National Institute for Health and Care Excellence

Draft for consultation

Colorectal cancer update

[E3] Information needs of people prior, during and after treatment for colorectal cancer

NICE guideline TBC

Evidence reviews

July 2019

Draft for Consultation

These evidence reviews were developed by the National Guideline Alliance hosted by the Royal College of Obstetricians and Gynaecologists

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Contents

Information needs of people prior, during and after treatment for colorectal cancer

This evidence review supports recommendations 1.2.1 to 1.2.8.

Review question

What are the information needs of people prior, during and after treatment for colorectal cancer?

Introduction

Survival for colorectal cancer is continuing to improve (Verdecchia 2007) and there is also a growing body of work on cancer survivorship in the UK. It is estimated that 25% of cancer survivors in the UK experience treatment-related consequences (Macmillan Cancer Support 2013). People undergoing treatment for colorectal cancer might experience a variety of consequences, depending on their treatment, including change in bowel function and stomas related to surgery, peripheral neuropathy related to chemotherapy and changes in quality of life related to radiotherapy (Brown 2016). While health care professionals are increasingly aware of the need to inform patients of treatment consequences, there is a lack of evidence regarding patients' information needs throughout their cancer journey. Therefore, the objective of this review is to determine the information needs and the gaps in current provision of information for people undergoing treatment for colorectal cancer.

Summary of the protocol

Please see Table 1 for a summary of the population, phenomenon of interest, and context (PICo) of this review.

Table 1: Summary of the protocol (PICo table)

Population	Adult patients who are undergoing or have undergone treatment (surgical and/or oncological) for colorectal cancer Exclusions: • Family members or carers • Health care professionals
Phenomenon of Interest	Information needs in regards to: • bowel function • sexual function & fertility • diet/nutrition • neuropathy • lifestyle factors – social life, exercise, employment
Context	Information needs for people prior, during and after treatment for colorectal cancer.

For further details see the review protocol in appendix A.

Methods and process

This evidence review was developed using the methods and process described in Developing NICE guidelines: the manual 2014 Methods specific to this review question are described in the review protocol in appendix A.

Declarations of interest were recorded according to NICE's 2014 conflicts of interest policy until 31 March 2018. From 1 April 2018, declarations of interest were recorded according to NICE's 2018 conflicts of interest policy. Those interests declared until April 2018 were reclassified according to NICE's 2018 conflicts of interest policy (see Register of Interests).

Clinical evidence

Included studies

Fifteen qualitative studies were included in this review (Abelson 2018; Anderson 2013; Beaver 2014; Brown 2016; Dowswell 2011; Gillis 2017; Hall 2012; Ho 2016; Hoedjes 2017; Maxwell-Smith 2017; McCaughan 2011; Steel 2016; Taylor 2013; Veitch 2006; Wilson 2010).

The included studies are summarised in Table 2.

One study focused on the perspective of male patients with colorectal cancer. Eleven studies focused on the perspective of both male and female patients with colorectal cancer.

Four studies used focus groups (Anderson 2013; Gillis 2017; Ho 2016; Hoedjes 2017), 10 studies used semi-structured interviews (Abelson 2018; Beaver 2014; Brown 2016; Bowswell 2011; Hall 2012; Maxwell-Smith 2017; McCaughan 2011; Steel 2011; Taylor 2013; Wilson 2010) and 1 study (Veitch 2006) used a combination of both focus groups and semi-structured interviews. The most common data analysis method was thematic content analysis.

See the literature search strategy in appendix B and study selection flow chart in appendix C.

Excluded studies

Studies not included in this review with reasons for their exclusions are provided in appendix K.

Summary of clinical studies included in the evidence review

Summaries of the studies that were included in this review are presented in Table 2.

Table 2: Summary of included studies

Study and setting	Participants	Methods	Themes
Studies included in analysis			
Abelson 2018 USA	N=24 Female sex, n (%)= 16 (67) White, %= 75 Black, %= 13 Hispanic, %= 8 Rectal cancer, n (%)= 15 (62) Colon cancer, n (%)= 9 (38)	**Sampling:** Purposive sampling with emphasis on pre-operative and postoperative patients to obtain their perceptions of sources of distress around the surgical experience. **Setting:** Not reported **Data collection:** Participants completed one on one, semi-structured, open ended interviews with a study researcher. Interviews were performed until data saturation was reached and were audio recorded and transcribed. **Data analysis:** Thematic content analysis was used.	**Prior** **Surgery** -Preparation for surgery -What to expect during surgery -What to expect after surgery **Treatment decision making** -Awareness of colorectal cancer and treatments

