range of different sources of information, in a range of formats. Patients, and families or caregivers, liked to discuss information with the surgeon or other members of the team, such as the perioperative nurse. This discussion was valued both before surgery, and for the family or caregiver, during surgery.

To supplement or confirm the information from the surgical team, patients often used other sources of information, such as written information provided by the surgical team, online resources, and learning about the experiences of others who had the same operation.

Patients emphasised the need for information to be tailored to their individual circumstances, in formats they were comfortable with, and for the information to be easily understood.

Some patients found the use of visual images (both photographs and video) to be helpful, particularly for women undergoing breast surgery. However, some patients found visual images to be quite distressing.

Overall, many patients expressed the value of simple and direct information, often in a written format, that they could use throughout their care pathway. Members of the surgical are also key sources of information, before, during, and after surgery.

This review finding was based on primary and secondary research addressing the experiences of people undergoing a range of different types of surgery and their families. There was a judgement of high confidence in this review finding, as there were no significant methodological limitations or concerns.

1.4.4.1.3 Support needs

Review Finding 1: Social relationships

Patients valued the support of family, friends, and community members throughout the care process. Patients also valued the support from the health care professionals involved in their care. Support involved helping with information seeking and recall, attending appointments, and particularly after discharge, help with activities of daily living. Whilst the experience of most patients was positive, some patients felt relationships could have a detrimental effect on their experience. Some patients felt that relying on other people was a burden for family and friends, but they appreciated the support regardless.

Overall, patients valued social relationships from a range of sources, to provide practical and emotional support through the process of care.

This review finding was based on primary and secondary research addressing the experiences of people undergoing a range of different types of surgery. There was a judgement of high confidence in this review finding, as there were no significant methodological limitations or concerns.

Review Finding 2: Support groups

Patients found support groups and communities of people who had similar experiences to be helpful in terms of support and information sharing. Support groups performed different functions for different patients, but most patients reported the value of being able to learn about and share experiences and information with people who had been in similar circumstances. Patients interacted with support groups in different ways (for example, in person or online) and this was often influenced by the individual preference of the patient.

Overall, support groups, either in person or online, were a valuable resource for people undergoing surgery.

This review finding was based on primary and secondary research addressing the experiences of people undergoing cancer-related surgery and knee replacement surgery. There was a judgement of moderate confidence in this review finding, as there were some concerns about relevance as most of the studies focused on people undergoing cancer-related surgery.

Review Finding 3: Home care

Patients wanted to be asked about what home care they might need before discharge from hospital.

This review finding was based on secondary research addressing the experiences of people undergoing lung cancer surgery in Norway. There was a judgement of low confidence in this review finding, because of concerns about relevance and adequacy.

1.4.5 Qualitative evidence summary

Table 4: Content of information – treatment planning and process of care

			Quality assessment		
Number of studies contributing to the finding	**Study design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Content of information – treatment planning and process of care					
9	A combination of interviews (8 studies) and secondary analysis (1 systematic review of qualitative research)	Patients and families value information on the treatment plan and process of care throughout the surgical journey, through to care after discharge.	Limitations	No or very minor concerns about methodological limitations[a]	HIGH
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance [b]	
			Adequacy	No concerns about adequacy [c]	

a. Two studies with minor issues; unclear relationship between the researchers and the participants (Stutzman 2017), Moderate concerns about the process of the analysis (Wickwar 2018)

b. Five studies with specific populations or procedures; people with soft tissue sarcoma (Hewitt 2019), older adults (Malley 2018, Samuelsson 2018),younger women (Recio-Saucedo 2018) cosmetic procedures (Wickwar 2018).

c. See (2018) included some survey data.

Table 5: Content of information-outcomes of surgery

			Quality assessment		
Number of studies contributing to the finding	**Study design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Content of information – outcomes of surgery					
20	A combination of interviews (13 studies), focus groups (2 studies), both interviews and focus groups (1 study) and secondary analysis (4 systematic reviews of qualitative research)	Patients want to know what outcomes of surgery, both positive and negative, they should expect and what a 'normal' recovery looks like.	Limitations	No or very minor concerns about methodological limitations[a]	HIGH
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance[b]	
			Adequacy	No concerns about adequacy [c]	

a. Three studies with unclear patient selection (Brands-Appledom 2019,Otutaba 2019, Rosassen 2017) , Four studies with some concerns around the process of analysis (Brands-Appledom 2019 ,Otutaba 2019, McMullen 2019 Wickwar 2018).

b. Eight studies with specific populations or procedures; women (Brands-Appledom 2019) , prostate cancer (Carrier 2018), people with soft tissue sarcoma (Hewitt 2019),people with lung cancer (Kyte 2018), post-surgical nutrition (Rattray 2019), younger women (Rosenberg 2018) Older people (Samuelsson 2018), cosmetic procedures (Wickwar 2018) .Four studies with a different care system; Høvik 2018, McMullen 2019, Otutaba 2019, Smith 2018.

c. See (2018) included some survey data.

Table 6: Content of information – care immediately after surgery

Number of studies contributing to the finding	Study design	Finding	Quality assessment		
			Criteria	**Rating**	**Overall assessment of confidence**
Content of information – care immediately after surgery					
2	Interviews	Patients want information on what to expect in the period immediately after surgery, both in terms of negative and positive outcomes and what kind of care they might expect.	Limitations	No or very minor concerns about methodological limitations	LOW
			Coherence	Moderate concerns about coherence [a.]	
			Relevance	Moderate concerns about relevance [b.]	
			Adequacy	No concerns about adequacy	

[a.] Rattray (2019) focused on effective communication of nutrition care information in post-operative period.

[b.] One study of older people (Samuelsson 2018) and Rattray (2019) focused on post- surgical nutrition.

Table 7: Content of information – self-care after surgery

Number of studies contributing to the finding	Study design	Finding	Quality assessment		
			Criteria	Rating	Overall assessment of confidence
Content of information – self-care after surgery					
14	A combination of interviews (8 studies), focus groups (1 study), both interviews and focus groups (2 studies), online forum analysis (1 study), and secondary analysis (2 systematic reviews of qualitative research)	Patients and families or caregivers want more information about self-care after surgery, in order for them to manage the self-care as effectively as possible.	Limitations	No or very minor concerns about methodological limitation, [a]	HIGH
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance [b]	
			Adequacy	No concerns about adequacy [c]	

a. Limitations noted around the unclear description of methods and potential impact of researchers on the process (Gustavell 2017, Mcmullen 2019, Meleo-Erwin 2019, Otutaba 2019 , Rosaasen 2017).

b. Specific patient populations or procedures; people with lung cancer (Baker 2018), some people did nott undergo surgery (Kyte 2018), older people (Malley 2018), Samuelsson 2018). Four studies with a different care system; McMullen (2019), Meleo- Erwin (2019), Otutaba (2019), Smith (2018).

c. See (2018) included some survey data

Table 8: Content of information – coordination of care

Number of studies contributing to the finding	Study design	Finding	Quality assessment		
			Criteria	Rating	Overall assessment of confidence
Content of information – coordination of care					
4	A combination of interviews (3 studies), focus groups (1 study) both interviews and focus groups (1 study), and secondary analysis (1 systematic review of qualitative research)	Patients and families or caregivers want information on how care would be coordinated, particularly on discharge from hospital.	Limitations	No or very minor concerns about methodological limitations [a]	HIGH
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance [b]	
			Adequacy	No concerns about adequacy [c]	

a.One study with limitations around the impact of the researchers on the process (McMullen 2019).

b. One study with a population of people with lung cancer (Kyte 2018). One study focused on people in pre-operative period (Malley 2017). One study had a different care system (McMullen 2019).

c. See (2018) included some survey data.

Table 9: Content of information – financial issues

Number of studies contributing to the finding	Study design	Finding	Quality assessment		
			Criteria	**Rating**	**Overall assessment of confidence**
Content of information – financial issues					
1	Secondary analysis (systematic review of qualitative research)	Patients want information on how to cope with financial and insurance issues.	Limitations	Serious concerns about methodological limitations [a]	VERY LOW
			Coherence	Not assessable	
			Relevance	Serious concerns about relevance [b]	
			Adequacy	Moderate concerns about adequacy	

[a].Limitations around the methods, including study selection, analysis, and adequacy of data.

[b].Two of the six included studies were based in the UK .

Table 10: Information provision and information seeking – level of detail

Number of studies contributing to the finding	Study design	Finding	Quality assessment		
			Criteria	**Rating**	**Overall assessment of confidence**
Information provision and information seeking – level of detail					
6	A combination of interviews (4 studies), both interviews and focus	Patients are generally satisfied with the amount and level of information, but this may vary with individual's needs and preferences.	Limitations	No or very minor concerns about methodological limitations [a]	HIGH
			Coherence	No or very minor concerns about coherence	

Number of studies contributing to the finding	Study design	Finding	Quality assessment		
			Criteria	Rating	Overall assessment of confidence
	groups (1 study), and secondary analysis (1 systematic review of qualitative research)		Relevance	No or very minor concerns about relevance [b]	
			Adequacy	No concerns about adequacy [c]	

a. Limitations with one study and concerns about the impact of the researchers process (McMullen 2019).

b. Three studies with specific populations or procedures; some people did not have surgery (Baker 2018),people with soft tissue sarcoma (Hewitt 2019), People with lung cancer (Kyte 2018).Three studies with a different care system; McMullen 2019

c. See (2018) included some survey data.

Table 11: Information provision and information seeking – balance and consistency

Number of studies contributing to the finding	Study design	Finding	Quality assessment		
			Criteria	Rating	Overall assessment of confidence
Information provision and information seeking – balance and consistency					
10	A combination of interviews (4 studies), focus groups (1 study), both interviews	Patients want information that is accurate, balanced and consistent from sources they can trust.	Limitations	No or very minor concerns about methodological limitations [a]	HIGH
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor	

Number of studies contributing to the finding	Study design	Finding	Quality assessment		
			Criteria	Rating	Overall assessment of confidence
	and focus groups (3 studies), and secondary analysis (2 systematic reviews of qualitative research)			concerns about relevance [b]	
			Adequacy	No concerns about adequacy	

[a] Limitations with three studies and unclear methods on patient selection and analysis; Dibley 2018, McMullen 2019, Stutzman 2017.

[b] One study with a population of men with prostate cancer (Carrier 2018), Three studies with a different care system; Høvik 2018, McMullen 2019, Smith 2018.

Table 12: Information provision and information seeking - information sources and mode of communication

Number of studies contributing to the finding	Study design	Finding	Quality assessment		
			Criteria	Rating	Overall assessment of confidence
Information provision and information seeking - information sources and mode of communication					
21	A combination of interviews (14 studies), focus groups (2 studies), both interviews and focus	Patients value simple and direct information, often in a written format, that they can use throughout their care pathway.	Limitations	No or very minor concerns about methodological limitations [a]	HIGH
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about	

Number of studies contributing to the finding	Study design	Finding	Quality assessment		
			Criteria	Rating	Overall assessment of confidence
	groups (2 studies), and secondary analysis (3 systematic reviews of qualitative research)			relevance	
			Adequacy	No concerns about adequacy	

[a.] Six studies with unclear detail on methods used and some concerns around the process of analysis; Brands-Appledoon 2019, Dibley 2018,Otutaba 2019,Roasaasen 2017,Stutzman 2017,Wickwar 2018.

b. Eight studies with specific populations or procedures; women (Brands-Appledom 2019), post-surgical nutrition (Rattray 2019), younger women (Rosenberg 2018, Recio-Saucedo 2018), older people (Samuelsson 2018, Malley 2018), cosmetic procedures (Wickwar 2018), some people did not have surgery (Baker 2018).

Three studies with a different care system; Høvik 2018,Otutaba 2019, Smith 2018 .

Table 13: Support needs – social relationships

Number of studies contributing to the finding	Study design	Finding	Quality assessment		
			Criteria	Rating	Overall assessment of confidence
Support needs – social relationships					
13	A combination of interviews (10 studies), focus groups (1 study),	Patients value social relationships from a range of sources, to provide practical and emotional support through the process of care.	Limitations	No or very minor concerns about methodological limitations [a]	HIGH
			Coherence	No or very minor concerns about	

Number of studies contributing to the finding	Study design	Finding	Quality assessment		
			Criteria	Rating	Overall assessment of confidence
	and secondary analysis (2 systematic reviews of qualitative research)			coherence	
			Relevance	No or very minor concerns about relevance[b]	
			Adequacy	No concerns about adequacy	

[a].Limitations with two studies and unclear methods on patient selection and analysis (Otutaba 2019, Rosaasen 2017)

[b.] Three studies with specific populations or conditions; prostate surgery (Carrier 2018), people with soft tissue sarcoma (Hewitt 2019), younger women (Rosenberg 2018). One study with a different care system (Otutaba 2019). One study specific to experiences of people waiting for surgery (Carr 2017).

Table 14: Support needs – support groups

Number of studies contributing to the finding	Study design	Finding	Quality assessment		
			Criteria	Rating	Overall assessment of confidence
Support needs – support groups					
7	A combination of interviews (3 studies), focus groups (2 studies), both interviews and focus groups (1 study) and	Support groups, either in person or online, are seen as a valuable resource for people undergoing surgery.	Limitations	No or very minor concerns about methodological limitations [a]	MODERATE
			Coherence	No or very minor concerns about coherence	
			Relevance	Moderate concerns about relevance [b]	
			Adequacy	No concerns about	

Number of studies contributing to the finding	Study design	Finding	Quality assessment		
			Criteria	Rating	Overall assessment of confidence
	secondary analysis (1 systematic review of qualitative research)			adequacy	

[a] Two studies with limitations; limited detail on the methods used (Dibley 2018), unclear impact of researchers on process (Gustavell 2017)

[b] Five studies with specific populations or conditions; people with soft tissue sarcoma (Hewitt 2019), some people didn't undergo surgery (Baker 2018), prostate surgey (Carrier 2018) , younger women (Rosenberg 2018), one study with a different care model (Høvik 2018).

Table 15: Support needs –co-ordination of care

Number of studies contributing to the finding	Study design	Finding	Quality assessment		
			Number of studies contributing to the finding	Design	
Support needs –co-ordination of care					
1	Interviews	Participants described a lack of care coordination amongst disciplines within the preoperative environment. As such, care coordination often fell to the family or caregivers.	Limitations	No or very minor concerns about methodological limitations	MODERATE
			Coherence	Not assessable	
			Relevance	Moderate concerns about relevance [a]	
			Adequacy	No concerns about adequacy	

a. Population of older people (Malley 2018)

Table 16: Support needs – home care

Number of studies contributing to the finding	Study design	Finding	Quality assessment		
			Number of studies contributing to the finding	**Design**	
Support needs – home care					
1	Interviews	Patients want to be asked about what home care they might need before discharge from hospital.	Limitations	No or very minor concerns about methodological limitations	LOW
			Coherence	Not assessable	
			Relevance	Moderate concerns about relevance [a]	
			Adequacy	Moderate concerns about adequacy	
a. Specific population of people with lung cancer (Kyte 2018)					

1.5 Economic evidence

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

1.6 Evidence statements

1.6.1 Qualitative evidence statements

Nine studies identified that patients and families value information on the treatment plan and process of care throughout the surgical journey, through to care after discharge (High quality evidence).

Twenty studies identified that patients want to know what outcomes of surgery, both positive and negative, they should expect and what a ‘normal’ recovery looks like (High quality evidence).

Two studies found that patients want information on what to expect in the period immediately after surgery, both in terms of negative and positive outcomes and what kind of care they might expect (Low quality evidence).

Fourteen studies identified that patients and families or caregivers want more information about self-care after surgery, in order for them to manage the self-care as effectively as possible (High quality evidence).

Six studies found that patients and families or caregivers want information on how care would be coordinated, particularly on discharge from hospital (High quality evidence).

One study reported that patients want information on how to cope with financial and insurance issues (Very low quality evidence)

Six studies found that patients are generally satisfied with the amount and level of information, but this may vary with individual’s needs and preferences (High quality evidence).

Ten studies reported that patients want information that is accurate, balanced and consistent from sources they can trust (High quality evidence).

Twenty one studies identified that patients value simple and direct information, often in a written format, that they can use throughout their care pathway (High quality evidence).

Thirteen studies reported that patients value social relationships from a range of sources, to provide practical and emotional support through the process of care (High quality evidence).

Seven studies reported that support groups, either in person or online, are seen as a valuable resource for people undergoing surgery (Moderate quality evidence).

One study reported that patients want to be asked about what home care they might need before discharge from hospital (Low quality evidence).

1.7 The committee's discussion of the evidence

Please see recommendations 1.1.1 – 1.1.3 in the guideline.

1.7.1 Interpreting the evidence

1.7.1.1 The quality of the evidence

The quality of evidence included ranged from very low to high, with the majority of evidence being of high quality. Evidence was downgraded for concerns about methodological limitations, concerns about contextual relevance, and concerns about adequacy of data.

1.7.1.2 Findings identified in the evidence synthesis

The evidence showed that patients routinely described the content of information they would find useful. Patients described their preferred format and style of information provision and potential sources of information seeking. Patients also highlighted their support needs with regards to information around surgery and recovery.

It was noted that information can help to reduce anxiety before, during, and after the surgical procedure for the person undergoing surgery, their family or carer. It may also assist in setting expectations and mitigating against complaints.

The committee discussed the findings and felt they reflected their experience of current practice. The recommendations were supported by the information from the evidence review and committee experience.

The whole perioperative pathway needs to be patient/carer/family member centred and patient information should be consistent throughout the whole process and in formats and styles which are accessible to and meet the needs of patients/carers/family members.

1.7.2 Cost effectiveness and resource use

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

1.7.3 Other factors the committee took into account

The committee referenced the recommendations made in the patient experience guideline, and highlighted the importance of ease of access to information throughout the care pathway.

At all stages of the perioperative process, patient information and communication must be delivered clearly, openly and in a manner that enables the patient and their family to be fully involved in shared decision making about their ongoing treatment pathway. The most useful source of information and support for all patients would be a clinical member of the perioperative team, who is aware of their specific needs and is the named and direct contact available to respond to their questions and provide information. In smaller units the dedicated point of contact may be a phone number or email address to a team of people. The committee emphasised that clear guidance needs to be given to people as to when contact is appropriate, for example, post-operative wound care and not for queries regarding scheduling. As well as ensuring that the patient is well informed and involved in decisions around their ongoing treatment, this approach would also assist in reducing stress and anxiety sometimes experienced by patients as their treatment pathway progresses and different clinicians become involved. The specific needs and beliefs of individual patients must be central to all information and communication, for example, those living with dementia, learning disabilities, mental health issues, patients from minority ethnic backgrounds, patients with English as a second language, patients with sensory/dual sensory loss and those with religious beliefs.