Study and setting	Participants	Methods	Themes
			-Preoperative assessments **During** Cancer prognosis
Anderson 2013 UK	N=40 Male, n (%)= 20 (50) Age, years, mean (SD)= 60 (12.16) BMI, mean (SD)= 26.2 (4.85) White British, n (%)= 40 (100)	**Sampling:** Purposive sampling through Bowel Cancer UK and local colorectal cancer nurse specialists **Setting:** Six community locations in Scotland and England. **Data collection:** All participants completed a short questionnaire on demographic background, health behaviours, height and weight. Focus groups lasted 1.5-2 hours each and were moderated by an experienced qualitative researcher with a topic guide developed to steer the discussion, but new topics were allowed to emerge from the participants. **Data analysis:** Thematic content analysis was used.	**After** **Lifestyle** -Diet -Managing bodily functions
Beaver 2010 UK	N=27 Male, n (%)= 14 (51.9) Age, years 59-64, n (%)= 4 (14.8) 65-74, n (%)= 14 (51.9) 75+, n (%) 9 (33.3) Surgery, n (%)= 27 (100) Radiotherapy, n (%)= 4 (14.8) Chemotherapy, n (%)= 7 (25.9) Never had a stoma, n (%)= 13 (48.1) Permanent stoma, n (%)= 11 (40.7) Stoma temporary/reversed, n (%)= 3 (11.1)	**Sampling:** Purposive sampling of patients who had been discharged from hospital wards and/or oncology departments and were returning to hospital clinics for routine monitoring of their condition. **Setting:** Patients' homes. **Data collection:** The interview guide consisted of open-ended questions related to the aims of the study and a short survey of participants' demographic information. Participants were allocated an identification number and all identifying features were removed from interview transcripts. **Data analysis:** Thematic content analysis was used.	**Prior** **Surgery** -What to expect during surgery -What to expect after surgery **Timing and delivery of information** **After** **Lifestyle** -Diet **Medical information** -Stoma care
Brown 2016 UK	N=19 Male, n (%)= 11 (57.9) Age, years,	**Sampling:** Convenience sampling. **Setting:** Participants' homes.	**Prior** **Surgery** -What to expect after surgery

Study and setting	**Participants**	**Methods**	**Themes**
	mean (SD)= White British, n (%)= 18 (94.7) Polish, n (%)= 1 (5.3) No stoma, n (%)= 9 (47.4) Temporary stoma, n (%)= 6 (31.6) Permanent stoma, n (%)= 4 (21.1) Surgery, n (%)= 19 (100) Chemotherapy, n (%)= 10 (52.6) Radiotherapy, n (%)= 5 (26.3)	**Data collection:** Interviews were audio-recorded and were based on a topic guide derived from a literature review that focused on treatment impact, awareness and understanding of treatment and its consequences, risk and support services. Interviews were 20-60 minutes in length and were transcribed verbatim with identification numbers used to preserve anonymity. **Data analysis:** Thematic content analysis was used.	**Recovery** -Diet
Dowswell 2011 UK	N=28 Male, n (%)= 28 (100) Age, years, mean (SD)= 59.4 (10) Surgery for colorectal cancer, n (%)= 24 (89) White, n (%)= 24 (89) In a sexual relationship, n (%)= 17 (61)	**Sampling:** Purposive sampling was used to select participants with a broad range of views and experiences **Setting:** Participants' homes or healthcare location. **Data collection:** The authors used semi-structured interviews that focused on beliefs about erectile dysfunction, impact on self-perception and relationships, satisfaction with information, and experience of treatment. Interviews were audio-recorded and transcribed verbatim. **Data analysis:** Thematic content analysis was used.	**Prior** **Recovery** -Effect of treatment on sexual function **After** **Medical information** -Sex specific issues
Gillis 2017 Canada	N= 27 Male, n (%)= 17 (63.0) Age, years, range= 29-89	**Sampling:** Purposive sampling aimed at recruiting a sample representative of varied postoperative lengths and experiences **Setting:** In a university or in hospital in the patient's hospital room. **Data collection:** Data collection and analysis were performed iteratively. With open coding used to identify emerging themes and guide the direction of recruitment and data collection strategies. Participants were encouraged to tell their story of surgery experience, followed by open ended questions to test emerging themes. Interviews were audio recorded and transcribed. Data saturation was achieved after 10 interviews. **Data analysis:** Thematic content analysis was used. Research colleagues were asked to	**Prior** **Surgery** -What to expect during surgery **Recovery** -Accessing resources and services **Treatment decision making** -Medical information Timing and delivery of information

Study and setting	Participants	Methods	Themes
		review and discuss coding and themes to confirm findings and achieve investigator triangulation.	**During** **Diet** **Cancer prognosis** **After** **Medical information** -Medical issues
Hall 2012 UK	N=30 Male n=17, female n=12 Age range (years) 37 to 85. All had colorectal cancer	**Sampling:** Purposive sampling aimed at recruiting a sample representative of varied experiences. **Setting:** Locations selected by the participants, usually their own home **Data collection:** A semi-structured interview schedule covered information needs, support for patients and their families and support from primary care and other professionals. **Data analysis** Themes were identified via inductive content analysis. Recruitment continued until data saturation was reached.	**Prior** **Recovery** -Effect of treatment on sexual function **After** **Lifestyle** -Diet **Medical information** -Stoma care -Medical issues
Ho 2016 Canada	N=30 Male, n (%)= 16 (53) Age, years, median (IQR)= 60 (41-75) Diagnosis of colon cancer, n (%)= 17 (57) Diagnosis of rectal cancer, n (%)= 13 (43) Stage III disease, n (%)= 28 (93)	**Sampling:** Participants were identified through the British Columbia Cancer Registry. **Setting:** British Columbia Cancer Agency Vancouver Centre. **Data collection:** The focus groups were held on weekdays and weekdays during the day and evening to accommodate participants. Each focus group had 4-8 participants and lasted 90-120 minutes at the British Columbia Cancer Agency Vancouver Centre. All sessions were audio-recorded and transcribed verbatim. **Data analysis:** Thematic content analysis was used. The research team believed that thematic saturation had been met by the end of the analysis and additional information was not needed.	**Prior** **Surgery** -What to expect during surgery **Treatment decision making** -Cost of care **Timing and delivery of information** **After** **Medical information** -Medical issues -Sex specific issues
Hoedjes 2017 Netherlands	N=16 Male, n (%)= 10 (62.5) Age, years, mean (SD)= BMI	**Sampling:** Eligible participants from the COLON-study were invited to participate in one of three focus groups. **Setting:** Not reported. **Data collection:** The focus groups were guided by a topic list based on sensitising concepts,	**After** **Lifestyle** -Diet **Medical information**

Study and setting	Participants	Methods	Themes
	classification - overweight, n (%)= 8 (50) BMI classification - obese, n (%), n (%)= 8 (50) Stage I colorectal cancer n (%)= 3 (18.8) Stage II colorectal cancer, n (%)= 11 (68.8) Stage III colorectal cancer, n (%)= 2 (12.5)	including: the perception of a healthy lifestyle, determinants of a healthy lifestyle, and lifestyle change. Focus groups were moderated by a qualitative researcher and observed by another researcher. Focus groups were transcribed verbatim and transcripts were supplemented by field notes taken by the observer. **Data analysis:** Thematic content analysis was used. To increase validity, the codes were verified by another researcher until consensus was attained.	-Stoma care -Medical issues
Maxwell-Smith 2017 Australia	N=24 Male, n (%)= 11 (45.8) Age, years, mean (SD)= 69.38 (4.19) American Society for Anesthesiologists (ASA) score 2, n (%)= 15 (62.5) ASA score 3, n (%)= 9 (37.5)	**Sampling:** Convenience sampling. **Setting:** Participants' homes or another suitable location. **Data collection:** Semi-structured interviews were performed by 3 interviewers to explore current physical activity levels, and motives and barriers to increasing physical activity levels. **Data analysis:** Thematic content analysis was used.	**After** **Lifestyle** -Physical activity
McCaughan 2011 UK	N= 38 Male, n (%)=24 (63.2) Married, n (%)= 32 (84)	**Sampling:** Nurses identified potential participants at their first oncology appointment. A researcher contacted those who agreed and explained the study and its implications, and also sought the patient's consent to participate. **Setting:** Participants' venue of choice (their own home). **Data collection:** In-person, in-depth were performed by the study authors. Interviews lasted 1 hour and were audio-recorded with the permission of the participants. Participants were asked to tell their story of what they experienced and how they coped from diagnosis to the time of the interview. **Data analysis:** Thematic content analysis was used.	**During** Cancer prognosis
Steel 2016 Australia	N= 18 Male, n (%)= 12 (66.7) Age at	**Sampling:** Patients were contacted by an ACCFR representative or one of their treating specialists. Those who agreed to receive additional information were sent a participant information sheet and then contacted by the first	**Prior** **Surgery** -Preparation for surgery

Study and setting	Participants	Methods	Themes
	interview, 30-49 years, n (%)= 8 (44.4) Age at interview, 50-69 years, n (%)= 10 (55.6) Temporary stoma, n (%)= 1 (5.6) Permanent stoma, n (%)= 2 (11.1) No stoma, n (%)= 15 (83.3)	author to arrange an interview. Recruitment ceased once thematic saturation was reached. **Setting:** Not reported. **Data collection:** Interviews took place in person or over the phone. Interviews were semi-structured and designed to obtain information about participants' experiences being diagnosed with colorectal cancer. Interviews were on average 50 minutes and were audio recorded and transcribed verbatim. The transcripts were de-identified. **Data analysis:** Thematic content analysis was used.	-What to expect during surgery -What to expect after surgery **After** **Lifestyle** -Managing bodily functions
Taylor 2013 UK	N=8 rectal cancer patients Male n=5, female n=3 Age, range in years 61 to 76	**Sampling:** Purposive sampling aimed at recruiting a sample of patients with anterior resection syndrome. **Setting:** Not reported. **Data collection:** Semi-structured face-to-face interviews. **Data analysis** Themes were identified via framework analysis.	**After** **Lifestyle** -Managing bodily functions
Veitch 2008 Australia	N=117 Focus groups, n=30 Male, n (%)= 12 (40) Age range= not reported Interviews, n=18 Male, n (%)= 10 (56) Age, years, median (range)= 64 (50-79) Postal survey, n=69 Male, n (%)= 38 (55) Age, years, median (range)= 65 (38-80)	**Sampling:** For the focus groups and interviews, participants were purposively sampled to include age range, gender and residence, treatment modalities, treatment stages, and disease stages. In the survey, all non-terminal living patients in the database were invited to participate. **Setting:** Focus groups: cities in Australia. **Data collection:** Focus groups - There were 4 focus group sessions. Each group contained 6 to 10 participants. Interviews - Interviews were audio-recorded and were guided by a semi-structured topic schedule devised from the focus group sessions. Participants were recruited until thematic saturation was reached. Postal survey - Participants completed a self-completed questionnaire that included open-ended questions derived from the focus groups and interviews with several validated health attitudes and belief instruments. **Data analysis:** Researchers noted recurrent themes and differences in viewpoints. Reliability was ensured through respondent validation during the focus groups, participants' review of their interview transcripts, and the transcripts	**Prior** **Surgery** -Preparation for surgery **Treatment decision making** -Awareness of colorectal cancer