The committee acknowledged that information provision and support is routinely included preoperatively as part of an enhanced recovery program. The committee added that improved information provision may improve compliance to a recovery program and could lead to improved recovery for the person undergoing surgery and earlier discharge from hospital.

The committee also considered that following discharge, people who have undergone surgery may consult primary care such as their general practitioner or ED for information, although a single point of contact within the surgical team may better provide support and information to the patient.

The committee noted that information and support needs to be tailored to the individual. The guideline committee were aware that for people with learning disabilities, there are recommendations on communicating and making information accessible in the NICE guideline on care and support of people growing older with learning disabilities.

The committee highlighted that treatment planning and the process of care would be discussed in pre-optimisation clinics but there was insufficient evidence to make a recommendation for practice in this area.

Outcomes after surgery would be part of the discussion on risk and this is supported by the recommendation on risk tools.

Care immediately after surgery is supported by the recommendation on a pain management plan.

The single point of contact would be able to provide information on self-care after surgery and to signpost to sources of support including home care and support groups.

The committee noted that the NICE guideline on patient experience in adult NHS services makes recommendations on the continuity of care and the provision of information

References

1. Aagaard K, Rasmussen BS, Sorensen EE, Laursen BS. Patients scheduled for general anesthesia: betwixt and between worrying thoughts and keeping focus. Journal of Perianesthesia Nursing. 2018; 33(6):844-854
2. Aasa A, Hovback M, Bertero CM. The importance of preoperative information for patient participation in colorectal surgery care. Journal of Clinical Nursing. 2013; 22(11-12):1604-1612
3. Aazami S, Jaafarpour M, Mozafari M. Exploring expectations and needs of patients undergoing angioplasty. Journal of Vascular Nursing. 2016; 34(3):93-99
4. Abbasi S, Akbari L. The effect of personnel primary communication on the pre-operative anxiety of patients admitted to operating room. Nursing Practice Today. 2015; 2(4):164-170
5. Abbott AD, Hedlund R, Tyni-Lenne R. Patients' experience post-lumbar fusion regarding back problems, recovery and expectations in terms of the International Classification of Functioning, Disability and Health. Disability and Rehabilitation. 2011; 33(15-16):1399-408
6. Abu-Nab Z, Grunfeld EA. Satisfaction with outcome and attitudes towards scarring among women undergoing breast reconstructive surgery. Patient Education and Counseling. 2007; 66(2):243-9
7. Adugbire BA, Aziato L, Dedey F. Patients' experiences of pre and intra operative nursing care in Ghana: A qualitative study. International Journal of Africa Nursing Sciences. 2017; 6:45-51
8. Agnew J, Jorgensen D. Informed consent: a study of the OR consenting process in New Zealand. AORN Journal. 2012; 95(6):763-70
9. Alawadi ZM, Leal I, Phatak UR, Flores-Gonzalez JR, Holihan JL, Karanjawala BE et al. Facilitators and barriers of implementing enhanced recovery in colorectal surgery at a safety net hospital: A provider and patient perspective. Surgery. 2016; 159(3):700-12
10. Allen KE, Wellard SJ. Older women's experiences with sternotomy. International Journal of Nursing Practice. 2001; 7(4):274-279
11. Allvin R, Ehnfors M, Rawal N, Idvall E. Experiences of the postoperative recovery process: an interview study. The Open Nursing Journal. 2008; 2:1-7
12. 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
13. Ang SGM, Siah RJC, Klainin-Yobas P. Stressors relating to patient psychological health following stoma surgery: An integrated literature review. Oncology Nursing Forum. 2013; 40(6):587-594
14. 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
15. Atinyagrika Adugbire B, Aziato L. Surgical patients' perspectives on nurses' education on post-operative care and follow up in Northern Ghana. BMC Nursing. 2018; 17:29

16. Atwood ME, Friedman A, Meisner BA, Cassin SE. The exchange of social support on online bariatric surgery discussion forums: A mixed-methods content analysis. Health Communication. 2018; 33(5):628-635

17. Aziato L, Adejumo O. An insight into the preoperative experiences of Ghanaian general surgical patients. Clinical Nursing Research. 2014; 23(2):171-87

18. Aziato L, Adejumo O. Psychosocial factors influencing ghanaian family caregivers in the post-operative care of their hospitalised patients. Africa Journal of Nursing and Midwifery. 2014; 16(2):112-124

19. Backstrom S, Wynn R, Sorlie T. Coronary bypass surgery patients' experiences with treatment and perioperative care - a qualitative interview-based study. Journal of Nursing Management. 2006; 14(2):140-147

20. Baker DM, Matthew James L, Jones GL, Brown SR, Lobo AJ. The informational needs and preferences of patients considering surgery for ulcerative colitis: Results of a qualitative study. Inflammatory Bowel Diseases. 2018; 24(1):179-190

21. Barros LM, Frota NM, de Araujo TM, Tellez M, Ciqueto HHP, Caetano JA. Analysis of Portuguese language blogs about bariatric surgery: key doubts of internauts regarding the postoperative period. Eating and Weight Disorders. 2017; Epublication

22. Berg K, Arestedt K, Kjellgren K. Postoperative recovery from the perspective of day surgery patients: a phenomenographic study. International Journal of Nursing Studies. 2013; 50(12):1630-8

23. Bernard H, Foss M. Patient experiences of enhanced recovery after surgery (ERAS). British Journal of Nursing. 2014; 23(2):100-2, 104-6

24. Bernat JL, Peterson LM. Patient-centered informed consent in surgical practice. Archives of Surgery. 2006; 141(1):86-92

25. Bhamrah G, Ahmad S, NiMhurchadha S. Internet discussion forums, an information and support resource for orthognathic patients. American Journal of Orthodontics and Dentofacial Orthopedics. 2015; 147(1):89-96

26. Bhardwaj R, Pickard R, Carrick-Sen D, Brittain K. Patients' perspectives on timing of urinary catheter removal after surgery. British Journal of Nursing. 2012; 21(18):S4, S6-9

27. Blazeby JM, Soulsby M, Winstone K, King PM, Bulley S, Kennedy RH. A qualitative evaluation of patients' experiences of an enhanced recovery programme for colorectal cancer. Colorectal Disease. 2010; 12(10 Online):e236-42

28. Bloom DL, Chapman BM, Wheeler SB, McGuire KP, Lee CN, Weinfurt K et al. Reframing the conversation about contralateral prophylactic mastectomy: Preparing women for postsurgical realities. Psycho-Oncology. 2019; 28(2):394-400

29. Borneman T, Chu DZ, Wagman L, Ferrell B, Juarez G, McCahill LE et al. Concerns of family caregivers of patients with cancer facing palliative surgery for advanced malignancies. Oncology Nursing Forum. 2003; 30(6):997-1005

30. Boughton M, Halliday L. Home alone: patient and carer uncertainty surrounding discharge with continuing clinical care needs. Contemporary Nurse. 2009; 33(1):30-40

31. Bramall AN, Bernstein M. Improving information provision for neurosurgical patients: a qualitative study. Canadian Journal of Neurological Sciences. 2014; 41(1):66-73

32. Brands-Appeldoorn A, Maaskant-Braat S, Schenk K, Roumen R. Cosmetic consequences of breast-conserving treatment for breast cancer: Something worth talking about. Oncologist. 2019; 24(2):172-177

33. Braude L, Kirsten L, Gilchrist J, Juraskova I. A systematic review of women’s satisfaction and regret following risk-reducing mastectomy. Patient Education and Counseling. 2017; 100(12):2182-2189

34. Brooke BS, Slager SL, Swords DS, Weir CR. Patient and caregiver perspectives on care coordination during transitions of surgical care. Translational Behavioral Medicine. 2018; 8(3):429-438

35. Bryson GL, Mercer C, Varpio L. Patient and caregiver experience following ambulatory surgery: qualitative analysis in a cohort of patients 65 yr and older. Canadian Journal of Anaesthesia. 2014; 61(11):986-94

36. Burt J, Caelli K, Moore K, Anderson M. Radical prostatectomy: men's experiences and postoperative needs. Journal of Clinical Nursing. 2005; 14(7):883-890

37. Butler L, Downe-Wamboldt B, Marsh S, Bell D, Jarvi K. Behind the scenes: partners' perceptions of quality of life post radical prostatectomy. Urologic Nursing. 2000; 20(4):254-258

38. Carney L, Jones L, Braddon F, Pullyblank AM, Dixon AR. A colorectal cancer patient focus group develops an information package. Annals of the Royal College of Surgeons of England. 2006; 88(5):447-9

39. Carr T, Teucher U, Casson AG. Waiting for scheduled surgery: A complex patient experience. Journal of Health Psychology. 2017; 22(3):290-301

40. Carr T, Teucher UC, Casson AG. Time while waiting: Patients’ experiences of scheduled surgery. Qualitative Health Research. 2014; 24(12):1673-1685

41. Carrier J, Edwards D, Harden J. Men's perceptions of the impact of the physical consequences of a radical prostatectomy on their quality of life: a qualitative systematic review. JBI Database Of Systematic Reviews And Implementation Reports. 2018; 16(4):892-972

42. Cater R, Taylor J. The experiences of heart transplant recipients' spouses during the pretransplant waiting period: integrative review. Journal of Clinical Nursing. 2017; 26(19-20):2865-2877

43. Chan Z, Kan C, Lee P, Chan I, Lam J. A systematic review of qualitative studies: patients' experiences of preoperative communication. Journal of Clinical Nursing. 2012; 21(5-6):812-824

44. Chaplin J, Kelly J, Kildea S. Maternal perceptions of breastfeeding difficulty after caesarean section with regional anaesthesia: A qualitative study. Women & Birth. 2016; 29(2):144-52

45. Chen S-C. Life experiences of Taiwanese oral cancer patients during the postoperative period. Scandinavian Journal of Caring Sciences. 2012; 26(1):98-103

46. Cheung CS, Bower WF, Kwok SC, van Hasselt CA. Contributors to surgical in-patient satisfaction--development and reliability of a targeted instrument. Asian Journal of Surgery. 2009; 32(3):143-50

47. Chou CC, Lee TY, Sun CC, Lin SS, Chen LF. Husbands' experiences before wives' hysterectomy. Journal of Nursing Research. 2006; 14(2):113-122

48. Clendenen SR, Rajendran S, Kopacz DJ, Greengrass RA, Robards CB, Weinstein DM et al. Pregabalin as an adjunct to a multimodal analgesic regimen to achieve opioid sparing in arthroscopic rotator cuff repair. Romanian Journal of Anaesthesia and Intensive Care. 2010; 17(1):5-10

49. 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):2798-2806

50. Crook TB, Banerjee S, de Souza K, Moran BJ, Farquharson SM. Supplementary preoperative information encourages return to work after inguinal hernia repair. Journal of One-Day Surgery. 2005; 15(1):18-21

51. Dancet EA, Spiessens C, Blocquiaux L, Sermeus W, Vanderschueren D, D'Hooghe TM. Testicular biopsy before ART: the patients' perspective on the quality of care. Human Reproduction. 2010; 25(12):3072-82

52. Das SS, Richards CJ. Pre-operative counselling - the patients' views. Journal of Obstetrics and Gynaecology. 2000; 20(3):308-309

53. Davidge KM, Eskicioglu C, Lipa J, Ferguson P, Swallow CJ, Wright FC. Qualitative assessment of patient experiences following sacrectomy. Journal of Surgical Oncology. 2010; 101(6):447-450

54. Davis LA, Ryszkiewicz E, Schenk E, Peipert J, LaSee C, Miller C et al. Lung transplant or bust: patients' recommendations for ideal lung transplant education. Progress in Transplantation. 2014; 24(2):132-41

55. Davis RE, Vincent C, Henley A, McGregor A. Exploring the care experience of patients undergoing spinal surgery: a qualitative study. Journal of Evaluation in Clinical Practice. 2013; 19(1):132-138

56. 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

57. Dewar SR, Pieters HC. Perceptions of epilepsy surgery: a systematic review and an explanatory model of decision-making. Epilepsy & Behavior. 2015; 44:171-8

58. Dibley L, Czuber-Dochan W, Wade T, Duncan J, Burch J, Warusavitarne J et al. Patient decision-making about emergency and planned stoma surgery for IBD: A qualitative exploration of patient and clinician perspectives. Inflammatory Bowel Diseases. 2018; 24(2):235-246

59. Doering LV, McGuire AW, Rourke D. Recovering from cardiac surgery: what patients want you to know. American Journal of Critical Care. 2002; 11(4):333-43

60. Does preoperative oral carbohydrate intake improve postoperative outcomes in patients undergoing coronary artery bypass grafts? Journal of Cardiothoracic and Vascular Anesthesia. 2017; Conference: 32nd Annual Meeting of the European Association of Cardiothoracic Anaesthelologists. Germany. 31(Supplement 1):S58-S59

61. Doyle A, Saunders P. Are patients well informed about their anaesthetic? Journal of One-Day Surgery. 2009; 19(4):88-91

62. Drageset S, Lindstrom TC, Giske T, Underlid K. "The support I need": women's experiences of social support after having received breast cancer diagnosis and awaiting surgery. Cancer Nursing`. 2012; 35(6):E39-47

63. Dunckley M, Ellard D, Quinn T, Barlow J. Coronary artery bypass grafting: patients' and health professionals' views of recovery after hospital discharge. European Journal of Cardiovascular Nursing. 2008; 7(1):36-42

64. Durity MB, Wyness A, Durity F, Ratel M. Education and information needs identified by patients and key family members prior to surgery for a skull base neoplasm: implications for practice. AXON. 2000; 22(1):32-45

65. Eckhardt AL, Swanlund SL. On vs off: perceptions of four patients' experiences of coronary artery bypass surgery. Progress in Cardiovascular Nursing. 2008; 23(4):178-83

66. Edem IJ, Banton B, Bernstein M, Lwu S, Vescan A, Gentilli F et al. A prospective qualitative study on patients' perceptions of endoscopic endonasal transsphenoidal surgery. British Journal of Neurosurgery. 2013; 27(1):50-5

67. Engstrom BL, Fridlund B. Women's views of counselling received in connection with breast-feeding after reduction mammoplasty. Journal of Advanced Nursing. 2000; 32(5):1143-51

68. Eriksson H, Haglund K, Leo Swenne C, Arakelian E. Patients' experiences of postoperative health related to cytoreductive surgery and hyperthermic intraoperative chemotherapy. Journal of Clinical Nursing. 2014; 23(1-2):201-210

69. Falco D. Patient satisfaction with anesthesia care what do we know? AANA Journal. 2017; 85(4):286-292

70. Fergus KD, Gray RE, Fitch MI, Labrecque M, Phillips C. Active consideration: Conceptualizing patient-provided support for spouse caregivers in the contest of prostate cancer. Qualitative Health Research. 2002; 12(4):492-514

71. Fitzgerald E, Perry A. Pre-operative counselling for laryngectomy patients: a systematic review. Journal of Laryngology and Otology. 2016; 130(1):15-20

72. Fletcher D, Moore AJ, Blom AW, Wylde V. An exploratory study of the long-term impact of difficulty kneeling after total knee replacement. Disability and Rehabilitation. 2019; 41(7):820-825

73. Fritzell K, Persson C, Björk J, Hultcrantz R, Wettergren L. Patients’ views of surgery and surveillance for familial adenomatous polyposis. Cancer Nursing. 2010; 33(2):e17-e23

74. Gainer RA, Curran J, Buth KJ, David JG, Légaré J-F, Hirsch GM. Toward optimal decision making among vulnerable patients referred for cardiac surgery: A qualitative analysis of patient and provider perspectives. Medical Decision Making. 2017; 37(5):600-610

75. 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

76. Gillis C, Martin L, Gill M, Gilmour L, Nelson G, Gramlich L. Food is medicine: A qualitative analysis of patient and institutional barriers to successful surgical nutrition practices in an enhanced recovery after surgery setting. Nutrition in Clinical Practice. 2019; 34(4):606-615

77. Gilmartin J. Day surgery: patients' perceptions of a nurse-led preadmission clinic. Journal of Clinical Nursing. 2004; 13(2):243-250

78. Gilmartin J. Contemporary day surgery: patients' experience of discharge and recovery. Journal of Clinical Nursing. 2007; 16(6):1109-1117

79. Gilmartin J, Wright K. Day surgery: patients' felt abandoned during the preoperative wait. Journal of Clinical Nursing. 2008; 17(18):2418-2425

80. Gupta KM, Harding JC, Othman MS, Merbs SL, Gower EW. Why do patients refuse trichiasis surgery? Lessons and an education initiative from Mtwara Region, Tanzania. PLoS Neglected Tropical Diseases. 2018; 12(6):e0006464

81. Gustavell T, Sundberg K, Frank C, Wengström Y, Browall M, Segersvärd R et al. Symptoms and self-care following pancreaticoduodenectomy: Perspectives from patients and healthcare professionals - Foundation for an interactive ICT application. European Journal of Oncology Nursing. 2017; 26:36-41

82. Haapala T, Palonen M, Åstedt-Kurki P. Shoulder operation counselling in day-surgery patients in finland: Patients’ perspective. British Journal of Anaesthetic & Recovery Nursing. 2013; 14(1/2):18-25

83. Hallowell N. A qualitative study of the information needs of high-risk women undergoing prophylactic oophorectomy. Psycho-Oncology. 2000; 9(6):486-95

84. Halm MA. Specific needs, concerns, strategies and advice of caregivers after coronary artery bypass surgery. Heart and Lung. 2016; 45(5):416-22

85. Halm MA. Age and gender influences on the needs, concerns and strategies of CABG caregivers. Heart and Lung. 2017; 46(3):159-165

86. Hamilton TD, Selby D, Tsang ME, Kim A, Wright FC. Patients' perceptions of palliative surgical procedures: a qualitative analysis. Annals of Palliative Medicine. 2017; 6(Suppl 1):S77-S84

87. Harcourt D, Rumsey N. Mastectomy patients' decision-making for or against immediate breast reconstruction. Psycho-Oncology. 2004; 13(2):106-115

88. Harker R, McLauchlan R, MacDonald H, Waterman C, Waterman H. Endless nights: patients' experiences of posturing face down following vitreoretinal surgery. Ophthalmic Nursing. 2002; 6(2):11-15

89. Hartford K. Telenursing and patients' recovery from bypass surgery. Journal of Advanced Nursing. 2005; 50(5):459-68

90. Hassel K, Andersson K, Koinberg I-L, Wennström B. Postoperative wound infections after a proctectomy—Patient experiences. International Journal of Qualitative Studies on Health and Well-being. 2016; 11:9

91. Hassling L, Babic A, Lonn U, Casimir-Ahn H. A web-based patient information system--identification of patients' information needs. Journal of Medical Systems. 2003; 27(3):247-257