Study and setting	Participants	Methods	Themes
		being independently reviewed by 2 other team members. Analysis of the open-ended questions from the questionnaires were collated and reviewed in a similar process that was used with the focus group and interview data.	
Wilson 2010 UK	N=20 Male, n (%)= 13 (65) Age, years, mean= 62.3 Temporary stoma, n (%)= 9 (45) No stoma, n (%)= 6 (30) Permanent stoma, n (%)= 5 (20)	**Sampling:** Participants were prospectively sampled to ensure adequate representation of demographic and medical factors that might impact on health related quality of life. Recruitment took place until thematic saturation was achieved. **Setting:** Participant's home or in a private university room. **Data collection:** Semi-structured interviews were recorded and transcribed. Participants talked about their experiences of being diagnosed and treated for colorectal cancer. Interviews were structured around a topic guide. The sequencing of topics was adapted for each interview to allow the individual to dictate the structure of the interview. **Data analysis:** Framework analysis was used to analyse the transcripts. Thematic analysis was used to create an appropriate coding scheme. The reliability of the final coding scheme was determined by double coding a random sample of the transcript data. Themes were graphically mapped to explore relationships between themes. Once the thematic analysis was complete, the themes were compared.	**Prior** **Surgery** -What to expect during surgery **Treatment decision making** -medical information

ACCFR: Australasian Colorectal Cancer Family Registry; ASA: American Society of Anesthesiologists; BMI: body mass index; IQR: inter-quartile range; N: number; SD: standard deviation

See the full evidence tables in appendix D. No meta-analysis was conducted as this was a qualitative review (and so there are no forest plots in appendix E).

See also appendix M – Qualitative evidence and quotes.

Quality assessment of themes included in the evidence review

See the GRADE CERQual tables in appendix F.

Economic evidence

Included studies

A systematic review of the economic literature was conducted but no economic studies were identified which were applicable to this review question.

Excluded studies

A global search of economic evidence was undertaken for all review questions in this guideline. See Supplement 2 for further information.

Economic model

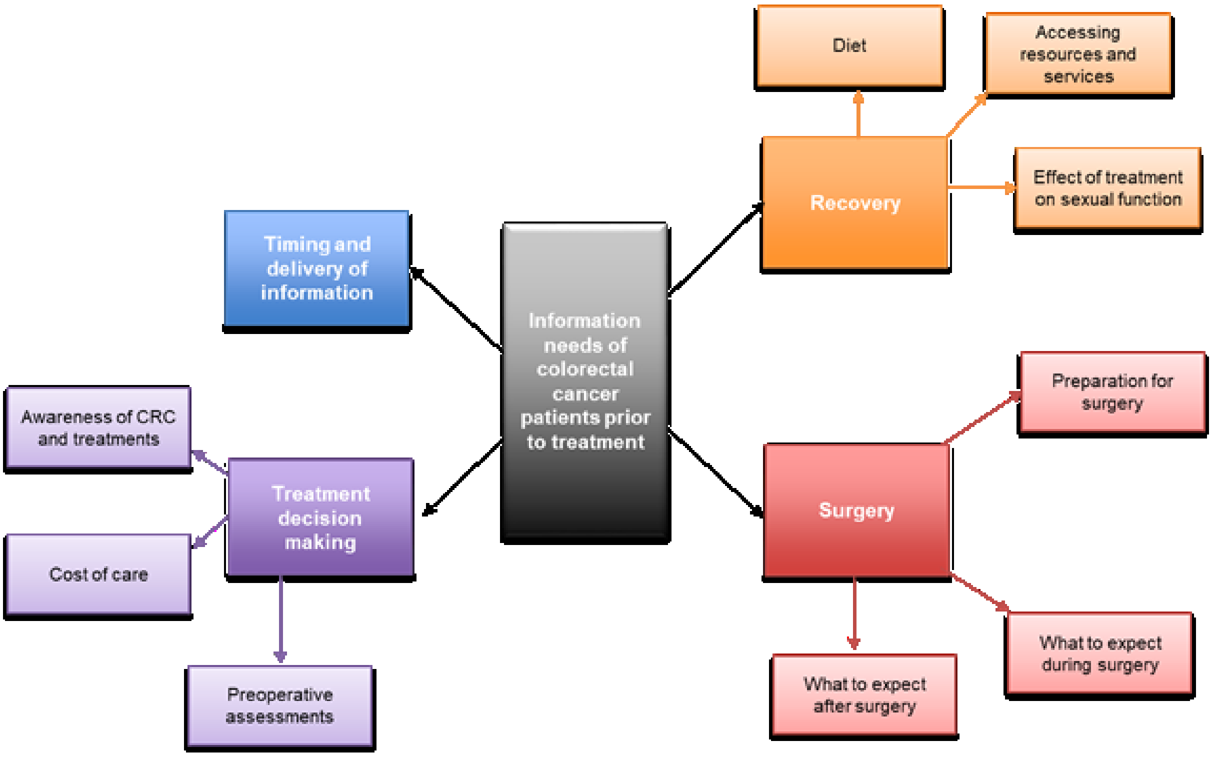
No economic modelling was undertaken for this review because the committee agreed that other topics were higher priorities for economic evaluation.

Evidence statements

Clinical evidence statements

Information needs prior to treatment

Figure 1: Thematic map – information needs prior to treatment



Theme 1: Surgery

Preparation for surgery

- Moderate quality evidence from 2 studies conducted in different countries (Australia, US) among 42 people with colorectal cancer found that people wanted to know what preparation was required prior to surgery. People wanted more thorough explanations, as receiving too much information at once regarding scheduling the surgery, colon preparation and reviewing test results could be overwhelming.

What to expect during surgery

- High quality evidence from 6 studies conducted in different countries (Australia, Canada, UK, US) among 146 people with colorectal cancer reported that participants wanted more information about what to expect during treatment, such as pain from inflating the abdomen for laparoscopic surgery, to feel better prepared for possible treatment side-effects. Participants wanted an explicit discussion prior to treatment about the possibility of changes to the treatment plan during the operation, such as the unexpected removal of additional organs, so as to not be taken by surprise.

What to expect after surgery

- High quality evidence from 4 studies conducted in different countries (Australia, UK, US) among 88 people with colorectal cancer reported that participants wanted to be informed about what to expect after surgery, including altered bowel function, potential treatment symptoms, other physical and mental changes, the presence of tubes and connections, and the length of the recovery process.

Theme 2: Recovery

Diet

- Moderate quality evidence from 1 study conducted in the UK among 19 people with colorectal cancer reported that prior to surgery, participants wanted to know about what adaptations to their diet would be required after surgery.

Accessing resources and services

- Moderate quality evidence from 1 study conducted in Canada among 27 people with colorectal cancer reported that participants were unaware of the resources available to them, therefore guidance on how to access the appropriate services could help reduce patients’ anxiety during the period prior to surgery.

Effect of treatment on sexual function

- High quality evidence from 2 studies conducted in the UK among 58 people with colorectal cancer reported that they did not think that they were adequately warned about the potential for sexual dysfunction post-surgery. When clinicians did provide information about the potential for altered sexual function, it was biased towards younger men and sometimes misleading. Most understood the importance of information about sexual matters being available to those that needed it.

Theme 3: Treatment decision making

Awareness of colorectal cancer and treatments

- Moderate quality evidence from 3 studies conducted in different countries (Australia, UK, US) among 92 people with colorectal cancer reported that they had limited knowledge on colorectal cancer prior to diagnosis and would have acted faster and sooner had they known more about the signs and symptoms. Additionally, ambiguous information about the efficacy of some treatments, such as adjuvant chemotherapy, made it difficult to make decisions. Participants noted the need to educate relatives on their need to be screened.

Cost of care

- Low quality evidence from 1 study conducted in Canada among 30 people with colorectal cancer reported that participants wanted to be informed about which supportive care medications were covered by the public healthcare system or private insurance, as the need to pay for medications out of pocket would affect their decision about whether to proceed with a medication.

Preoperative assessments

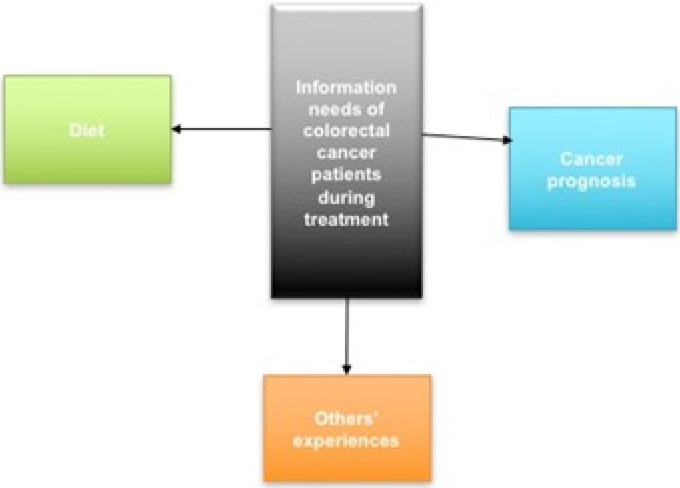
- Moderate quality evidence from 2 studies conducted in different countries (Canada, US) among 51 people with colorectal cancer reported that unawareness of the time needed to review and report preoperative assessments and results, such as biopsy results, caused undue preoperative stress. Receiving insufficient information could result in people regretting treatment decisions.