92. Hedman AM, Stromberg L, Grafstrom M, Heikkila K. Hip fracture patients' cognitive state affects family members' experiences - a diary study of the hip fracture recovery. Scandinavian Journal of Caring Sciences. 2011; 25(3):451-8

93. Heggland LH, Hausken K. A qualitative identification of categories of patient participation in decision-making by health care professionals and patients during surgical treatment. Clinical Nursing Research. 2013; 22(2):206-27

94. Henselmans I, Jacobs M, van Berge Henegouwen MI, de Haes HC, Sprangers MA, Smets EM. Postoperative information needs and communication barriers of esophageal cancer patients. Patient Education and Counseling. 2012; 88(1):138-46

95. Herling SF, Palle C, Moeller AM, Thomsen T. The experience of robotic-assisted laparoscopic hysterectomy for women treated for early-stage endometrial cancer: A qualitative study. Cancer Nursing. 2016; 39(2):125-33

96. Hermansen A, Peolsson A, Kammerlind AS, Hjelm K. Women's experiences of daily life after anterior cervical decompression and fusion surgery: a qualitative interview study. Journal of Rehabilitation Medicine. 2016; 48(4):352-358

97. Hewitt L, Powell R, Zenginer K, Coyle C, Murray H, Cooper L et al. Patient perceptions of the impact of treatment (surgery and radiotherapy) for soft tissue sarcoma. Sarcoma. 2019; 2019:9581781

98. Hill O, White K. Exploring women's experiences of TRAM flap breast reconstruction after mastectomy for breast cancer. Oncology Nursing Forum. 2008; 35(1):81-8

99. Hoermann S, Doering S, Richter R, Walter MH, Schüßler G. Aufklärungsbedürfnisse chirurgischer Patienten. Psychotherapie Psychosomatik Medizinische Psychologie. 2001; 51(2):56-61

100. Holliman D, Bernstein M. Patients' perception of error during craniotomy for brain tumour and their attitudes towards pre-operative discussion of error: a qualitative study. British Journal of Neurosurgery. 2012; 26(3):326-30

101. Horstman MJ, Mills WL, Herman LI, Cai C, Shelton G, Qdaisat T et al. Patient experience with discharge instructions in postdischarge recovery: a qualitative study. BMJ Open. 2017; 7(2):e014842

102. Høvik 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

103. Hovind IL, Bredal IS, Dihle A. Women's experience of acute and chronic pain following breast cancer surgery. Journal of Clinical Nursing. 2013; 22(7-8):1044-1052

104. Huber J, Ihrig A, Herzog W, Huber CG, Konyango B, Loser E et al. Patients' view of their preoperative education for radical prostatectomy: does it change after surgery? Journal of Cancer Education. 2012; 27(2):377-82

105. Hudson BF, Ogden J, Whiteley MS. A thematic analysis of experiences of varicose veins and minimally invasive surgery under local anaesthesia. Journal of Clinical Nursing. 2015; 24(11-12):1502-1512

106. Huetteman HE, Shauver MJ, Nasser JS, Chung KC. The desired role of health care providers in guiding older patients with distal radius fractures: a qualitative analysis. Journal of Hand Surgery - American Volume. 2018; 43(4):312-320.e4

107. Hughes LC, Hodgson NA, Muller P, Robinson LA, McCorkle R. Information needs of elderly postsurgical cancer patients during the transition from hospital to home. Journal of Nursing Scholarship. 2000; 32(1):25-30

108. Ingadottir B, Blondal K, Jaarsma T, Thylen I. Perceptions about traditional and novel methods to learn about postoperative pain management: a qualitative study. Journal of Advanced Nursing. 2016; 72(11):2672-2683

109. Ivarsson B, Hommel A, Sandberg M, Sjostrand D, Johansson A. The experiences of pre- and in-hospital care in patients with hip fractures: A study based on critical incidents. International Journal of Orthopaedic and Trauma Nursing. 2018; 30:8-13

110. Jacobs V. Informational needs of surgical patients following discharge. Applied Nursing Research. 2000; 13(1):12-8

111. Johnson LP, Asigbee FM, Crowell R, Negrini A. Pre-surgical, surgical and post-surgical experiences of weight loss surgery patients: a closer look at social determinants of health. Clinical Obesity. 2018; 8(4):265-274

112. Kaplan AL, Klein MP, Tan HJ, Setlur NP, Agarwal N, Steinberg K et al. Use of patient ethnography to support quality improvement in benign prostatic hyperplasia. Healthcare. 2014; 2(4):263-7

113. Kaptain K, Bregnballe V, Dreyer P. Patient participation in postoperative pain assessment after spine surgery in a recovery unit. Journal of Clinical Nursing. 2017; 26(19-20):2986-2994

114. Kelly KN, Noyes K, Dolan J, Fleming F, Monson JR, Gonzalez M et al. Patient perspective on care transitions after colorectal surgery. Journal of Surgical Research. 2016; 203(1):103-12

115. 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

116. Khu KJ, Doglietto F, Radovanovic I, Taleb F, Mendelsohn D, Zadeh G et al. Patients' perceptions of awake and outpatient craniotomy for brain tumor: a qualitative study. Journal of Neurosurgery. 2010; 112(5):1056-60

117. Kiessling T, Kjellgren KI. Patients' experiences of participation in care. Nordic Journal of Nursing Research & Clinical Studies. 2004; 24(4):31-35

118. King J, Chamberland P, Rawji A, Ager A, Leger R, Michaels R et al. Patient educational needs of patients undergoing surgery for lung cancer. Journal of Cancer Education. 2014; 29(4):802-7

119. Kunneman M, Marijnen CA, Baas-Thijssen MC, van der Linden YM, Rozema T, Muller K et al. Considering patient values and treatment preferences enhances patient involvement in rectal cancer treatment decision making. Radiotherapy and Oncology. 2015; 117(2):338-42

120. Kyte K, Ekstedt M, Rustoen T, Oksholm T. Longing to get back on track: Patients' experiences and supportive care needs after lung cancer surgery. Journal of Clinical Nursing. 2018; 28(9-10):1546-1554

121. Lally RM. In the moment: women speak about surgical treatment decision making days after a breast cancer diagnosis. Oncology Nursing Forum. 2009; 36(5):E257-65

122. Lane-Carlson ML, Kumar J. Engaging patients in managing their health care: patient perceptions of the effect of a total joint replacement presurgical class. Permanente Journal. 2012; 16(3):42-7

123. Lapum J, Angus JE, Peter E, Watt-Watson J. Patients' narrative accounts of open-heart surgery and recovery: authorial voice of technology. Social Science and Medicine. 2010; 70(5):754-62

124. Larnebratt A, Fomichov V, Bjornsson B, Sandstrom P, Lindhoff Larsson A, Drott J. Information is the key to successful participation for patients receiving surgery for upper gastrointestinal cancer. European Journal of Cancer Care. 2019; 28(2):e12959

125. Latifi M, Salimi S, Barahmand N, Fahimnia F, Allahbakhshian Farsani L. Postmastectomy information needs and information-seeking motives for women with breast cancer. Advanced Biomedical Research. 2018; 7:75

126. Laursen J. Spouses needs for professional support: The spouses' perspective on communication. Medsurg Nursing. 2015; 24(5):325-362

127. Lee TS, Kilbreath SL, Sullivan G, Refshauge KM, Beith JM. Patient perceptions of arm care and exercise advice after breast cancer surgery. Oncology Nursing Forum. 2010; 37(1):85-91

128. Leegaard M, Nåden D, Fagermoen MS. Postoperative pain and self-management: Women's experiences after cardiac surgery. Journal of Advanced Nursing. 2008; 63(5):476-485

129. Lehto RH. Identifying primary concerns in patients newly diagnosed with lung cancer. Oncology Nursing Forum. 2011; 38(4):440-447

130. Leo Swenne C, Cederholm K, Gustafsson M, Arakelian E. Postoperative health and patients' experiences of efficiency and quality of care after cytoreductive surgery and hyperthermic intraperitoneal chemotherapy, two to six months after surgery. European Journal of Oncology Nursing. 2015; 19(2):191-7

131. Letterstal A, Eldh AC, Olofsson P, Forsberg C. Patients' experience of open repair of abdominal aortic aneurysm--preoperative information, hospital care and recovery. Journal of Clinical Nursing. 2010; 19(21-22):3112-3122

132. Lim SH, Chan SWC, He H-G. Patients' experiences of performing self-care of stomas in the initial postoperative period. Cancer Nursing. 2015; 38(3):185-193

133. Liu RH, Irwin JD. Understanding the post-surgical bariatric experiences of patients two or more years after surgery. Quality of Life Research. 2017; 26(11):3157-3168

134. Malkin KF. Patients' perceptions of a pre-admission clinic. Journal of Nursing Management. 2000; 8(2):107-113

135. Malley AM, Bourbonniere M, Naylor M. A qualitative study of older adults’ and family caregivers’ perspectives regarding their preoperative care transitions. Journal of Clinical Nursing. 2018; 27(15-16):2953-2962

136. Malley AM, Young GJ. A qualitative study of patient and provider experiences during preoperative care transitions. Journal of Clinical Nursing. 2017; 26(13-14):2016-2024

137. Malmstrom M, Klefsgard R, Johansson J, Ivarsson B. Patients' experiences of supportive care from a long-term perspective after oesophageal cancer surgery - a focus group study. European Journal of Oncology Nursing. 2013; 17(6):856-62

138. Masuda M, Oishi H, Yamamoto M. Uncertainty in patients with unruptured intracranial aneurysms undergoing endovascular surgery: a qualitative and inductive study. Nursing Research. 2014; 63(5):366-74

139. May V, Clarke T, Coulling S, Cowie L, Cox R, Day D et al. What information patients require on graduated compression stockings. British Journal of Nursing. 2006; 15(5):263-70

140. McMullen C, Nielsen M, Firemark A, Price PM, Nakatani D, Tuthill J et al. Designing for impact: identifying stakeholder-driven interventions to support recovery after major cancer surgery. Supportive Care in Cancer. 2018; 26(12):4067-4076

141. McMullen CK, Kwan ML, Colwell JC, Munneke JR, Davis JV, Firemark A et al. Recovering from cystectomy: Patient perspectives. Bladder Cancer. 2019; 5(1):51-61

142. McMurray A, Johnson P, Wallis M, Patterson E, Griffiths S. General surgical patients' perspectives of the adequacy and appropriateness of discharge planning to facilitate health decision-making at home. Journal of Clinical Nursing. 2007; 16(9):1602-1609

143. McNair AGK, MacKichan F, Donovan JL, Brookes ST, Avery KNL, Griffin SM et al. What surgeons tell patients and what patients want to know before major cancer surgery: A qualitative study. BMC Cancer. 2016; 16 258

144. McQuestion M, Fitch M. Patients' experience of receiving radiation treatment for head and neck cancer: Before, during and after treatment. Canadian Oncology Nursing Journal. 2016; 26(4):325-347

145. Megyesi JF. Providing information to our patients: Published and personal perspectives. Canadian Journal of Neurological Sciences. 2014; 41(1):3-4

146. Meleo-Erwin ZC. 'No one is as invested in your continued good health as you should be:' an exploration of the post-surgical relationships between weight-loss surgery patients and their home bariatric clinics. Sociology of Health and Illness. 2019; 41(2):285-302

147. Mills ME, Sullivan K. Patients with operable oesophageal cancer: their experience of information-giving in a regional thoracic unit. Journal of Clinical Nursing. 2000; 9(2):236-246

148. Milne JL, Spiers JA, Moore KN. Men's experiences following laparoscopic radical prostatectomy: a qualitative descriptive study. International Journal of Nursing Studies. 2008; 45(5):765-74

149. Mohamed NE, Chaoprang Herrera P, Hudson S, Revenson TA, Lee CT, Quale DZ et al. Muscle invasive bladder cancer: examining survivor burden and unmet needs. Journal of Urology. 2014; 191(1):48-53

150. Mordiffi SZ, Tan SP, Wong MK. Information provided to surgical patients versus information needed. AORN Journal. 2003; 77(3):546-9, 552-8, 561-2

151. Murray CD, Turner A, Rehan C, Kovacs T. Satisfaction following immediate breast reconstruction: Experiences in the early post-operative stage. British Journal of Health Psychology. 2015; 20(3):579-93

152. Nabozny MJ, Kruser JM, Steffens NM, Pecanac KE, Brasel KJ, Chittenden EH et al. Patient-reported limitations to surgical buy-in: A qualitative study of patients facing high-risk surgery. Annals of Surgery. 2017; 265(1):97-102

153. 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: https://www.nice.org.uk/process/pmg20/chapter/introduction-and-overview

154. Neault G. Self-care needs of cataract patients following ambulatory surgery. Insight - Journal of the American Society of Ophthalmic Registered Nurses. 2005; 30(4):7-11

155. Nelson CJ, Lacey S, Kenowitz J, Pessin H, Shuk E, Roth AJ et al. Men's experience with penile rehabilitation following radical prostatectomy: A qualitative study with the goal of informing a therapeutic intervention. Psycho-Oncology. 2015; 24(12):1646-1654

156. Newell R, Ziegler L, Stafford N, Lewin RJ. The information needs of head and neck cancer patients prior to surgery. Annals of the Royal College of Surgeons of England. 2004; 86(6):407-10

157. Noordegraaf AV, Huirne JAF, Pittens CA, van Mechelen W, Broerse JEW, Brölmann HAM et al. eHealth program to empower patients in returning to normal activities and work after gynecological surgery: intervention mapping as a useful method for development. Journal of Medical Internet Research. 2012; 14(5):99-115

158. Odom-Forren J, Reed DB, Rush C. Postoperative symptom distress of laparoscopic cholecystectomy ambulatory surgery patients. Journal of Perianesthesia Nursing. 2018; 33(6):801-813

159. Olsson K, Näslund U, Nilsson J, Hörnsten Å. Experiences of and coping with severe aortic stenosis among patients waiting for transcatheter aortic valve implantation. Journal of Cardiovascular Nursing. 2016; 31(3):255-261

160. Olsson K, Näslund U, Nilsson J, Hörnsten Å. Patients’ decision making about undergoing transcatheter aortic valve implantation for severe aortic stenosis. Journal of Cardiovascular Nursing. 2016; 31(6):523-528

161. Olsson L-E, Nyström AEM, Karlsson J, Ekman I. Admitted with a hip fracture: patient perceptions of rehabilitation. Journal of Clinical Nursing. 2007; 16(5):853-859

162. Olsson U, Bergbom I, Bosaeus I. Patients' experiences of the recovery period 3 months after gastrointestinal cancer surgery. European Journal of Cancer Care. 2002; 11(1):51-60

163. Orpen N, Harris J. Patients' perceptions of preoperative home-based occupational therapy and/or physiotherapy interventions prior to total hip replacement. British Journal of Occupational Therapy. 2010; 73(10):461-469

164. Otutaha B, Srinivasa S, Koea J. Patient information needs in upper gastrointestinal cancer: what patients and their families want to know. ANZ Journal of Surgery. 2019; 89(1-2):20-24

165. Owers C, Halliday V, Saradjian A, Ackroyd R. Designing pre-bariatric surgery education: The value of patients' experiences. Journal of Diabetes Nursing. 2017; 21(4):119-125

166. Ozel S, Karabacak U. Discharge after surgical treatment: What do patients in Turkey want to know? HealthMED. 2012; 6(2):525-530

167. Parretti HM, Hughes CA, Jones LL. 'The rollercoaster of follow-up care' after bariatric surgery: a rapid review and qualitative synthesis. Obesity Reviews. 2019; 20(1):88-107

168. Patients define value of pre-op information...second part of a two-part series. Same-Day Surgery. 2000; 24(5):63-64

169. Pennbrant S, Törn JG, Munthe H. Information about sexual activity after hip replacement: A literature review. Nordic Journal of Nursing Research. 2018; 38(3):119-127

170. Pfeil M. Patients' perception of the nursing contribution to gastric band surgery. British Journal of Nursing. 2014; 23(2):95-9

171. Pilot study on the existence of empowering education of orthopaedic patients in Greece. Journal of Orthopaedic Nursing. 2009; 13(4):211-212

172. Powell R, McKee L, Bruce J. Information and behavioural instruction along the health-care pathway: the perspective of people undergoing hernia repair surgery and the role of formal and informal information sources. Health Expectations. 2009; 12(2):149-59

173. Pratt AL, Byrne G. The lived experience of Dupuytren's disease of the hand. Journal of Clinical Nursing. 2009; 18(12):1793-802

174. Rattray M, Marshall AP, Desbrow B, Roberts S. A qualitative exploration of patients' experiences with and perceptions of recommencing feeding after colorectal surgery. Journal of Human Nutrition & Dietetics. 2019; 32(1):63-71

175. Recio-Saucedo A, Gilbert AW, Gerty S, Cutress RI, Eccles D, Foster C. "It's like we don't exist": Tailoring education for young women undergoing surgery for early-stage breast cancer. Oncology Nursing Forum. 2018; 45(2):165-175

176. Rhodes L, Miles G, Pearson A. Patient subjective experience and satisfaction during the perioperative period in the day surgery setting: a systematic review. International Journal of Nursing Practice. 2006; 12(4):178-92

177. Richards HS, Jenkinson E, Rumsey N, Harrad RA. Pre-operative experiences and post-operative benefits of ptosis surgery: A qualitative study. Orbit. 2017; 36(3):147-153

178. Ronaldson S. Patient stories: the cystectomy experience. N2N: Nurse2Nurse. 2004; 4(1):21-22

179. Rosaasen N, Mainra R, Shoker A, Wilson J, Blackburn D, Mansell H. Education before kidney transplantation: What do patients need to know? Progress in Transplantation. 2017; 27(1):58-64

180. Rosenberg SM, Greaney ML, Patenaude AF, Sepucha KR, Meyer ME, Partridge AH. "I don't want to take chances.": A qualitative exploration of surgical decision making in young breast cancer survivors. Psycho-Oncology. 2018; 27(6):1524-1529

181. Rozmovits L, Khu KJ, Osman S, Gentili F, Guha A, Bernstein M. Information gaps for patients requiring craniotomy for benign brain lesion: a qualitative study. Journal of Neuro-Oncology. 2010; 96(2):241-7

182. Rushton A, Heneghan NR, Heap A, White L, Calvert M, Goodwin PC. Patient and physiotherapist perceptions of rehabilitation following primary lumbar discectomy: a qualitative focus group study embedded within an external pilot and feasibility trial. BMJ Open. 2017; 7(4):e015878

183. Sa AS, Ziviani LC, Castro ESO, Galvao CM, Mendes KD. Information needs of family caregivers regarding liver transplant candidates. Revista Gaúcha de Enfermagem. 2016; 37(1):e54650

184. Samuelsson KS, Egenvall M, Klarin I, Lokk J, Gunnarsson U, Iwarzon M. The older patient's experience of the healthcare chain and information when undergoing colorectal cancer surgery according to the enhanced recovery after surgery concept. Journal of Clinical Nursing. 2018; 27(7-8):e1580-e1588

185. Sanger PC, Hartzler A, Han SM, Armstrong CAL, Stewart MR, Lordon RJ et al. Patient perspectives on post-discharge surgical site infections: Towards a patient-centered mobile health solution. PloS One. 2014; 9(12):e114016

186. Sawka AM, Goldstein DP, Brierley JD, Tsang RW, Rotstein L, Ezzat S et al. The impact of thyroid cancer and post-surgical radioactive iodine treatment on the lives of thyroid cancer survivors: a qualitative study. PloS One. 2009; 4(1):e4191

187. Schou L, Egerod I. A qualitative study into the lived experience of post-CABG patients during mechanical ventilator weaning. Intensive and Critical Care Nursing. 2008; 24(3):171-9

188. Screeche-Powell C, Owen S. Early experiences of patients waiting to be accepted for CABG. British Journal of Nursing. 2003; 12(10):612-9

189. 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

190. Seibaek L, Petersen LK, Blaakaer J, Hounsgaard L. Hoping for the best, preparing for the worst: The lived experiences of women undergoing ovarian cancer surgery. European Journal of Cancer Care. 2012; 21(3):360-371

191. Senn B, Gafner D, Happ MB, Eicher M, Mueller MD, Engberg S et al. The unspoken disease: Symptom experience in women with vulval neoplasia and surgical treatment: A qualitative study. European Journal of Cancer Care. 2011; 20(6):747-758

192. Shahmoon S, Smith JA, Jahanshahi M. The lived experiences of deep brain stimulation in Parkinson's disease: An interpretative phenomenological analysis. Parkinson's Disease. 2019; 2019:1937235

193. Sharman M, Hensher M, Wilkinson S, Williams D, Palmer A, Venn A et al. What are the support experiences and needs of patients who have received bariatric surgery? Health Expectations. 2017; 20(1):35-46

194. 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

195. Shaw RM. Rethinking elements of informed consent for living kidney donation: findings from a New Zealand study. Health Sociology Review. 2015; 24(1):109-122

196. Showalter A, Burger S, Salyer J. Patients' and their spouses' needs after total joint arthroplasty: a pilot study. Orthopaedic Nursing. 2000; 19(1):49-57, 62

197. Sibbern T, Bull Sellevold V, Steindal SA, Dale C, Watt-Watson J, Dihle A. Patients' experiences of enhanced recovery after surgery: a systematic review of qualitative studies. Journal of Clinical Nursing. 2017; 26(9-10):1172-1188

198. Siddins M, Hart G, He B, Kanchanabat B, Mohan Rao M. Laparoscopic donor nephrectomy: meeting the challenge of consumerism? ANZ Journal of Surgery. 2003; 73(11):912-5

199. Silva GPS, de Jesus MCP, Merighi MAB, Domingos SRdF, Oliveira DMd. The experience of women regarding cesarean section from the perspective of social phenomenology. Online Brazilian Journal of Nursing. 2014; 13(1):5-14

200. Siyam T, Ross S, Shandro T, Hagen S, Battochio L, Yuksel N. Perspectives and decision-making about menopausal therapies in women who had bilateral oophorectomy. Menopause. 2018; 25(7):795-802

201. Sjöling M, Norbergh K, Malker H, Asplund K. What information do patients waiting for and undergoing arthroplastic surgery want? Their side of the story. Journal of Orthopaedic Nursing. 2006; 10(1):5-14

202. 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

203. Spalding NJ. Reducing anxiety by pre-operative education: make the future familiar. Occupational Therapy International. 2003; 10(4):278-93

204. Spalding NJ, Poland FM, Gregory S, McCulloch J, Sargen K, Vicary P. Addressing patients' colorectal cancer needs in preoperative education. Health Education. 2013; 113(6):502-516

205. Specht K, Agerskov H, Kjaersgaard-Andersen P, Jester R, Pedersen BD. Patients' experiences during the first 12 weeks after discharge in fast-track hip and knee arthroplasty - a qualitative study. International Journal of Orthopaedic and Trauma Nursing. 2018; 31:13-19

206. 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):836-845

207. Stern C, Lockwood C. Knowledge retention from preoperative patient information. JBI Library of Systematic Reviews. 2005; 3(3):1-31

208. Strickland LH, Kelly L, Hamilton TW, Murray DW, Pandit HG, Jenkinson C. Early recovery following lower limb arthroplasty: qualitative interviews with patients undergoing elective hip and knee replacement surgery. Initial phase in the development of a patient-reported outcome measure. Journal of Clinical Nursing. 2018; 27(13-14):2598-2608

209. Stutzman SE, Olson DM, Greilich PE, Abdulkadir K, Rubin MA. The patient and family perioperative experience during transfer of care: A qualitative inquiry. AORN Journal. 2017; 105(2):193-202

210. Svensson M, Nilsson U, Svantesson M. Patients' experience of mood while waiting for day surgery. Journal of Clinical Nursing. 2016; 25(17-18):2600-2608

211. Tastan S, Kose G, Iyigun E, Ayhan H, Coskun H, Hatipoglu S. Experiences of the relatives of patients undergoing cranial surgery for a brain tumor: a descriptive qualitative study. Journal of Neuroscience Nursing. 2011; 43(2):77-84

212. Taylor C, Norton C. Information booklets for patients with major bowel resection. British Journal of Nursing. 2000; 9(12):785-91

213. Taylor C, Richardson A, Cowley S. Surviving cancer treatment: An investigation of the experience of fear about, and monitoring for, recurrence in patients following treatment for colorectal cancer. European Journal of Oncology Nursing. 2011; 15(3):243-249

214. Thomsen D, Jensen BO. Patients' experiences of everyday life after lung transplantation. Journal of Clinical Nursing. 2009; 18(24):3472-3479

215. Toonstra JL, Howell D, English RA, Lattermann C, Mattacola CG. Patient experiences of recovery after autologous chondrocyte implantation: a qualitative study. Journal of Athletic Training. 2016; 51(12):1028-1036

216. Urstad KH, Wahl AK, Andersen MH, Oyen O, Fagermoen MS. Renal recipients' educational experiences in the early post-operative phase--a qualitative study. Scandinavian Journal of Caring Sciences. 2012; 26(4):635-42

217. van Kasteren Y, Freyne J, Hussain MS. Total knee replacement and the effect of technology on cocreation for improved outcomes and delivery: qualitative multi-stakeholder study. Journal of Medical Internet Research. 2018; 20(3):e95

218. Vogelsang AC, Milton C, Ericsson I, Strömberg L. 'Wouldn't it be easier if you continued to be a guy?' - a qualitative interview study of transsexual persons' experiences of encounters with healthcare professionals. Journal of Clinical Nursing. 2016; 25(23-24):3577-3588

219. Wagner L, Carlslund AM, Sørensen M, Ottesen B. Women's experiences with short admission in abdominal hysterectomy and their patterns of behaviour. Scandinavian Journal of Caring Sciences. 2005; 19(4):330-336

220. Walsh E, Hegarty J. Men's experiences of radical prostatectomy as treatment for prostate cancer. European Journal of Oncology Nursing. 2010; 14(2):125-133

221. Warner DO, Klesges RC, Dale LC, Offord KP, Schroeder DR, Vickers KS et al. Telephone quitlines to help surgical patients quit smoking: Patient and provider attitudes. American Journal of Preventive Medicine. 2008; 35(6, Suppl 1):S486-S493

222. Watts GD, Christou P, Antonarakis GS. Experiences of individuals concerning combined orthodontic and orthognathic surgical treatment: A qualitative twitter analysis. Medical Principles and Practice. 2018; 27(3):227-235

223. Webb C, Sharma V, Temple-Oberle C. Delivering breast reconstruction information to patients: Women report on preferred information delivery styles and options. Plastic Surgery. 2018; 26(1):26-32

224. Westerling K, Bergbom I. The importance of nursing in perioperative care: a patient's perspective. Journal of Advanced Perioperative Care. 2008; 3(4):133-144

225. Wickwar S, McBain H, Edmunds MR, Ezra DG, Rose GE, Newman SP. Patients' expectations for the functional and psychosocial outcomes of orbital decompression surgery for thyroid eye disease: a qualitative study. Psychology Health & Medicine. 2018; 23(4):475-484

226. Wittmann D, Carolan M, Given B, Skolarus TA, An L, Palapattu G et al. Exploring the role of the partner in couples' sexual recovery after surgery for prostate cancer. Supportive Care in Cancer. 2014; 22(9):2509-15

227. Wong J, Mendelsohn D, Nyhof-Young J, Bernstein M. A qualitative assessment of the supportive care and resource needs of patients undergoing craniotomy for benign brain tumours. Supportive Care in Cancer. 2011; 19(11):1841-8

228. Worster B, Holmes S. The preoperative experience of patients undergoing surgery for colorectal cancer: a phenomenological study. European Journal of Oncology Nursing. 2008; 12(5):418-24

229. Worster B, Holmes S. A phenomenological study of the postoperative experiences of patients undergoing surgery for colorectal cancer. European Journal of Oncology Nursing. 2009; 13(5):315-22

230. Wyness MA, Durity MB, Durity F. Narratives of patients with skull base tumors and their family members: lessons for nursing practice. AXON. 2002; 24(1):18-35

231. Yeh WL, Tsai YF, Hsu KY, Chen DW, Chen CY. Factors related to the indecision of older adults with knee osteoarthritis about receiving physician-recommended total knee arthroplasty. Disability and Rehabilitation. 2017; 39(22):2302-2307

232. Yiu HY, Chien WT, Lui MH, Qin B. Information needs of Chinese surgical patients on discharge: a comparison of patients' and nurses' perceptions. Journal of Advanced Nursing. 2011; 67(5):1041-52

233. Yu A, Devine CA, Kasdin RG, Orizondo M, Perdomo W, Davis AM et al. Pain management among Dominican patients with advanced osteoarthritis: a qualitative study. BMC Musculoskeletal Disorders. 2016; 17:211

234. Zener R, Bernstein M. Gender, patient comfort and the neurosurgical operating room. Canadian Journal of Neurological Sciences. 2011; 38(1):65-71

235. Zhang JE, Wong FKY, You LM, Zheng MC. A qualitative study exploring the nurse telephone follow-up of patients returning home with a colostomy. Journal of Clinical Nursing. 2012; 21(9-10):1407-1415

Appendices

Appendix A: Review protocols

Table 17: Review protocol: Information and support needs

ID	Field	Content
0.	PROSPERO registration number	Not registered on PROSPERO
1.	Review title	What information and support is useful for adults undergoing surgery, and their families and carers, before, during and after an operation?
2.	Review question	What information and support is useful for adults undergoing surgery, and their families and carers, before, during and after an operation?
3.	Objective	To determine what information and support people with undergoing surgery and their families value.
4.	Searches	Medline, Embase, CINAHL, PsycINFO
5.	Condition or domain being studied	Perioperative care
6.	Population	Inclusion: Adults 18 years and over having surgery, and their families and carers. Exclusion: • Children and young people aged 17 years and younger • surgery for burns, traumatic brain injury or neurosurgery
7.	Intervention/Exposure/Test	Any information, education or support specified in studies
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); quantitative data from questionnaires will only be considered if insufficient qualitative evidence is identified.
10.	Other exclusion criteria	• non-English language studies • studies published before 2000
11.	Context	Review is intended to outline the information and support that is useful for adults undergoing surgery, and their families and carers, before, during and after an operation. Review will supplement NICE’s guideline on Patient experience in adult NHS services

12.	Primary outcomes (critical outcomes)	Themes will be derived from the evidence identified for this review and not pre-specified. However for information to guide the technical team, relevant themes may include: • Decision making (including involvement in discharge planning) • Preferred format of information provision (e.g. plain English, web-based) • Content of information (including ongoing care needs) • Impact of treatment on lifestyle • Information sources other than healthcare professionals (e.g. support groups, online resources) • Psychological support • Financial support • Employment rights
13.	Secondary outcomes (important outcomes)	n/a
14.	Data extraction (selection and coding)	EndNote will be used for reference management, sifting, citations and bibliographies. All references identified by the searches and from other sources will be screened for inclusion. 10% of the abstracts will be reviewed by two reviewers, with any disagreements resolved by discussion or, if necessary, a third independent reviewer. The full text of potentially eligible studies will be retrieved and will be assessed in line with the criteria outlined above. No duplicate screening was deemed necessary for this question, for more information please see the separate Methods report for this guideline. Additional qualitative studies will be added to the review until themes within the analysis become saturated; i.e. studies will only be included if they contribute towards the development of existing themes or to the development of new themes.
15.	Risk of bias (quality) assessment	Risk of bias will be assessed using the appropriate checklist as described in Developing NICE guidelines: the manual. Appraisal of methodological quality: The methodological quality of each study will be assessed using the CASP qualitative checklist. 10% of all evidence reviews are quality assured by a senior research fellow. This includes checking: • papers were included /excluded appropriately • a sample of the data extractions

		• correct methods are used to synthesise data • a sample of the risk of bias assessments Disagreements between the review authors over the risk of bias in particular studies will be resolved by discussion, with involvement of a third review author where necessary.
16.	Strategy for data synthesis	Evidence will be analysed using thematic analysis; findings will be presented narratively and diagrammatically where appropriate. Findings will be reported according to GRADE CERQual standards
17.	Analysis of sub-groups	n/a

18.	Type and method of review	☐	Intervention
		☐	Diagnostic
		☐	Prognostic
		☒	Qualitative
		☐	Epidemiologic
		☐	Service Delivery
		☐	Other (please specify)

19.	Language	English
20.	Country	England
21.	Anticipated or actual start date	
22.	Anticipated completion date	

23.	Stage of review at time of this submission	Review stage	Started	Completed
		Preliminary searches	☐	☐
		Piloting of the study selection process	☐	☐
		Formal screening of search results against eligibility criteria	☐	☐
		Data extraction	☐	☐
		Risk of bias (quality) assessment	☐	☐
		Data analysis	☐	☐

24.	Named contact	5a. Named contact National Guideline Centre 5b Named contact e-mail

		perioperativecare@nice.org.uk 5e Organisational affiliation of the review National Institute for Health and Care Excellence (NICE) and the National Guideline Centre
25.	Review team members	From the National Guideline Centre: Ms Kate Ashmore Ms Kate Kelley Ms Sharon Swaine Mr Ben Mayer Ms Maria Smyth Mr Vimal Bedia Mr Audrius Stonkus Ms Madelaine Zucker Ms Margaret Constanti Ms Annabelle Davis Ms Lina Gulhane
26.	Funding sources/sponsor	This systematic review is being completed by the National Guideline Centre which receives funding from NICE.
27.	Conflicts of interest	All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must declare any potential conflicts of interest in line with NICE's code of practice for declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a member's declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.
28.	Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of Developing NICE guidelines: the manual. Members of the guideline committee are available on the NICE website: [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	Perioperative care, surgery, information, support	
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 2014, updated 2018.[153]

For more detailed information, please see the Methodology Review.

B.1 Clinical search literature search strategy

Searches were constructed using a PICO framework where population (P) terms were combined with Intervention (I) and in some cases Comparison (C) terms. Outcomes (O) are rarely used in search strategies for interventions as these concepts may not be well described in title, abstract or indexes and therefore difficult to retrieve. Search filters were applied to the search where appropriate.

Table 18: Database date parameters and filters used

Database	Dates searched	Search filter used
Medline (OVID)	2000 – 30 May 2019	Exclusions Qualitative studies
Embase (OVID)	2000 – 30 May 2019	Exclusions Qualitative studies
CINAHL, Current Nursing and Allied Health Literature (EBSCO)	2000 – 30 May 2019	Exclusions Qualitative studies
PsycINFO (ProQuest)	2000 – 1 March 2019	Exclusions Qualitative studies

Medline (Ovid) search terms

1.	exp Perioperative Care/ or exp Perioperative Period/ or Preoperative Care/
2.	((pre-operative* or preoperative* or preop* or pre-op* or pre-surg* or presurg*) adj3 (care* or caring or treat* or nurs* or monitor* or recover* or medicine)).ti,ab.
3.	((care* or caring or treat* or nurs* or recover* or monitor*) adj3 (before or prior or advance or during or after) adj3 (surg* or operat* or anaesthes* or anesthes*)).ti,ab.
4.	((perioperative* or peri-operative* or intraoperative* or intra-operative* or intrasurg* or intra-surg* or peroperat* or per-operat*) adj3 (care* or caring or treat* or nurs* or monitor* or recover* or medicine)).ti,ab.
5.	((care* or caring or treat* or nurs* or recover* or monitor*) adj3 during adj3 (surg* or operat* or anaesthes* or anesthes*)).ti,ab.
6.	((postoperative* or postop* or post-op* or post-surg* or postsurg*) adj3 (care* or caring or treat* or nurs* or monitor* or recover* or medicine)).ti,ab.
7.	((care* or caring or treat* or nurs* or recover* or monitor*) adj3 after adj3 (surg* or operat* or anaesthes* or anesthes*)).ti,ab.
8.	or/1-7
9.	limit 8 to English language
10.	(exp child/ or exp pediatrics/ or exp infant/) not (exp adolescent/ or exp adult/ or exp middle age/ or exp aged/)
11.	9 not 10
12.	letter/
13.	editorial/
14.	news/
15.	exp historical article/

1

16.	exp Perioperative Care/ or exp Perioperative Period/ or Preoperative Care/
17.	((pre-operative* or preoperative* or preop* or pre-op* or pre-surg* or presurg*) adj3 (care* or caring or treat* or nurs* or monitor* or recover* or medicine)).ti,ab.
18.	((care* or caring or treat* or nurs* or recover* or monitor*) adj3 (before or prior or advance or during or after) adj3 (surg* or operat* or anaesthes* or anesthes*)).ti,ab.
19.	((perioperative* or peri-operative* or intraoperative* or intra-operative* or intrasurg* or intra-surg* or peroperat* or per-operat*) adj3 (care* or caring or treat* or nurs* or monitor* or recover* or medicine)).ti,ab.
20.	((care* or caring or treat* or nurs* or recover* or monitor*) adj3 during adj3 (surg* or operat* or anaesthes* or anesthes*)).ti,ab.
21.	((postoperative* or postop* or post-op* or post-surg* or postsurg*) adj3 (care* or caring or treat* or nurs* or monitor* or recover* or medicine)).ti,ab.
22.	((care* or caring or treat* or nurs* or recover* or monitor*) adj3 after adj3 (surg* or operat* or anaesthes* or anesthes*)).ti,ab.
23.	or/1-7
24.	limit 8 to English language
25.	(exp child/ or exp pediatrics/ or exp infant/) not (exp adolescent/ or exp adult/ or exp middle age/ or exp aged/)
26.	9 not 10
27.	letter/
28.	editorial/
29.	news/
30.	exp historical article/
31.	Anecdotes as Topic/
32.	comment/
33.	case report/
34.	(letter or comment*).ti.
35.	or/12-19
36.	randomized controlled trial/ or random*.ti,ab.
37.	20 not 21
38.	animals/ not humans/
39.	exp Animals, Laboratory/
40.	exp Animal Experimentation/
41.	exp Models, Animal/
42.	exp Rodentia/
43.	(rat or rats or mouse or mice).ti.
44.	or/22-28
45.	11 not 29
46.	Patients/ or Inpatients/ or Outpatients/
47.	Caregivers/ or exp Family/ or exp Parents/ or exp Legal-Guardians/
48.	(patient* or carer* or caregiver* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or next of kin or significant other* or partner* or guardian* or inpatient* or outpatient* or in patient* or out patient*).ti,ab.
49.	or/31-33
50.	exp Information-Services/ or Publications/ or Books/ or Pamphlets/ or Counseling/ or Directive-Counseling/ or Decision Making/
51.	34 and 35