Theme 4: Timing and delivery of information

- High quality evidence from 4 studies conducted in different countries (Canada, UK, the Netherlands) among 100 people with colorectal cancer reported that many participants spoke of 'information overload' during the first consultation appointment and would have preferred that preoperative information be conveyed later when they were better able to absorb information, along with a binder or resource that they could consult. Participants also wanted to receive information updates directly after surgery, on the first hospital visit post-discharge, and during the follow-up period.

Information needs during treatment

Figure 2: Thematic map – information needs during treatment



Theme 1: Diet

- Moderate quality evidence from 1 study conducted in the UK among 27 people with colorectal cancer reported that participants would have liked some guidance while they were in hospital as to the type of food that relatives could bring for them from home.

Theme 2: Others' experiences

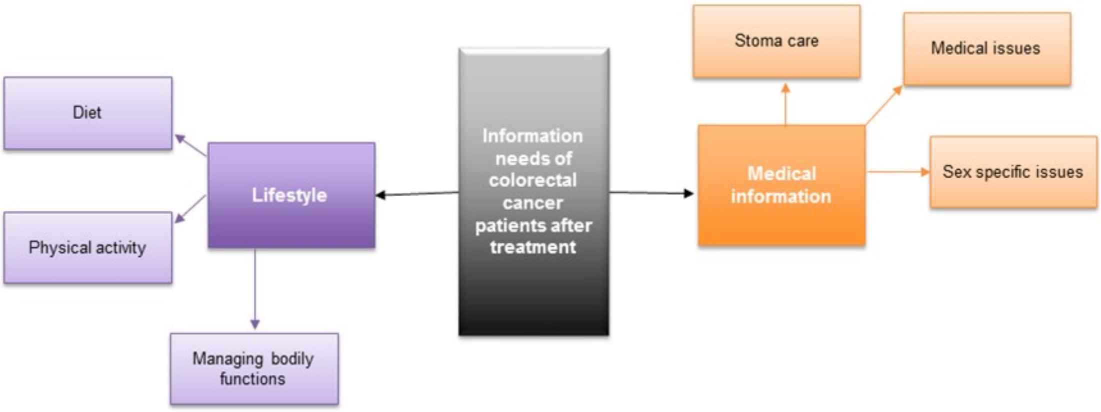
- Moderate quality evidence from 1 study conducted in the UK among 38 people with colorectal cancer reported that during treatment participants wanted to have the opportunity to learn from people who had similar experiences and to learn about possible treatment effects, such as chemotherapy side effects, from other patients.

Theme 3: Cancer prognosis

- Moderate quality evidence from 3 studies conducted in different countries (Canada, UK, US) among 89 people with colorectal cancer reported that lack of information regarding biopsy results and inaccessibility of surgeons caused anxiety during patients' hospital stays. While some participants wanted to know how long they were likely to live with cancer and how long they could expect to be disease-free, others found that too much information about complication risks was unhelpful and caused more anxiety.

Information needs after treatment

Figure 3: Thematic map – information needs after treatment



Theme 1: Lifestyle

Diet

- High quality evidence from 5 studies conducted in different countries (the Netherlands, UK) among 132 people with colorectal cancer reported that prior to hospital discharge, participants needed information on practical advice on dietary adaptations required following the removal of part of the bowel and on foods to avoid to prevent diarrhoea and flatulence. Participants also felt that it was important to have access to a dietician or support person to be able to ask questions and receive individually-tailored advice relating to appropriate nutrition and dietary supplements. Many interviewees reported the availability of leaflets or diet sheets from the dieticians whilst in hospital.

Physical activity

- Moderate quality evidence from 1 study conducted in Australia among 24 people with colorectal cancer reported that many participants were unaware of government guidelines and did not receive adequate advice regarding physical activity and would have liked information from medical professionals about the recommended duration, intensity, and frequency of exercising.

Managing bodily functions

- High quality evidence from 3 studies conducted in Australia and the UK among 66 people with colorectal cancer reported that after treatment, many participants struggled with changes in bowel function, diarrhoea and weight gain and would have liked more information on how to manage symptoms to facilitate adjusting to life post-surgery and return-to-work.

Theme 2: Medical information

Stoma care

- High quality evidence from 3 studies conducted in different countries (the Netherlands, UK) among 73 people with colorectal cancer reported that participants with a stoma received insufficient information on the provision of stoma bags and care. Participants needed practical information on how to dress with a stoma bag and how to adapt their lifestyles and diet in order to reduce the noise and odours caused by certain foods.

Medical issues

- High quality evidence from 5 studies conducted in different countries (Canada, the Netherlands, UK) among 122 people with colorectal cancer reported that many participants were unaware of medical issues, such as bleeding from the rectum or pain from radiotherapy that could arise as a result of treatment. Participants sought advice in regard to treatment-related issues, including lack of strength or energy, and lymphedema.