52.	Patient Education as Topic/
53.	patient acceptance of health care/
54.	patient satisfaction/
55.	patient education handout/
56.	Consumer Health Information/
57.	Patient participation/
58.	Physician-patient relations/ or Professional-Patient Relations/
59.	((patient* or carer* or caregiver* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or next of kin or significant other* or partner* or guardian* or inpatient* or outpatient* or in patient* or out patient*) adj3 (inform* or educat* or support* or advice* or advise*)).ti,ab.
60.	(information* adj3 (service* or need* or requirement* or support* or seek* or access* or disseminat* or barrier*)).ti,ab.
61.	((patient* or carer* or caregiver* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or next of kin or significant other* or partner* or guardian* or inpatient* or outpatient* or in patient* or out patient*) adj3 (service* or information* or material* or virtual*or app or apps or blog* or booklet* or brochure* or dvd* or elearn* or e-learn* or email* or e-mail* or e mail* or facebook or facetime or face time or forum* or handout* or hand-out* or hand out* or helpline* or hotline* or internet* or ipad* or iphone* or leaflet* or online or magazine* or mobile phone* or newsletter* or pamphlet* or palm pilot* or personal digital assistant* or pocket pc* or podcast* or poster? or skype* or smartphone* or smart phone* or social media or social network* or sms or text messag* or twitter or tweet* or video* or web* or wiki* or youtube* or manual* or publication* or literature or computer* or interactive or telephone* or phone*)).ti,ab.
62.	((educat* or learn* or support*) adj3 (service* or information* or material* or virtual* or app or apps or blog* or booklet* or brochure* or dvd* or elearn* or e-learn* or email* or e-mail* or e mail* or facebook or facetime or face time or forum* or handout* or hand-out* or hand out* or helpline* or hotline* or internet* or ipad* or iphone* or leaflet* or online or magazine* or mobile phone* or newsletter* or pamphlet* or palm pilot* or personal digital assistant* or pocket pc* or podcast* or poster? or skype* or smartphone* or smart phone* or social media or social network* or sms or text messag* or twitter or tweet* or video* or web* or wiki* or youtube* or manual* or publication* or literature or computer* or interactive or telephone* or phone*)).ti,ab.
63.	((decision* or decid*) adj3 (support* or aid* or tool*)).ti,ab.
64.	((decision making or choice) adj (behavior* or behaviour*)).ti,ab.
65.	(informed adj (choice* or decision*)).ti,ab.
66.	or/36-50
67.	Qualitative research/ or Narration/ or exp Interviews as Topic/ or exp Questionnaires/ or Health care surveys/
68.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
69.	(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.
70.	or/52-54
71.	30 and 51 and 55

Embase (Ovid) search terms

1.	*preoperative period/ or *preoperative care/ or *peroperative care/ or *intraoperative period/ or *postoperative period/ or *postoperative care/ or *perioperative nursing/ or *surgical patient/
2.	((pre-operative* or preoperative* or preop* or pre-op* or pre-surg* or presurg*) adj3

	(care* or caring or treat* or nurs* or monitor* or recover* or medicine)).ti,ab.
3.	((care* or caring or treat* or nurs* or recover* or monitor*) adj3 (before or prior or advance or during or after) adj3 (surg* or operat* or anaesthes* or anesthes*)).ti,ab.
4.	((perioperative* or peri-operative* or intraoperative* or intra-operative* or intrasurg* or intra-surg* or peroperat* or per-operat*) adj3 (care* or caring or treat* or nurs* or monitor* or recover* or medicine)).ti,ab.
5.	((care* or caring or treat* or nurs* or recover* or monitor*) adj3 during adj3 (surg* or operat* or anaesthes* or anesthes*)).ti,ab.
6.	((postoperative* or postop* or post-op* or post-surg* or postsurg*) adj3 (care* or caring or treat* or nurs* or monitor* or recover* or medicine)).ti,ab.
7.	((care* or caring or treat* or nurs* or recover* or monitor*) adj3 after adj3 (surg* or operat* or anaesthes* or anesthes*)).ti,ab.
8.	or/1-7
9.	(exp child/ or exp pediatrics/) not (exp adult/ or exp adolescent/)
10.	8 not 9
11.	limit 10 to English language
12.	letter.pt. or letter/
13.	note.pt.
14.	editorial.pt.
15.	case report/ or case study/
16.	(letter or comment*).ti.
17.	or/12-16
18.	randomized controlled trial/ or random*.ti,ab.
19.	17 not 18
20.	animal/ not human/
21.	nonhuman/
22.	exp Animal Experiment/
23.	exp Experimental Animal/
24.	animal model/
25.	exp Rodent/
26.	(rat or rats or mouse or mice).ti.
27.	or/19-26
28.	11 not 27
29.	*patient/ or *hospital patient/ or *outpatient/
30.	*caregiver/ or *family/ or *adult child/ or *family relation/ or *grandparent/ or *parent/ or *father/ or *mother/ or *legal guardian/
31.	(patient* or carer* or caregiver* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or next of kin or significant other* or partner* or guardian* or inpatient* or outpatient*).ti,ab.
32.	or/29-31
33.	*information service/ or *documentation/ or *publication/ or *book/ or *counseling/ or *directive counseling/
34.	32 and 33
35.	*patient education/
36.	*consumer health information/
37.	*patient satisfaction/ or *patient attitude/
38.	*patient participation/
39.	*patient information/

40.	*doctor patient relation/
41.	((patient* or carer* or caregiver* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or next of kin or significant other* or partner* or guardian* or inpatient* or outpatient* or in patient* or out patient*) adj3 (inform* or educat* or support* or advice* or advise*)).ti,ab.
42.	((patient* or carer* or caregiver* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or next of kin or significant other* or partner* or guardian* or inpatient* or outpatient* or in patient* or out patient*) adj3 (service* or information* or material* or virtual*or app or apps or blog* or booklet* or brochure* or dvd* or elearn* or e-learn* or email* or e-mail* or e mail* or facebook or facetime or face time or forum* or handout* or hand-out* or hand out* or helpline* or hotline* or internet* or ipad* or iphone* or leaflet* or online or magazine* or mobile phone* or newsletter* or pamphlet* or palm pilot* or personal digital assistant* or pocket pc* or podcast* or poster? or skype* or smartphone* or smart phone* or social media or social network* or sms or text messag* or twitter or tweet* or video* or web* or wiki* or youtube* or manual* or publication* or literature or computer* or interactive or telephone* or phone*)).ti,ab.
43.	(information* adj3 (service* or need* or requirement* or support* or seek* or access* or disseminat* or barrier*)).ti,ab.
44.	((educat* or learn* or support*) adj3 (service* or information* or material* or virtual* or app or apps or blog* or booklet* or brochure* or dvd* or elearn* or e-learn* or email* or e-mail* or e mail* or facebook or facetime or face time or forum* or handout* or hand-out* or hand out* or helpline* or hotline* or internet* or ipad* or iphone* or leaflet* or online or magazine* or mobile phone* or newsletter* or pamphlet* or palm pilot* or personal digital assistant* or pocket pc* or podcast* or poster? or skype* or smartphone* or smart phone* or social media or social network* or sms or text messag* or twitter or tweet* or video* or web* or wiki* or youtube* or manual* or publication* or literature or computer* or interactive or telephone* or phone*)).ti,ab.
45.	((decision* or decid*) adj3 (support* or aid* or tool*)).ti,ab.
46.	((decision making or choice) adj (behavior* or behaviour*)).ti,ab.
47.	(informed adj (choice* or decision*)).ti,ab.
48.	or/34-47
49.	health survey/ or exp questionnaire/ or exp interview/ or qualitative research/ or narrative/
50.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
51.	(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.
52.	or/49-51
53.	28 and 48 and 52

CINAHL, Current Nursing and Allied Health Literature (EBSCO)

#1.	(MH "Preoperative Care+")
#2.	(MH "Perioperative Care+")
#3.	(MH "Preoperative Period+")
#4.	(MH "Perioperative Nursing")
#5.	(MH "Postoperative Care+")
#6.	(MH "Intraoperative Care")
#7.	(MM "Intraoperative Period")
#8.	(MM "Postoperative Period")
#9.	TI (((care* or caring or treat* or nurs* or recover* or monitor*) N3 (before or prior or advance or during or after) N3 (surg* or operat* or anaesthes* or anesthes*))) OR AB (

	((care* or caring or treat* or nurs* or recover* or monitor*) N3 (before or prior or advance or during or after) N3 (surg* or operat* or anaesthes* or anesthes*)))
#10.	TI (((pre-operative* or preoperative* or preop* or pre-op* or pre-surg* or presurg*) N3 (care* or caring or treat* or nurs* or monitor* or recover* or medicine))) OR AB (((pre-operative* or preoperative* or preop* or pre-op* or pre-surg* or presurg*) N3 (care* or caring or treat* or nurs* or monitor* or recover* or medicine)))
#11.	TI (((care* or caring or treat* or nurs* or recover* or monitor*) n3 during n3 (surg* or operat* or anaesthes* or anesthes*))) OR AB (((care* or caring or treat* or nurs* or recover* or monitor*) n3 during n3 (surg* or operat* or anaesthes* or anesthes*)))
#12.	TI (((intraoperative* or intra-operative* or intrasurg* or intra-surg* or peroperat* or per-operat*) n3 (care* or caring or treat* or nurs* or monitor* or recover* or medicine))) OR AB (((intraoperative* or intra-operative* or intrasurg* or intra-surg* or peroperat* or per-operat*) n3 (care* or caring or treat* or nurs* or monitor* or recover* or medicine)))
#13.	TI (((postoperative* or postop* or post-op* or post-surg* or postsurg*) n3 (care* or caring or treat* or nurs* or monitor* or recover* or medicine))) OR AB (((postoperative* or postop* or post-op* or post-surg* or postsurg*) n3 (care* or caring or treat* or nurs* or monitor* or recover* or medicine)))
#14.	TI (((care* or caring or treat* or nurs* or recover* or monitor*) n3 after n3 (surg* or operat* or anaesthes* or anesthes*))) OR AB (((care* or caring or treat* or nurs* or recover* or monitor*) n3 after n3 (surg* or operat* or anaesthes* or anesthes*)))
#15.	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14
#16.	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
#17.	S15 not S16
#18.	((MH "Child+") OR (MH "Pediatrics+") OR (MH "Infant+")) NOT ((MH "Adult+") OR (MH "Adolescence+") OR (MH "Middle Age") OR (MH "Aged+"))
#19.	S17 NOT S18
#20.	(MH "Patients")
#21.	(MH "Inpatients")
#22.	(MH "Outpatients")
#23.	(MH "Caregivers")
#24.	(MH "Family+")
#25.	(MH "Parents+")
#26.	(MH "Guardianship, Legal+")
#27.	TI ((patient* or carer* or caregiver* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or next of kin or significant other* or partner* or guardian* or inpatient* or outpatient* or in patient* or out patient*)) OR AB ((patient* or carer* or caregiver* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or next of kin or significant other* or partner* or guardian* or inpatient* or outpatient* or in patient* or out patient*))
#28.	S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27
#29.	(MH "Information Services+") OR (MH "Books") OR (MH "Counseling") OR (MH "Pamphlets") OR (MH "Decision Making")
#30.	S28 AND S29
#31.	(MH "Patient Education+") OR (MH "Patient Satisfaction") OR (MH "Patient Preference") OR (MH "Consumer Health Information+") OR (MH "Consumer Participation") OR (MH "Physician-Patient Relations") OR (MH "Professional-Patient Relations")
#32.	TI (((patient* or carer* or caregiver* or famil* or parent* or father* or mother* or

	spouse* or wife or wives or husband* or next of kin or significant other* or partner* or guardian* or inpatient* or outpatient* or in patient* or out patient*) N3 (inform* or educat* or support* or advice* or advise*))) OR AB (((patient* or carer* or caregiver* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or next of kin or significant other* or partner* or guardian* or inpatient* or outpatient* or in patient* or out patient*) N3 (inform* or educat* or support* or advice* or advise*)))
#33.	TI ((information* N3 (service* or need* or requirement* or support* or seek* or access* or disseminat* or barrier*))) OR AB ((information* N3 (service* or need* or requirement* or support* or seek* or access* or disseminat* or barrier*)))
#34.	TI (((patient* or carer* or caregiver* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or next of kin or significant other* or partner* or guardian* or inpatient* or outpatient* or in patient* or out patient*) N3 (service* or information* or material* or virtual*or app or apps or blog* or booklet* or brochure* or dvd* or elearn* or e-learn* or email* or e-mail* or e mail* or facebook or facetime or face time or forum* or handout* or hand-out* or hand out* or helpline* or hotline* or internet* or ipad* or iphone* or leaflet* or online or magazine* or mobile phone* or newsletter* or pamphlet* or palm pilot* or personal digital assistant* or pocket pc* or podcast* or poster? or skype* or smartphone* or smart phone* or social media or social network* or sms or text messag* or twitter or tweet* or video* or web* or wiki* or youtube* or manual* or publication* or literature or computer* or interactive or telephone* or phone*))) OR AB (((patient* or carer* or caregiver* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or next of kin or significant other* or partner* or guardian* or inpatient* or outpatient* or in patient* or out patient*) N3 (service* or information* or material* or virtual*or app or apps or blog* or booklet* or brochure* or dvd* or elearn* or e-learn* or email* or e-mail* or e mail* or facebook or facetime or face time or forum* or handout* or hand-out* or hand out* or helpline* or hotline* or internet* or ipad* or iphone* or leaflet* or online or magazine* or mobile phone* or newsletter* or pamphlet* or palm pilot* or personal digital assistant* or pocket pc* or podcast* or poster? or skype* or smartphone* or smart phone* or social media or social network* or sms or text messag* or twitter or tweet* or video* or web* or wiki* or youtube* or manual* or publication* or literature or computer* or interactive or telephone* or phone*)))
#35.	TI (((educat* or learn* or support*) N3 (service* or information* or material* or virtual* or app or apps or blog* or booklet* or brochure* or dvd* or elearn* or e-learn* or email* or e-mail* or e mail* or facebook or facetime or face time or forum* or handout* or hand-out* or hand out* or helpline* or hotline* or internet* or ipad* or iphone* or leaflet* or online or magazine* or mobile phone* or newsletter* or pamphlet* or palm pilot* or personal digital assistant* or pocket pc* or podcast* or poster? or skype* or smartphone* or smart phone* or social media or social network* or sms or text messag* or twitter or tweet* or video* or web* or wiki* or youtube* or manual* or publication* or literature or computer* or interactive or telephone* or phone*))) OR AB (((educat* or learn* or support*) N3 (service* or information* or material* or virtual* or app or apps or blog* or booklet* or brochure* or dvd* or elearn* or e-learn* or email* or e-mail* or e mail* or facebook or facetime or face time or forum* or handout* or hand-out* or hand out* or helpline* or hotline* or internet* or ipad* or iphone* or leaflet* or online or magazine* or mobile phone* or newsletter* or pamphlet* or palm pilot* or personal digital assistant* or pocket pc* or podcast* or poster? or skype* or smartphone* or smart phone* or social media or social network* or sms or text messag* or twitter or tweet* or video* or web* or wiki* or youtube* or manual* or publication* or literature or computer* or interactive or telephone* or phone*)))
#36.	TI (((decision* or decid*) N3 (support* or aid* or tool*))) OR AB (((decision* or decid*) N3 (support* or aid* or tool*)))
#37.	TI (((decision making or choice) N1 (behavior* or behaviour*))) OR AB (((decision making or choice) N1 (behavior* or behaviour*)))
#38.	TI ((informed N1 (choice* or decision*))) OR AB ((informed N1 (choice* or decision*)))
#39.	S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38
#40.	(MH "Qualitative Studies+")

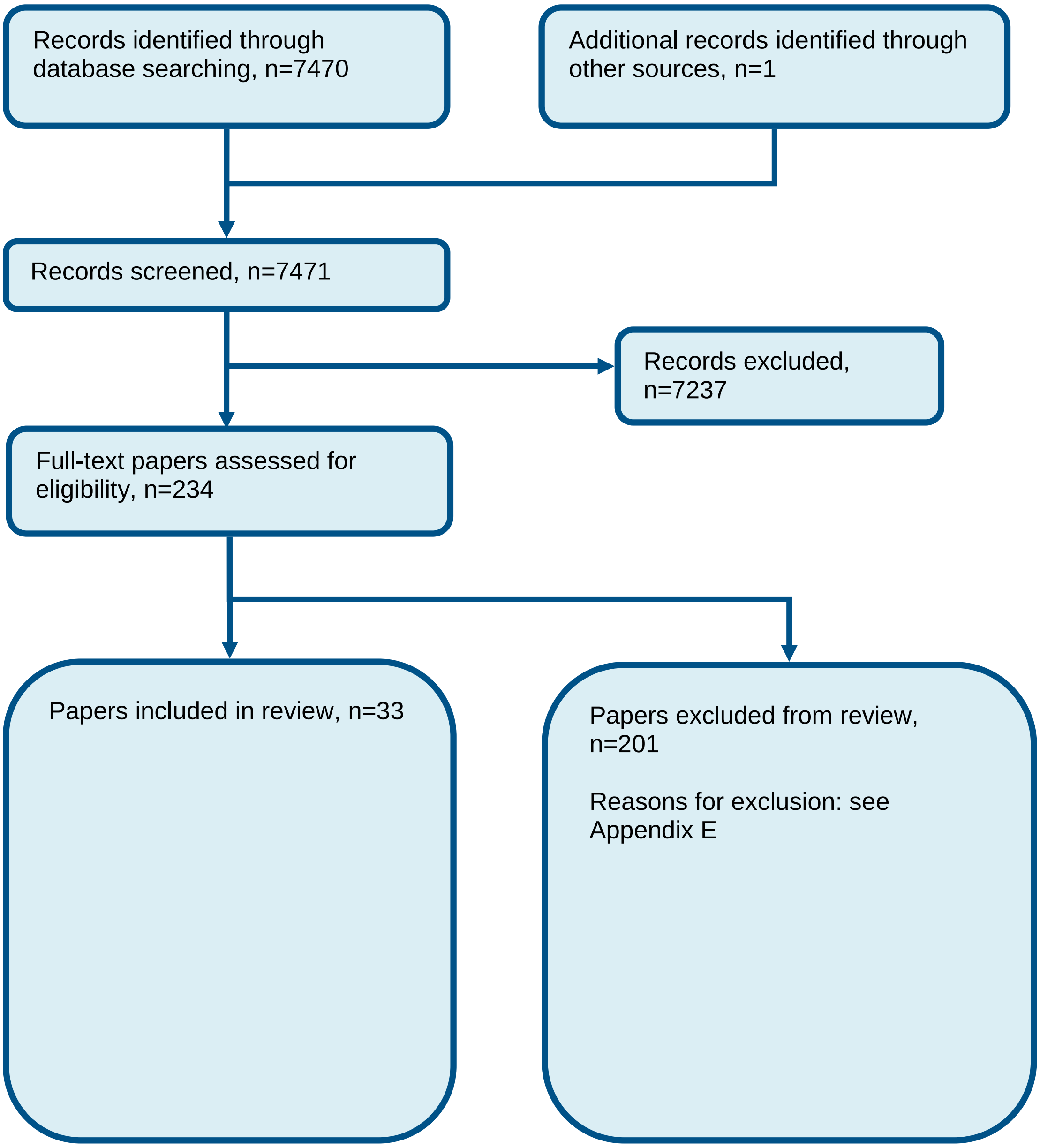
#41.	(MH "Qualitative Validity+")
#42.	(MH "Interviews+") OR (MH "Focus Groups") OR (MH "Surveys") OR (MH "Questionnaires+")
#43.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*)
#44.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* 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*)
#45.	S40 OR S41 OR S42 OR S43 OR S44
#46.	S19 AND S39 AND S45

PsycINFO (ProQuest)

1.	(((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 ti,ab(patient* OR carer* OR caregiver* OR famil* OR parent* OR father* OR mother* OR spouse* OR wife OR wives OR husband* OR next of kin OR significant other* OR partner* OR guardian* OR inpatient* OR outpatient* OR in patient* OR out patient*)) AND (mainsubject.Exact("preoperative care" OR "intraoperative care" OR "preoperative period" OR "perioperative care" OR "postoperative care" OR "postoperative period" OR "intraoperative period" OR "perioperative period" OR "perioperative nursing") OR ti,ab(pre-operative* OR preoperative* OR preop* OR pre-op* OR pre-surg* OR presurg* OR perioperative* OR peri-operative* OR intraoperative* OR intra-operative* OR intrasurg* OR intra-surg* OR peroperat* OR per-operat* OR postoperative* OR postop* OR post-op* OR post-surg* OR postsurg*))) AND (MAINSUBJECT.EXACT("Client Participation") OR MAINSUBJECT.EXACT("Client Education") OR (MAINSUBJECT.EXACT("Client Attitudes") OR MAINSUBJECT.EXACT("Client Satisfaction")) OR ab((information OR educat* OR learn* OR support* OR decision* OR decide* OR choice* OR satisfaction* OR participat*)) OR ti((information OR educat* OR learn* OR support* OR decision* OR decide* OR choice* OR satisfaction* OR participat*))) AND ((su.exact.explode("qualitative research") OR su.exact("narratives") OR su.exact.explode("questionnaires") OR su.exact.explode("interviews") OR su.exact.explode("health care services") OR ti,ab(qualitative OR interview* OR focus group* OR theme* OR questionnaire* OR survey*) OR ti,ab(metasynthes* OR meta-synthes* OR metasummar* OR meta-summar* OR metastud* OR meta-stud* OR metathem* OR meta-them* OR ethno* OR emic OR etic OR phenomenolog* OR grounded theory OR constant compar* OR (thematic* NEAR/3 analys*) OR theoretical-sampl* OR purposive-sampl* OR hermeneutic* OR heidegger* OR husserl* OR colaizzi* OR van kaam* OR van manen* OR giorgi* OR glaser* OR strauss* OR ricoeur* OR spiegelberg* OR merleau*))) 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))Limits applied

Appendix C: Qualitative evidence selection

Figure 1: Flow chart of qualitative study selection for the review of information and support needs



Appendix D: Qualitative evidence tables

Study	**Baker 2018**[20]
Aim	To explore patient information preferences prior to undergoing surgery for ulcerative colitis
Population	Patients who had undergone surgery for ulcerative colitis and patients who had considered but not undergone surgery n=16; Age range, 22 to 74 years (median 42 years); Sex, 9 female, 7 male; Considered surgery, 8: Underwent surgery, 8; Median time since first operation, 4 years 1 month (range, 10 months–18 years 6 months); Accessed some form of peer support, 10
Setting	General teaching hospital
Study design	Qualitative interviews
Methods and analysis	In-depth semi-structured face-to-face interviews with inductive thematic analysis
Findings	**Content of information – self-care after surgery** Patients wanted better information about long-term recovery and sources of long-term support to ensure patients undergoing surgery know who to contact for support or advice should they require it
	Information provision and information seeking – information sources and mode of communication Patients commonly reported the difficulty of assimilating the volume of information during consultations. In particular, there was mention of the length of clinic appointments, with 10–20 minutes being perceived as inadequate for a number of patients. Statistics related to risk of side effects were viewed variably by patients—with some patients reporting numerical quantification of risk as unhelpful, whereas some felt it aided decision making. Using a diagram in practice to help explain operations to patients was common, and all patients agreed that visual presentation of the operation helped in their understanding. It was also fairly common for patients to see stoma nurses to be provided with “practice packs.” Patients reported receiving a large number of leaflets which were often described as containing unhelpful information. Written information focused on operative details, and information about postoperative practicalities were described as “vague” and “generic,” particularly diet advice. Despite a lack of information about the long-term effects of surgery on daily life, patients felt that surgeons were not best placed to give advice about daily issues encountered post-surgery. The stoma and IBD nurses were commonly cited as preferred sources of practical information**.** Many people used the internet as a key source of information, but they preferred peer support to be by telephone or face-to-face rather than using online forums.

Study	Baker 2018[20]
	There was concern about the content of leaflets from the younger participants, with leaflets not providing information on the long-term impacts of surgery.
	Information provision and information seeking - level of detail Patients had differing views about the depth of information that should be provided about operations and their complications. Some patients reported not receiving detailed surgical information, and it was therefore retrieved from other sources such as the internet. Other patients discussed not wanting detailed surgical information for fear of this putting them off surgery.
	Support needs – support groups Patients found talking to another person who had undergone the same procedure to be very helpful in understanding day-to-day life with a stoma as it gave them a “real-life” perspective. Most patients reported they would welcome information on practical issues from someone who had undergone the same procedure.
	Other themes were identified in the study but they were not directly related to information or support needs, so are not reported here.
Limitations and applicability of evidence	No significant methodological limitations noted Study conducted in the UK Results appear generally applicable, although this did include people who had not undergone surgery

Study	Brands-Appeldoorn 2019[32]
Aim	To investigate the information needs of breast cancer patients regarding the long-term cosmetic outcome after breast conserving treatment
Population	Women who had undergone breast conserving treatment n=6; Age range, 49 to 68 years (median 56 years); Sex, all female
Setting	Cancer unit in a general teaching hospital
Study design	Qualitative interviews
Methods and analysis	In-depth semi-structured interviews with thematic analysis
Findings	**Content of information – outcomes of surgery** All patients felt it was important to discuss the cosmetic impact of the surgery. Views varied on the timing of this information, from before surgery through to after all other treatments had been completed.
	Information provision and information seeking – information sources and mode of communication Patients valued both written and verbal information, as well as visual information. In this context, some patients felt that the use of visual information may make women less reluctant to undergo surgery.

Study	**Brands-Appeldoorn 2019**[32]
	Other themes were identified in the study but they were not directly related to information or support needs, so are not reported here.
Limitations and applicability of evidence	Moderate limitations noted around patient selection and the depth of analysis Study conducted in the Netherlands Results appear generally applicable, although this is a population of women after a specific surgery

Study	**Brooke 2018**[34]
Aim	To understand how patients and caregivers perceived care coordination during transitions of surgical care
Population	Adults who had undergone surgery for a chronic health condition and caregivers Patients n=90; Age mean, 62.5 years; Sex, 38 female, 52 male; Ethnicity, 19 Hispanic Caregivers n=24; Age mean, 63.2 years; Sex, 14 female, 10 male; Ethnicity, 4 Hispanic
Setting	Community healthcare clinics
Study design	Focus groups
Methods and analysis	Semi-structured focus groups with iterative thematic analysis
Findings	**Content of information – treatment planning** Patients and their families needed accurate expectations of the processes of care coordination before, during, and after surgery. But healthcare providers often failed to provide adequate information and support resources to help coordinate care before or after surgery. Patients and caregivers wanted detailed information on risks and benefits, what would happen in hospital, and the process of recovery. This need increased as patients became more engaged with the healthcare providers, and communication improved when patients felt more informed.
	Other themes were identified in the study but they were not directly related to information or support needs, so are not reported here.
Limitations and applicability of evidence	No significant methodological limitations noted Study conducted in the US Results appear generally applicable

Study	**Carr 2017**[39]
Aim	To understand experiences of wait time among patients awaiting scheduled orthopaedic or cardiac surgery
Population	Adults awaiting scheduled orthopaedic or cardiac surgery n=32; Age range, 43 to 89 years; Sex, 16 female, 16 male; Median wait time, 102 days (range 41 to 218 days)
Setting	Community
Study design	Qualitative interviews
Methods and analysis	In-depth telephone or face-to-face interviews with phenomenological analysis
Findings	**Support needs – social relationships** Patients valued the support of family and friend whilst waiting for surgery. However, social networks can also exert a negative pressure whilst waiting.
	Other themes were identified in the study but they were not directly related to information or support needs, so are not reported here.
Limitations and applicability of evidence	No significant methodological limitations noted Study conducted in Canada Results are limited to this stage of the care pathway only

Study	**Carrier 2018**[41]
Aim	To identify men's perceptions of the impact of the physical consequences of a radicalized prostatectomy on their quality of life
Population	Men of all ages and nationalities who had a radicalized prostatectomy as treatment for all stages of prostate cancer n=19 qualitative studies
Setting	Not specified
Study design	Systematic review of qualitative studies
Methods and analysis	Qualitative research findings were pooled using the Joanna Briggs Institute method of meta-synthesis. This involved the aggregation or synthesis of findings to generate a set of statements that represented that aggregation, through assembling the findings rated according to their quality, and categorizing these findings on the basis of similarity in meaning. These categories were then subjected to a meta-synthesis.
Findings	**Content of information – outcomes of surgery** Men wanted to know what to expect in terms or urinary incontinence, and this helped them to prepare and information gathering pre-operatively was a vital part of this. Men often felt men felt ill prepared for the physical impact of surgery.

Study	Carrier 2018[41]
	Information provision and information seeking – information sources and mode of communication Some men liked receiving written pre-operative information.
	Information provision and information seeking - balance and consistency Men felt that accurate, detailed and honest information was lacking concerning the practical and emotional side of dealing with incontinence after surgery.
	Support needs – social relationships Varied sources of support were sought throughout postoperative recovery periods, some men felt that there was a need for information, but not support, although a good relationship with the urologist was describes as a form of support
	Support needs – support groups Men also sought alternative sources of information from peers and the internet and stated that they gained support from online prostate cancer forums and buddying systems with a friend or family member who had previously undergone the same surgery.
	Other themes were identified in the study but they were not directly related to information or support needs, so are not reported here.
Limitations and applicability of evidence	No significant methodological limitations noted Review included 2 UK-based studies Focused on a specific outcome, but likely to have some wider applicability

Study	Dibley 2018[58]
Aim	To explore influences on patients' decision-making and compared preoperative concerns with postoperative outcomes related to stoma surgery
Population	Adults who had undergone stoma surgery or who were considering stoma surgery Clinicians were also included, but their results are not reported further <u>Focus groups</u> n=19; Age range, 20 to 73 years (median, 40.5 years); Sex, 10 female, 9 male; Ethnicity, 17 white British, 1 other white, 1 Indian <u>Interviews</u> n=29; Age range, 22 to 58 years (median, 39.4 years); Sex, 13 female, 16 male; Ethnicity, 28 white British, 1 Indian
Setting	Community
Study design	Focus groups and interviews
Methods and	Semi-structured focus groups, using trigger questions, and telephone or face-to-face interviews, using a topic guide, with thematic

Study	Dibley 2018[58]
analysis	analysis, guided by a pragmatic analytical hierarchy
Findings	**Information provision and information seeking – information sources and mode of communication** Patients described ‘many paths’ of information seeking, with some people deliberately avoiding information and some people actively seeking information on the internet or from others with a stoma directly. This behaviour is often influenced by the rapport and relationship with healthcare professionals. Patients wanted information to dispel the ‘fear of the unknown’. This included images of stomas after surgery and in the longer term, as well as seeing the stoma bag and being able to practise with this before surgery.
	Information provision and information seeking – balance and consistency Patients wanted information that was honest and balanced from the MDT, and they wanted accurate information on possible complications and issues in the early stages after surgery. Patients noted the use of language, such as ‘the last resort’ was not helpful, and messages could be framed more positively.
	Support needs – support groups Patients considered meeting someone else who had a stoma as being particularly beneficial.
	Other themes were identified in the study but they were not directly related to information or support needs, so are not reported here.
Limitations and applicability of evidence	Moderate methodological limitations noted because of limited detail on the methods used Study conducted in the UK Results appear generally applicable

Study	Fletcher 2019[72]
Aim	To explore the long-term impact of difficulty with kneeling and how healthcare services could be improved to help patients kneel after total knee replacement
Population	Adults who had undergone total knee replacement and who continued to have extreme difficulty kneeling 7 to 10 years after surgery n=56; Age median, 75 years (range, 71 to 80 years); Sex, 39 female, 17 male
Setting	Community
Study design	Qualitative interviews
Methods and analysis	Brief, structured telephone interviews with descriptive content analysis
Findings	**Content of information – outcomes after surgery** Patients considered that more information before surgery on postoperative problems kneeling would be useful. Other information that might be of value was guidance on what can or cannot be done after knee surgery, more holistic approaches to care, the use of

Study	**Fletcher 2019**[72]
	kneeling demonstrations, and advice to encourage people not to worry about damaging the prosthesis.
	Other themes were identified in the study but they were not directly related to information or support needs, so are not reported here.
Limitations and applicability of evidence	No significant methodological limitations noted Study conducted in the UK Results appear generally applicable

Study	**Gainer 2017**[74]
Aim	To investigate the optimal approach to decision making
Population	Older adults who had undergone CABG surgery n=15; Age mean, 74.9 years (range, 65 to 85); Sex, 3 female, 12 male
Setting	Community
Study design	Focus groups
Methods and analysis	Semi-structured focus groups with thematic analysis
Findings	**Content of information – outcomes of surgery** Patients and families needed time to understand expectations of care that are realistic.
	Information provision and information seeking – information sources and mode of communication Patients wanted risk and benefits to be presented in a range of different ways and individualised to each patient.
	Support needs – social relationships Many patients reported that a mutually respectful relationship with the care team was important.
	Other themes were identified in the study but they were not directly related to information or support needs, so are not reported here.
Limitations and applicability of evidence	No significant methodological limitations noted Study conducted in Canada Results appear generally applicable

Study	**Gustavell 2017**[81]
Aim	To explore common symptoms and self-care in the first 6 months after pacreaticoduodenectomy

Study	Gustavell 2017[81]
Population	Adults who had undergone pacreaticoduodenectomy Healthcare professionals were also included, but their results are not reported further n=14; Age mean, 63 years (range, 49 to 69 years); Sex, 7 female, 7 male; Months since surgery, median 6 (range, 1 to 7)
Setting	University hospital
Study design	Qualitative interviews
Methods and analysis	Semi-structured interviews, face-to-face and by telephone, with inductive content analysis
Findings	**Content of information – self-care after surgery** Patients reported a lack of self-care advice on specific symptoms and medication use at discharge. This resulted in adverse effects that could have been avoided. Patients also reported a lack of advice about pain management and how to reduce opioids. **Support needs – social relationships** Self-care activities included engaging in social activities, including meeting with friends or visiting a former workplace. Patients reported this activity as being very important in their recovery. However, sometimes fatigue made social activities hard or impossible. Other themes were identified in the study but they were not directly related to information or support needs, so are not reported here.
Limitations and applicability of evidence	Moderate limitations noted around the impact of the researchers on the process Study conducted in Sweden Results appear generally applicable, although this is a rare cancer

Study	Halm 2017[85]
Aim	To describe age and gender-specific concerns, needs, and strategies during the first 3 months after CABG
Population	Caregivers for adults who had undergone CABG surgery n=32; Age mean, 61 years in the younger cohort (defined as > 55 and < 70), and 76 in the older cohort (defined as > 70); Sex, 8 female, 8 male; Ethnicity, white; Mean length of stay, 6 to 8 days
Setting	Community and a regional hospital
Study design	Qualitative interviews
Methods and analysis	Structured interviews, opened with a ‘grand tour’ question, with constant comparative analysis
Findings	**Content of information – self-care after surgery**

Study	Halm 2017[85]
	Female caregivers wanted to know what to look for in the incision, and that it takes time to heal. Repeated information on what can be done by the patient could sometimes be a source of strain for female caregivers. Female caregivers wanted simplified information on diet that they could use to plan meals and make joint changes to their diets.
	Support needs – social relationships Female caregivers identified the need for moral support, but did not describe the preferred source of support.
	Information provision and information seeking – balance and consistency Male caregivers found navigating inconsistent information burdensome. Inconsistent information on diet, preparation, and medical management occurred throughout the care pathway.
	Other themes were identified in the study but they were not directly related to information or support needs, so are not reported here.
Limitations and applicability of evidence	No significant methodological limitations noted Study conducted in the US Results appear generally applicable

Study	Hewitt 2019[97]
Aim	To gain a deeper understanding of patients' perceptions of treatment sequencing (surgery and radiotherapy) for soft tissue sarcoma, to identify concerns throughout treatment, and consider what patients found helpful
Population	Adults diagnosed with soft tissue sarcoma within the last 5 years (between 2011 and 2016), not currently receiving radiotherapy or chemotherapy treatment n=19; Age range, 29 to 84 years (median 65 years); Sex, 8 female and 11 male; Radiotherapy, 9 participants received preoperative radiotherapy, 10 received radiotherapy postoperatively; Time since diagnosis, range 7 to 48 months (median 22 months); Time since treatment ended, range 2.5 to 48 months (median 18 months)
Setting	Hospital
Study design	Qualitative interviews
Methods and analysis	In-depth semi-structured face-to-face interviews with thematic qualitative analysis
Findings	**Content of information – treatment planning and process of care** Participants said that their initial concern or uncertainty upon hearing the treatment plan was reduced when information about their condition was provided and the reasons behind their treatment plans were explained by healthcare professionals.
	Content of information – outcomes of surgery All participants wanted basic information about the potential outcomes.