Sex specific issues

- Moderate quality evidence from 2 studies conducted in different countries (Canada, UK) among 58 people with colorectal cancer reported that they received insufficient sex-related advice and support after surgery. Many men did not know how or where to seek support for erectile dysfunction. Men sought information on how to ask for help and to gain a sense of what new norms might be. Women reported that male health care providers appeared uncomfortable discussing gynaecological side effects and would have preferred access to a gynaecologist.

Economic evidence statements

No economic evidence was identified which was applicable to this review question.

The committee's discussion of the evidence

Interpreting the evidence

The outcomes that matter most

The committee considered that information regarding dietary adaptations to manage bowel function, ERAS (Enhanced Recovery After Surgery protocols) and neuropathy were the most important themes for decision making due to these topics' abilities to improve people's quality of life throughout the treatment process and once the person is discharged.

The quality of the evidence

The quality of the evidence was assessed using GRADE CERQual and varied from moderate to high, with the majority of the evidence being of high quality. The quality of evidence was most often downgraded because of methodological limitations affecting the risk of bias and the adequacy of the findings.

Methodological limitations affecting the risk of bias were attributable to studies not critically reflecting on the researchers' roles in the research, not describing methods to maintain ethical standards, or not discussing methods to ensure credibility, such as triangulation or participant validation.

The confidence in the adequacy of the evidence was downgraded as a result of data saturation not being reached. This was a result of evidence only being available from one study, which meant that themes were under-developed and analysing further data would likely reveal new data and concepts.

Benefits and harms

The evidence identified several benefits of the recommendations including people being better prepared for treatment, experiencing a faster recovery and being better able to manage side effects and enhance their quality of life post-discharge.

The evidence showed the importance of sharing information continuously throughout the treatment process. Based on the evidence as well as their expertise, the committee agreed that all information shared, regardless of topic, should be timely and in a manner that is sensitive to the person's individual needs and preferences and taking into account the individuals circumstances and coexisting conditions, in line with NICE guideline on patient experience in adult NHS services (CG138) and NICE guideline on decision-making and mental capacity (NG108).

The evidence showed that people needed to be made aware of all of the treatment options available to them so as to better inform their treatment decision making process. The evidence also showed that it is also important to inform the people of potential changes to their care, particularly information needs specific to people receiving surgery included the need to have a flexible plan during surgery and information on stomas.

Based on their experience, the committee agreed that Enhanced Recovery After Surgery (ERAS) protocols and their value should be explained as they would allow for people to be aware of what changes they may need to make to prepare for treatment and also be able to actively manage their symptoms during and after treatment. The committee noted from their clinical experience that many people are unaware of ERAS and that a lack of understanding of the value and importance of protocols leads to noncompliance.

The evidence showed the importance of giving information on dietary adjustments to prevent issues with bowel function and potential changes to sexual function after surgery. The evidence also showed that people would have liked to receive information about potential medical problems arising from the treatment, such as bleeding from the rectum. The committee agreed that appropriate specialists, such as dietitians or stoma professionals, should be involved in discussing potential side effects with the patient.

The committee noted that there was no evidence on information needs regarding neuropathy (caused by some chemotherapy drugs) and therefore discussed this based on their experience. During and after treatment, the committee highlighted the need for people to be informed of possible short-term, long-term, potentially permanent or late side-effects of surgical and non-surgical treatments (particularly radiotherapy or chemotherapy). The committee agreed that people should be told about the importance of monitoring side effects during non-surgical treatment in order to try to prevent permanent damage. The committee agreed that colorectal cancer and the potential consequences of the treatments can have a major impact on people’s mental and emotional life as well as influence their self-perception and social identity. This could mean changes from being a previously fit person to being someone with physical or mental problems, needing care and help from others, and potentially having limited life expectancy.

The committee agreed that it is important to prepare people for discharge after treatment by giving information about a number of issues that may impact their everyday life and quality of life. The evidence showed that after receiving treatment people wanted to receive guidance on physical activity as well as practical advice on dietary adaptations following surgical treatment, what foods to avoid to prevent diarrhoea and flatulence or other bowel dysfunction. Based on the evidence and the committee’s experience, people might also benefit from advice on weight management and life style choices. The evidence showed that people wanted to know how long the recovery after surgery would take. Finally, the committee agreed, based on their experience that it is important that people are made aware how, when and where to seek help if side effects of the cancer or its treatment become problematic.

Cost effectiveness and resource use

There was no economic evidence on the cost-effectiveness of information provision to people before, during and after treatment for colorectal cancer.

The committee expressed the view that providing information regarding colorectal cancer treatment, including what to expect, recovery, prognosis and lifestyle changes are integral parts of most services and providing such supplementary advice would have only modest resource implications, if any, which are justifiable as these principles and factors are deemed essential in ensuring the success of care in people receiving treatment for colorectal cancer.