Study	**Hewitt 2019[97]**
	Information provision and information seeking - level of detail Most participants said they received sufficient information from healthcare professionals. Others sought more information and used online resources; these participants felt that a better understanding of treatment helped improve their emotional response to treatment, as they knew what to expect. Information-seeking behaviour also varied across an individual's treatment process and by individual preference.
	Support needs – social relationships Participants derived psychological and physical support from a network of family, friends, community members, and social support groups. Whilst social support could be beneficial, interaction with others could also be perceived as having a detrimental impact.
	Support needs – support groups Although all participants were aware of additional sources of support for people with cancer, the extent to which these services were used appeared to be inversely related to how much support was received from close family and friends. Individuals who accessed support groups reported doing so as it enabled them to feel understood by someone who had experienced a similar situation
	Other themes were identified in the study but they were not directly related to information or support needs, so are not reported here.
Limitations and applicability of evidence	No significant methodological limitations noted Study conducted in the UK Focused on a specific condition (soft tissue sarcoma) and the experience of treatment sequencing, but results appear generally applicable

Study	**Høvik 2018[102]**
Aim	To explore the experience of patients undergoing total knee arthroplasty in a fast-track pathway during the first 2 weeks after surgery
Population	Patients undergoing TKA in a fast-track pathway n=13: Age, 1 aged 40 to 49, 4 aged 50 to 59, 4 aged 60 to 69, 4 aged 70 to 79; Sex, 8 female and 5 male; Living arrangements, 8 living with someone, 5 living alone; Employment, 4 employed, 9 retired
Setting	University hospital
Study design	Qualitative focus groups
Methods and analysis	Semi-structured face-to-face focus groups with systematic text condensation
Findings	**Information provision and information seeking - balance and consistency** Information was repeated by nurses and physiotherapists throughout the hospital stay, thereby creating confidence and predictability. However, there were discrepancies in provider information after surgery.

Study	Høvik 2018[102]
	Information provision and information seeking – information sources and mode of communication The pamphlet of written information in the fast-track trajectory was highlighted as the most important piece of patient information.
	Support needs – support groups Many patients expressed satisfaction in meeting other patients at the patient school.
	Content of information – self-care after surgery The participants found it challenging but satisfactory to use their own resources to direct their own recovery at home, based on the information gathered from health personnel.
	Content of information – outcomes of surgery Participants realised that postsurgical impairment was temporary, with prospects of improvement in daily functioning.
	Other themes were identified in the study but they were not directly related to information or support needs, so are not reported here.
Limitations and applicability of evidence	No significant methodological limitations noted Study conducted in Norway Focused on a specific care model, but results appear generally applicable

Study	Ivarsson 2018[109]
Aim	To elucidate perceived situations of significance experienced by people with hip fracture during prehospital and in-hospital care
Population	Adults who had undergone hip fracture surgery n=14; Age mean, 79 years women, 68 years men; Sex, 8 female, 6 male; Length of hospital stay, 6 days women, 9 days men; Living alone, 8 in total
Setting	University hospital
Study design	Qualitative interviews
Methods and analysis	In-depth semi-structured face-to-face interviews with critical incident analysis
Findings	**Content of information – treatment planning** Information about the preoperative process was good, with people feeling they knew what was going to happen and feeling able to ask questions. However, some people did not understand the detailed information about the process.
	Content of information – outcomes of surgery Patients wanted information about their prognosis, and how activities, such as travel or exercise, might be affected.

Study	Ivarsson 2018[109]
	Information provision and information seeking – information sources and mode of communication Patients often wanted to ask questions of the operating surgeon in the postoperative period, but this was not always possible.
	Support needs – social relationships Patients wanted to maintain contact with their family, using social media or through visits, during their hospital stay. Before discharge, patients valued the support and continued care from healthcare staff. They also reported receiving adequate information and that the process of planning for care after returning home worked well.
	Other themes were identified in the study but they were not directly related to information or support needs, so are not reported here.
Limitations and applicability of evidence	No significant methodological limitations noted Study conducted in Sweden Results appear generally applicable

Study	Kennedy 2017[115]
Aim	To determine the informational needs and delivery preferences for education of families and patients undergoing hip or knee replacement
Population	Adults attending follow-up visits for hip or knee replacement surgery n=32: Age, mean 67.9 (range 46 to 78); Sex, 16 female and 16 male; Time from surgery, 44% up to 3 months, 44% between 3 months and 9 months, and 12% 9 months to a year
Setting	Specialist hospital
Study design	Qualitative focus groups and interviews
Methods and analysis	Semi-structured face-to-face focus groups and interviews with inductive analysis
Findings	**Content of information – self-care after surgery** Patients wanted more education 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.
	Information provision and information seeking - balance and consistency Patients identified several sources of information that they drew on most frequently, including online sources. They found information that was consistent as being helpful. Information from other patients was also seen as useful, and although these were recognised as being ‘anecdotal’, a range of views was valued.

Study	Kennedy 2017[115]
	Information provision and information seeking – information sources and mode of communication 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. Several participants were interested in accessing information from newer technologies including mobile health applications and social media, although other participants were less certain.
	Other themes were identified in the study but they were not directly related to information or support needs, so are not reported here.
Limitations and applicability of evidence	No significant methodological limitations noted Study conducted in Canada Results appear generally applicable

Study	Kyte 2018[120]
Aim	To describe surgically treated lung cancer patients' experiences of coming home after discharge from hospital to expand the knowledge about their supportive care needs
Population	Adults who had surgery for primary lung cancer n=14; Age, mean 72 years (range of 56–87 years); Sex 8 female and 6 male; Living arrangements, 9 lived with family members (spouse/children), 5 lived alone. At the time of the interviews, none of the participants received adjuvant chemotherapy or radiation treatment
Setting	University hospitals
Study design	Qualitative interviews
Methods and analysis	Semi-structured face-to-face interviews with qualitative content analysis
Findings	**Content of information – self-care after surgery** Several of the patients were discharged with unmet information needs on how to manage their care at home.
	Content of information – outcomes of surgery Several of the patients were discharged with unmet information needs on symptoms to be aware of and signs of complications.
	Content of information – coordination of care Several of the patients were discharged with unmet information needs on whom to contact in case of problems or how to obtain more information.
	Information provision and information seeking - level of detail

Study	**Kyte 2018**[120]
	Some of the participants wished for more information and emphasised the need to talk to someone outside their families, preferably a healthcare professional, about their worries and their future. However, they did not know whom to contact. Others felt that they were in safe hands, treated with a caring attitude and empathy and provided with sufficient information by their healthcare providers.
	Support needs – home care Some participants became very frustrated because they felt that they were neither being heard nor receiving the support they needed. Only a few participants had been asked by the hospital nurse if they needed help from home care after being discharged.
	Support needs – social relationships Participants often had to rely on their spouses, families, friends and neighbours to fulfil their needs for daily living support. Many participants underlined the importance of managing life by themselves and not being a burden to their families or public healthcare. Nevertheless, they appreciated the care and support from their families
	Other themes were identified in the study but they were not directly related to information or support needs, so are not reported here.
Limitations and applicability of evidence	No significant methodological limitations noted Study conducted in Norway Focused on a specific condition (lung cancer), but results appear generally applicable

Study	**Malley 2017**[136]
Aim	To explore the issues and challenges of care transitions in the preoperative environment
Population	Adults in the preoperative phase of surgical care n=10; no further information reported
Setting	Medical centre
Study design	Qualitative interviews
Methods and analysis	Semi-structured interviews with thematic analysis
Findings	**Content of information – treatment planning and process of care** Patients described the value of the preoperative phase of care in the context of preparing them for what to expect, not only for the surgical procedure but also for the entire perioperative course and after care.
	Content of information –coordination of care Patients described a lack of care coordination once they had entered the perioperative environment that seemed rooted in communication gaps

Study	**Malley 2017**[136]
	Other themes were identified in the study but they were not directly related to information or support needs, so are not reported here.
Limitations and applicability of evidence	No significant methodological limitations noted Study conducted in the US Focused on a specific period of care

Study	**Malley 2018**[135]
Aim	To explore how older patients with multiple chronic conditions and their family caregivers perceive their engagement and overall care experience throughout the preoperative phase of elective orthopaedic hip or knee joint replacement
Population	Older adults hospitalised for an elective hip or knee joint replacement n=11 patients; Age, median 81 year; Sex 9 female and 2 male; Ethnicity, 9 Caucasian, 2 African American n=5 family caregivers consisting of adult children or elderly spouses
Setting	Medical centre
Study design	Qualitative interviews
Methods and analysis	Semi-structured telephone interviews with qualitative content analysis Key themes were further conceptualised within the framework of the Quality Health Outcomes Model elements consisting of client, system, intervention and outcome.
Findings	**Information provision and information seeking – information sources and mode of communication** Some participants found computer or web-based information difficult to access. Participant often managed to find other ways to engage and obtain the knowledge that they felt was needed to prepare them for their surgery. Patients y frequently relied on information from conversations with those who have had the experience.
	Support needs – coordination of care Participants described a lack of care coordination amongst disciplines within the preoperative environment. As such, care coordination often fell to the family or caregivers.
	Content of information – outcomes of surgery Some participants noted a sense of lack of preparation regarding the perioperative care trajectory, and this was also noted by the family or caregivers.
	Content of information – self-care after surgery Patients and families or caregivers also reported the lack of preparation extended into the experience of care when discharged.
	Other themes were identified in the study but they were not directly related to information or support needs, so are not reported here.

Study	**Malley 2018**[135]
Limitations and applicability of evidence	No significant methodological limitations noted Study conducted in the US Results appear generally applicable, although this is a population of older adults

Study	**McMullen 2019**[141]
Aim	To identify patients' needs and challenges from pretreatment to approximately 2 years after surgery, and to identify how these needs were addressed across 2 different delivery systems
Population	Adults (at least 21 years of age at the time of surgery) who received a cystectomy with urinary diversion (ileal conduit, neobladder, or continent pouch) for the treatment of bladder cancer n=62 (32 patients in the integrated care setting, with 25 patients and 5 caregivers in the comprehensive cancer care setting); Integrated care setting Age, mean 70 years (range: 47–87 years); Surgeries took place an average of 2.6 years before study participation (range: 1–6 years); Ethnicity, 7 racial/ethnic minority participants and 1 unknown Comprehensive cancer care setting Age, mean 68 years (range: 38–93 years); Surgeries took place an average of 2.1 years before study participation (range: 0–5 years); Ethnicity, 1 racial/ethnic minority participant
Setting	Integrated care and comprehensive cancer
Study design	Qualitative focus groups and interviews
Methods and analysis	Structured guides use for both the focus groups and the interviews Modified grounded theory approach used for analysis to identify themes across the dataset, complemented by analytic memos and comparative analysis
Findings	**Information provision and information seeking – level of detail** Some participants felt overwhelmed by the amount of information they were given, while others felt their doctors did not inform them adequately about the options. Participants also varied in whether they preferred to follow a clear recommendation from their provider or whether they wanted a more active role in the decision, including seeking more information through other sources, such as the internet or another doctor. Information seeking continued in the post-surgery phase, often including learning about the experience of others undergoing a similar operation using online groups or other support groups.
	Information provision and information seeking – balance and consistency Participants reported that their urologist expressed a strong preference for one type of diversion, whereas others were presented with

Study	**McMullen 2019**[141]
	more neutral information.
	Content of information – outcomes of surgery Perceptions about the benefits and disadvantages of different diversion types were not consistently presented to participants. Participants also wanted to know what was a ‘normal’ recovery experience, including likely complications.
	Content of information – self-care after surgery Participants wanted information on self-care processes for their return to home, and this included information on how to use self-care equipment and how to order further supplies, as needed. Caregivers also needed to know how to care for the patient at home after surgery.
	Content of information – coordination of care Depending on the healthcare system, patients did not always know who to contact to get their needs met after leaving the hospital.
	Other themes were identified in the study but they were not directly related to information or support needs, so are not reported here.
Limitations and applicability of evidence	Moderate limitations noted around the impact of the researchers on the process Study conducted in the US May be limited in some aspects around applicability to the NHS

Study	**Meleo-Erwin 2019**[146]
Aim	To describe the post-operative experience of bariatric surgery from the perspective of patients themselves
Population	People who posted on 2 online weight-loss surgery forums No information on the participants was reported
Setting	Home surgical clinics
Study design	Qualitative analysis of online forum comments
Methods and analysis	Thematic analysis of selected online comments, using web-based software (single reviewer only)
Findings	**Content of information – self-care after surgery** Participants valued healthcare professionals who offered explicit post-operative diet and nutritional supplement protocols, which included not only what to eat or take, but how much, how often, and at what stage in the recovery process and recommended exercise regimens. Participants also expressed they were confident that the information they were given was grounded in best practices and the latest scientific research.
	Other themes were identified in the study but they were not directly related to information or support needs, so are not reported here.

Study	**Meleo-Erwin 2019**[146]
Limitations and applicability of evidence	Significant limitations noted around the methods, including participant selection, analysis, and adequacy Study conducted in the US May be limited in some aspects around applicability to the NHS

Study	**Otutaha 2019**[164]
Aim	To determine the specific information needs of patients with upper GI cancer
Population	Adults with upper GI cancer n=6 studies; 2 based in the UK; 5 from single-institutions; 3 in people at diagnosis or pre-treatment, 1 during treatment, 1 post-treatment, and 1 at multiple stages
Setting	Not specified
Study design	Systematic review of qualitative studies
Methods and analysis	No detail was provided, and results were reported narratively by study No methods of synthesis or quality assessment were reported
Findings	**Content of information – outcomes of surgery** Participants wanted information regarding post-operative recovery, quality of life, and their expected survival.
	Content of information – self-care after surgery Participants wanted information regarding on the management of post-operative symptoms.
	Support needs – financial issues Participants wanted support with coping strategies for insurance and financial issues.
	Support needs – social relationships Participants reported that relationships and family were most important to them.
	Information provision and information seeking – information sources and mode of communication One-on-one consultations with senior medical staff were the preferred method of information transfer followed by web-based information services
	Other themes were identified in the study but they were not directly related to information or support needs, so are not reported here.
Limitations and applicability of evidence	Significant limitations noted around the methods, including study selection, analysis, and adequacy of data Study included UK-based studies May be limited in some aspects around applicability to the NHS

Study	**Owers 2017[165]**
Aim	To explore issues missing from preoperative education for bariatric surgery
Population	Adults who had undergone bariatric surgery n=12; Age mean, 55 years (range, 41 to 76 years); Sex, 11 female, 1 male; Ethnicity, 11 white
Setting	Teaching hospital
Study design	Qualitative interviews
Methods and analysis	In-depth interviews, with a general inductive analysis
Findings	**Content of information – outcomes** Patients considered that information on the side-effects of surgery was lacking.
	Support needs – social relationships Information on the need for social support after surgery was felt to be lacking. Social support could be from friends, family, healthcare providers, and the wider community.
	Other themes were identified in the study but they were not directly related to information or support needs, so are not reported here.
Limitations and applicability of evidence	No significant methodological limitations noted Study conducted in the UK Results appear generally applicable

Study	**Rattray 2019[174]**
Aim	To explore patients’ perceptions of recommencing feeding after colorectal surgery to determine areas of improvement to meet their needs and expectations
Population	Adults admitted for a lower GI surgical procedure n=16; Age, range 36 to 79 years; Sex 9 female and 7 male
Setting	Tertiary teaching hospital
Study design	Qualitative interviews
Methods and analysis	In-depth semi-structured face-to-face interviews with thematic qualitative analysis

Study	**Rattray 2019**[174]
Findings	**Content of information – care immediately after surgery** Effective communication of nutrition care information, such as delivering nutrition-related messages and explaining dietary changes, was seen as an important part of the post-operative experience for some patients.
	Information provision and information seeking – information sources and mode of communication Clear and simple dietary-related messages delivered by doctors were appreciated by patients and heavily shaped their behaviour and attitudes towards nutrition in the period immediately after surgery.
	Other themes were identified in the study but they were not directly related to information or support needs, so are not reported here.
Limitations and applicability of evidence	No significant methodological limitations noted Study conducted in Australia May have some limited applicability as focused on a specific intervention (post-surgical nutrition)

Study	**Recio-Saucedo 2018**[175]
Aim	To investigate the information requirements of young women to support their treatment decision making at diagnosis
Population	Women diagnosed with breast cancer aged 40 years or younger who had undergone surgery n=20; Age at diagnosis, mean 35 years (range 23 to 40); Ethnicity, 19 White/Caucasian; Relationships, 4 were single, 11 had children; Employment, 19 were working; Education, 14 went to college or had higher education
Setting	Not clear
Study design	Qualitative interviews
Methods and analysis	Semi-structured face-to-face interviews with qualitative framework analysis
Findings	**Information provision and information seeking – information sources and mode of communication** Women discussed the need for visual materials (photographs) of different surgical procedures, particularly showing women in their age group.
	Content of information – treatment planning and process of care Women expressed the need to understand how effective one type of surgery would be over another and whether a more conservative surgical procedure, such as breast-conserving surgery, would be enough to ensure non-recurrence
	Other themes were identified in the study but they were not directly related to information or support needs, so are not reported here.
Limitations and applicability of	No significant methodological limitations noted Study conducted in the UK

Study	**Recio-Saucedo 2018**[175]
evidence	Results appear generally applicable, although this is a population of younger women

Study	**Rosaasen 2017**[179]
Aim	To identify pre transplant education topics from the post-transplant patient perspective
Population	Adults who had a kidney transplant n=7; Age, range 29 to 65; Sex, 3 female and 4 male; Employment, 5 employed, 2 retired; Ethnicity, 6 White, 1 Aboriginal; Time since transplant, range 3.5 years to 21 years
Setting	Not specified
Study design	Qualitative interviews
Methods and analysis	Semi-structured interviews with thematic analysis
Findings	**Information provision and information seeking – information sources and mode of communication** Written information was valued, Although the group supported the production of supplemental videos, they unanimously believed that written materials should continue to be provided during transplant assessment. Although online technology is important, they warned that transplant candidates should be cautious when researching information and interpreting online data.
	Support needs – social relationships A supporting relationship, including attending health care appointments, was seen as important, including after surgery.
	Content of information – outcomes of surgery Participants felt well informed about the transplant surgery, however there were some gaps in knowledge about the procedure and the outcomes after surgery.
	Content of information – self-care after surgery Although the group collectively felt they received adequate education about taking transplant medications, they felt overwhelmed once they were discharged home. Participants also reported gaps in knowledge about complications, such as rejection
	Other themes were identified in the study but they were not directly related to information or support needs, so are not reported here.
Limitations and applicability of evidence	Moderate limitations noted around patient selection and analysis Study conducted in Canada Results appear generally applicable, although the time from surgery is long, participants were asked about what they wish they had known at the time of surgery

Study	Rosenberg 2018[180]
Aim	To explore the process of surgical decision-making in young women, including how issues particular to younger women affected their decision and the post-surgical experience
Population	Women aged 40 years or younger with stage 0 to III breast cancer, 1 to 3 years from diagnosis who had undergone breast cancer surgery n=20; Age at diagnosis, median 37 years (range: 29-40 years); Ethnicity, 90% identified as White non-Hispanic; Stage of disease 70% (n = 14) of women had either Stage I (n = 4) or II (n = 10) disease at diagnosis
Setting	Not clear
Study design	Qualitative focus groups
Methods and analysis	4 focus groups, using a semi-structured approach with thematic content analysis
Findings	**Information provision and information seeking – information sources and mode of communication** Women used a range of sources, including pictures to help women see what their breasts might look like after surgery.
	Support needs – social relationships Women spoke of how family, friends, colleagues, and breast cancer survivors were sources of information. The majority of women appreciated and found helpful a range of both emotional and material support from partners, family, friends, colleagues, and other breast cancer survivors.
	Content of communication – outcomes of surgery Overall, most participants articulated that they generally received sufficient information from their providers about what recovery would be like and that this information was clearly communicated. Nonetheless, while in many cases women were aware of the potential challenges they might encounter after surgery, there was a sense that they had underestimated what these challenges would be like. Other women felt the information provided to them was inadequate and that they were not well prepared for what to expect after surgery
	Support needs – support groups Some women spoke of having difficulty finding adequate peer support resources or support groups when they needed it, and sometimes attributed this to their being diagnosed at a younger age than most women with breast cancer
	Other themes were identified in the study but they were not directly related to information or support needs, so are not reported here.
Limitations and applicability of evidence	No significant methodological limitations noted Study conducted in the US Results appear generally applicable, although this is a population of younger women

Study	**Samuelsson 2018**[184]
Aim	To describe how older patients experience the healthcare chain and information given before, during and after colorectal cancer (CRC) surgery
Population	Older adults who had undergone elective CRC surgery with curative intent n=16; Age, women median age 82.5 years (range 78 to 84) men median age 82.5 years (range 76 to 89); Sex, 8 female and 8 male; Housing status, all lived in their own accommodation; Relationships, 6 ongoing relationships, 10 widowed
Setting	University hospital
Study design	Qualitative interviews
Methods and analysis	Semi-structured face-to-face interviews with inductive content analysis
Findings	**Content of information – outcomes of surgery** A few participants said that they had not received any information at all on the potential of having to have a stoma. Some participants expressed the need for information about functional restrictions and long-term problems such as diarrhoea and nutrition after surgery
	Content of information – care immediately after surgery Some participants would have liked much more information about care on the surgical ward to reduce uncertainty about the forthcoming events. An important reflection was the need for information on what to expect, in both positive and negative terms.
	Content of information – treatment planning and process of care Some participants would have liked much more information about the operation itself to reduce uncertainty about the forthcoming events. An important reflection was the need for information on what to expect, in both positive and negative terms.
	Information provision and information seeking – information sources and mode of communication Information provided during the hospital stay was perceived as one-way communication, and not adapted to the needs of the individual patient. Participants felt that there was no time for questions or discussion. Information provided was difficult to understand because of the use of medical terms or it was given at an inappropriate time, for example directly after waking up from anaesthesia. Furthermore, no consideration was felt to be taken for the older patient's need for time to understand. After surgery, information was described as hard to understand (i.e., not converted to lay language), and written information needed further explanation.
	Content of information – self-care after surgery The need for information in the post discharge period mostly concerned wound care, bowel dysfunction, weight loss and activities of daily life. There was great uncertainty regarding whom to contact about these problems, their general practitioner or the hospital department.
	Other themes were identified in the study but they were not directly related to information or support needs, so are not reported here.

Study	**Samuelsson 2018**[184]
Limitations and applicability of evidence	No significant methodological limitations noted Study conducted in the US Results appear generally applicable, although this is a population of older people

Study	**See 2018**[189]
Aim	To systematically summarize and synthesize osteoarthritic patients' expectations and experiences in undergoing total joint arthroplasty to identify their educational needs
Population	Adults undergoing total joint arthroplasty n=20 studies (13 qualitative and 6 quantitative); 3 studies based in the UK
Setting	Not specified
Study design	Systematic review of patient education needs
Methods and analysis	Thematic analysis, reported narratively
Findings	**Content of information – treatment planning and process of care** Patients with preoperative anxiety before surgery reported the need to bridge informational gaps that patients had before surgery to dispel fears and allay anxiety.
	Content of information – outcomes of surgery Patients sought information on what to expect during recovery from health-care providers and those who had completed their surgery. Patients can use information to understand their condition and avoid unrealistic expectations that might impede actual recovery. Patients also wanted information on how their functional abilities might return, including activities of daily living, but there was often felt to be little information on this aspect of recovery.
	Information provision and information seeking – level of detail While information should be personalised, there is the need to maintain a successful balance between provision of information and relevancy of knowledge to patients.
	Content of information – self-care after surgery Patients wanted information on pain medication and nonpharmacological strategies to cope with pain.
	Content of information – coordination of care Patients lacked continuity of care and access to services with health-care professional–led education, support, and guidance upon discharge from hospital.

Study	**See 2018**[189]
	Other themes were identified in the study but they were not directly related to information or support needs, so are not reported here.
Limitations and applicability of evidence	Moderate concern about the adequacy of the data, also some survey data was included Review included studies based in the UK Little concern about applicability

Study	**Sibbern 2017**[197]
Aim	To aggregate, interpret and synthesise findings from qualitative studies to further our knowledge regarding patients' pre- and postoperative experiences when participating in an enhanced recovery after surgery
Population	Adults who had undergone colorectal, cardiac, gynaecological, and orthopaedic surgery in an ERAS program, and were hospitalised equal to or longer than 36 hours n=11 studies, 4 of which were based in the UK
Setting	Enhanced recovery after surgery services
Study design	Systematic review of qualitative studies
Methods and analysis	Meta-synthesis of included data
Findings	**Information provision and information seeking – information sources and mode of communication** Written material was highly valued and used as a reference throughout the care encounter.
	Information provision and information seeking – balance and consistency Some patients reported a lack of consistency of information, and this could lead to feelings of insecurity when the written information did not correspond with the verbal information
	Content of information – outcomes of surgery Patients were informed about their mobility levels in the hospital, but some wanted more detailed guidelines about their recovery of physical function upon discharge. Those who developed serious postoperative complications found that the information provided at discharge was insufficient. In particular, they reported that they had missed information regarding how to identify possible complications. Throughout the recovery process, the patients experienced new informational needs. For example, it was important that healthcare professionals provide information about the timing to recommence work.
	Other themes were identified in the study but they were not directly related to information or support needs, so are not reported here.

Study	**Sibbern 2017**[197]
Limitations and applicability of evidence	No significant methodological limitations noted Review included studies conducted in the UK Results appear generally applicable

Study	**Smith 2018**[202]
Aim	To understand patients’ educational needs on pain management when undergoing hip or knee arthroplasty
Population	Adults who had undergone hip or knee arthroplasty and who used high doses of opioids after surgery Clinicians and other health care providers were also included, but their results are not reported further n=11; Age not reported; Sex, 9 female, 2 male
Setting	Community
Study design	Qualitative interviews
Methods and analysis	Semi-structured face-to-face interviews with content analysis
Findings	**Content of information – outcomes after surgery** Patients were surprised how long their pain lasted after surgery, particularly as they had been told that hip surgery is generally less painful than knee surgery.
	Content of information – self-care after surgery Patients received information on the surgery, but most people felt that pain management was not addressed adequately. Most people did not receive information on how or when to taper opioids. People also wanted to know what to do is pain increased after exercise or physical therapy.
	Information provision and information seeking – balance and consistency People reported receiving mixed messages about the use of opioids and other approaches to pain management. Patients also felt they were treated ‘like an addict’ and were not fully informed on the potency of opioids.
	Information provision and information seeking – information sources and mode of communication The information from the surgeon was clear and helpful regarding pain management after surgery. However, not all patients recollected this information being provided.
	Other themes were identified in the study but they were not directly related to information or support needs, so are not reported here.
Limitations and applicability of	No significant methodological limitations noted Study conducted in the US

Study	Smith 2018[202]
evidence	Results may be less applicable to countries other than the US, because of the differences in opioid prescribing and use

Study	Strickland 2018[208]
Aim	To explore patients' perspective of surgery and early recovery when undergoing lower limb (hip or knee) arthroplasty
Population	Adults undergoing lower limb (hip or knee) arthroplasty n=30; Age, mean 70.97 years (range 45 to 92); Sex, 16 female and 14 male; Ethnicity, 28 White-British, 2 other White; Time since surgery, mean 28.5 days (range 0 to 63); Employment, 7 employed: 21 retired, 2 unemployed; Living situation, 6 alone, 24 with family; Home situation 4 1-level, 26 with stairs
Setting	Specialist hospital
Study design	Qualitative interviews
Methods and analysis	Semi-structured face-to-face interviews with thematic analysis
Findings	**Content of information – treatment planning and process of care** Participants reported that going through the postoperative physiotherapy and occupational therapy requirements prior to the operation was beneficial
	Information provision and information seeking – information sources and mode of communication One patient suggested that being given more printed information sheets could be beneficial to help understand their available drug combinations, therapeutic actions, dosing and timing.
	Information provision and information seeking – balance and consistency Some found that the information they were given regarding the early recovery phase during hospitalisation was contradictory. This leads to confusion and uncertainty over what to expect and who to believe.
	Other themes were identified in the study but they were not directly related to information or support needs, so are not reported here.
Limitations and applicability of evidence	No significant methodological limitations noted Study conducted in the UK Results appear generally applicable

Study	Stutzman 2017[209]
Aim	To identify important patient and family perspectives regarding the transition from the operating room to the ICU

Study	**Stutzman 2017**[209]
Population	Patients and family members experiencing a perioperative event that would result in a transfer to the ICU n=7; no further information reported
Setting	University medical centre
Study design	Qualitative interviews
Methods and analysis	Semi-structured face-to-face interviews with hermeneutic cycling, and thematic analysis Also included triangulation with existing literature, and maximising variation
Findings	**Information provision and information seeking – information sources and mode of communication** In the hospital, patients reported that they would like to see the surgeon before the procedure. Patients also mentioned that if they had seen or talked to the perioperative nurse before the surgical procedure, they felt more at ease. The family wanted to be able to ask the ICU nurse about the patient and his or her care in the operating room.
	Content of information – treatment planning and process of care During the surgical procedure, communication with the family was pivotal, especially regarding the length of the surgical procedure, medications, patient condition, changes in condition, and what to expect in the short term. Communication about upcoming postoperative testing was also important.
	Other themes were identified in the study but they were not directly related to information or support needs, so are not reported here.
Limitations and applicability of evidence	Moderate methodological limitations noted around ethics and the relationship of the researchers to the patients Study conducted in the US Results appear generally applicable

Study	**Webb 2018**[223]
Aim	To discover missed opportunities for providing information to women undergoing breast reconstruction in an effort to decrease regret and improve patient education, teaching modalities, and satisfaction
Population	Women undergoing breast reconstruction n=19; Age, mean 54 years (range 38 to 69); Time since surgery, mean 108 days (range 15 to 286)
Setting	Not specified
Study design	Qualitative interviews
Methods and analysis	Semi-structured face-to-face interviews with thematic analysis

Study	Webb 2018[223]
Findings	**Information provision and information seeking – balance and consistency** Participants noted that the plastic surgeon was a trusted source to guide patients to trustworthy online or print sources, thus supplementing the information transfer that takes place during the consultation process and allowing patients to confidently, and at their own pace, consult outside sources. Some participants supplemented information from the surgeon with information from online sources.
	Support needs – social relationships Informants emphasized the importance of bringing a companion to health-care appointments, and this support continued to be positive after surgery.
	Information provision and information seeking – information sources and mode of communication Written information in the form of pamphlets, brochures, books, and online resources was also generally welcomed, although tolerance for the amount of information varied. Women felt they did not have access to enough before and after pictures, images of scars, immediate post-operative images, or photographs of reconstructive complications. It was felt that photographs were much better at communicating than diagrams or written materials. Overall, women felt an FAQ resource might be useful.
	Content of information – outcomes of surgery Participants felt they were not given information on everything they needed to know about the surgery.
	Information provision and information seeking – level of detail An individualized approach to information provision, in terms of the type and quantity of information, as well as the delivery method, is necessary to adapt to different learning styles, personality types, and information tolerance levels.
	Support needs – support groups Women regularly sought out the experience of others who had previously undergone breast reconstruction, and whilst not everyone wanted to meet in person, the benefit of speaking with someone who “had been there” remained.
	Other themes were identified in the study but they were not directly related to information or support needs, so are not reported here.
Limitations and applicability of evidence	No significant methodological limitations noted Study conducted in Canada Results appear generally applicable

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Study	Wickwar 2018[225]
Aim	To explore patients’ expectations of orbital decompression surgery for thyroid eye disease (TED) and whether these were met
Population	Adults undergoing orbital decompression surgery for thyroid eye disease

Study	**Wickwar 2018**[225]
	n=14; Age, mean 47.2 yeas (range 23 to 76); Sex, 10 female and 4 male; Ethnicity, 10 White-British, 2 Asian, 2 Black African/Caribbean/Other; Employment, 7 employed, 3 retired, 4 unemployed; Relationship, 10 living with another, 4 single or other
Setting	Outpatient clinic
Study design	Qualitative interviews
Methods and analysis	Semi-structured face-to-face interviews with thematic analysis
Findings	**Content of information – outcomes of surgery** Not all patients could fully imagine their appearance after surgery was worrying for some, and was often attributed to a lack of information. Participants felt the information they received prior to surgery had prepared them for the worst possible outcome, which was not always experienced. Participants were generally satisfied with the information they had been given about recovery.
	Content of information – treatment planning and process of care Some participants attributed their lack of understanding about what surgery would involve to the difficulty in recalling information from pre-operative consultations
	Information provision and information seeking – information sources and mode of communication Participants described the various sources of information they used to find out more about orbital decompression, including websites, blogs and forums. Videos of the procedure and 'before-and-after' photos of other patients were commonly found online, with mixed reactions. Some found graphic information reassuring, while others actively avoided it as they found it too distressing.
	Other themes were identified in the study but they were not directly related to information or support needs, so are not reported here.
Limitations and applicability of evidence	Moderate concerns about the process of analysis Study conducted in the UK Results appear generally applicable, particularly to procedures with a substantial cosmetic impact

Appendix E: Excluded studies

E.1 Excluded qualitative studies

Table 19: Studies excluded from the qualitative review

Reference	Reason for exclusion
Aagaard 2018[1]	No relevant outcomes and does not match review question (describes the process, not the information or support needs)
Atinyagrika Adugbire 2017[7]	No relevant outcomes and does not match review question (focus more on what information was provided, not the value of that information)
Atinyagrika Adugbire 2018[15]	No relevant outcomes and does not match review question (focus more on what information was provided, not the value of that information)
Attwood 2018[16]	No relevant outcomes and does not match review question (not focused on the information people wanted from their healthcare professional)
Barros 2017[21]	No relevant outcomes and does not match review question (analysis of blog posts, but no clear link to information provision by healthcare professionals)
Bloom 2019[28]	No relevant outcomes and does not match review question (describes the process of surgery, not the information or support needs)
Braude 2017[33]	Incorrect study design (majority of included studies were quantitative)
Cater 2017[42]	Incorrect study design (majority of included studies were quantitative)
Falco 2017[69]	Incorrect study design (majority of included studies were quantitative)
Gillis 2019[76]	Intervention does not match protocol (focus on the implementation of a specific programme)
Gupta 2018[80]	Population does not match protocol (participants refused surgery)
Hamilton 2017[86]	No relevant outcomes and does not match review question (describes the experience of surgery, not the information or support needs)
Hortsman 2017[101]	Intervention does not match protocol (focus on a specific information-providing intervention)
Huetteman 2018[106]	Population does not match protocol (not all participants had surgery)
Johnson 2018[111]	No relevant outcomes and does not match review question (describes the process of surgery, not the information or support needs)
Kaptain 2017[113]	Population does not match protocol (focus on the information needs of nurses)
Latifi 2017[125]	Population does not match protocol (not adults in the perioperative period)
Lui 2017[133]	Population does not match protocol (not adults in the perioperative period)
McMullen 2018[140]	Population does not match protocol (the majority of participants were not patients or caregivers)
Nabozny 2017[152]	No relevant outcomes and does not match review question (describes the process of decision making, not the information or support needs)
Odom-Forren 2018[158]	Unable to obtain paper (not available through the British Library)

Reference	Reason for exclusion
Parretti 2019[167]	Population does not match protocol (not adults in the perioperative period)
Pennbrant 2018[169]	Incorrect study design (review of patient surveys)
Richards 2017[177]	No relevant outcomes and does not match review question (describes the process of surgery, not the information or support needs)
Rushton 2017[182]	Intervention does not match protocol (focus on a specific rehabilitation intervention)
Shahmoon 2019[192]	Population does not match protocol (adults undergoing neurosurgery)
Sharman 2017[193]	Population does not match protocol (not adults in the perioperative period)
Siyam 2018[200]	No relevant outcomes and does not match review question (describes the outcomes of surgery, not the information or support needs)
van Kasteren 2018[217]	No relevant outcomes and does not match review question (focus more on what information was provided, not the value of that information)
Watts 2018[222]	No relevant outcomes and does not match review question (focus more on what information was provided, not the value of that information)
Yeh 2017[231]	Population does not match protocol (participants had not yet decided to undergo surgery)

Table 20: Studies identified but not included in the qualitative review due to saturation being reached

Reference
Anon 2000a[168]
Anon 2000b[171]
Aasa 2013[2]
Aazami 2016[3]
Abbasi2015[4]
Abbott 2011[5]
Abu-Nab 2007[6]
Agnew 2012[8]
Alawadi 2016[9]
Allen 2001[10]
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Ang 2013[13]
Aquilina 2007[14]
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Azatio 2014[18]
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Reference
Bhardwaj 2012[26]
Blazeby 2010[27]
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