Similarly, the committee was of the view that staff training in providing effective support to people being treated for colorectal cancer undertaken by professionals (including medical staff) would not incur significant extra resource implications. The committee expressed the view that the cost of providing training of professionals is relatively small, taking into account that it has the potential to significantly change the behaviour of professionals in meaningful and positive ways (for example, making patients fully aware of treatment options, better preparing patients for treatment and facilitating patients to manage post-treatment symptoms) and making their overall interactions more efficient when dealing with patients. Overall, the committee considered that such staff training is expected to lead to savings to the NHS.

Other factors the committee took into account

The committee highlighted several moderated health forums and websites that provide reputable information on treatment for colorectal cancer and discussed the need for there to be greater awareness of the resources.

The committee recognised that information sharing and shared decision making may be more difficult with people with learning difficulties and people with dementia. It is important that people's co-existing conditions, personal circumstances and mental capacity are taken into consideration when providing information about treatment options and about care in general. Therefore, a reference to NICE guideline on patient experience in adult NHS services (CG138) and NICE guideline on decision-making and mental capacity (NG108).

Given the absence of the published evidence about information needs related to peripheral neuropathy the committee discussed making a research recommendation about the information needs of people with colorectal cancer regarding long-term severe peripheral neuropathy following chemotherapy. Following their discussion the committee decided not to make this research recommendation because it was not considered a priority in comparison to the other research topics within this guideline. Implementing Enhanced Recovery After Surgery (ERAS) protocols and ensuring compliance was also discussed as a potential research topic, but this was outside the scope of the evidence review protocol.

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Appendices

Appendix A – Review protocol

Review protocol for review question: What are the information needs of people prior, during and after treatment for colorectal cancer?

Table 3: Review protocol for information needs of people prior, during and after treatment for colorectal cancer

Field (based on PRISMA-P)	Content
Review question in guideline	What are the information needs of people prior, during and after treatment for colorectal cancer?
Type of review question	Qualitative
Objective of the review	The objective of this review is to determine the information needs and the gaps in current provision of information for people undergoing treatment for colorectal cancer.
Eligibility criteria – population/disease/condition/issue/domain	Adult patients who are undergoing or have undergone treatment (surgical and/or oncological) for colorectal cancer Exclusions: • Family members or carers • Health care professionals
Eligibility criteria – intervention(s)/exposure(s)/prognostic factor(s)	Phenomenon of interest: Information needs in regard to: • bowel function • sexual function & fertility • diet/nutrition • neuropathy • lifestyle factors – social life, exercise, employment
Eligibility criteria – comparator(s)/control or reference (gold) standard	Context: Information needs for people prior, during and after treatment for colorectal cancer
Outcomes and prioritisation	Qualitative themes Themes will be identified from the literature, but will relate to the context of the information needs.
Eligibility criteria – study design	• Systematic reviews of qualitative studies (meta-syntheses) • Qualitative studies using interviews or focus groups • Surveys (from which only qualitative data will be included)
Other inclusion exclusion criteria	Inclusion: • English-language • Published full texts • All settings will be considered that consider medications and treatments available in the UK • Studies published 1997 onwards

Field (based on PRISMA-P)	Content
	Studies published post 1997 will be considered for this review question because the guideline committee considered that treatment techniques, and thus information needs, have evolved and evidence prior to 1997 would no longer be relevant. Exclusion: • Commentaries or programme descriptions
Proposed sensitivity/sub-group analysis, or meta-regression	Where possible, consideration should be given to how information needs might differ: • For different ethnic groups • Between men and women • For people of different ages • For people with language barriers • For people with learning difficulties.
Selection process – duplicate screening/selection/analysis	Sifting, data extraction, appraisal of methodological quality and GRADE-CERQual assessment will be performed by the systematic reviewer. Resolution of any disputes will be with the senior systematic reviewer and the Topic Advisor. Quality control will be performed by the senior systematic reviewer. Dual sifting will be undertaken for this question for a random 10% sample of the titles and abstracts identified by the search.
Data management (software)	Microsoft Excel will be used to organise data into themes. NGA STAR software will be used for study sifting, data extraction, recording quality assessment using checklists and generating bibliographies/citations.
Information sources – databases and dates	Potential sources to be searched (to be confirmed by the Information Scientist): Medline, Medline In-Process, CCTR, CDSR, DARE, HTA, Embase, CINAHL, Web of Science, ASSIA, Social Sciences Abstracts Limits (e.g. date, study design): Apply standard animal/non-English language exclusion Dates: from 1997
Identify if an update	Not an update
Author contacts	https://www.nice.org.uk/guidance/indevelopment/gid-ng10060 Developer: NGA
Highlight if amendment to previous protocol	Not applicable.
Search strategy – for one database	For details please see appendix B.
Data collection process – forms/duplicate	A standardised evidence table format will be used, and published as appendix D (clinical evidence tables) or H (economic evidence tables).

Field (based on PRISMA-P)	Content
Data items – define all variables to be collected	For details please see evidence tables in appendix D (clinical evidence tables) or H (economic evidence tables).
Methods for assessing bias at outcome/study level	The methodological quality of each study will be assessed using the Critical Appraisal Skills Programme (CASP) tool.
Criteria for quantitative synthesis (where suitable)	Not applicable.
Methods for analysis – combining studies and exploring (in)consistency	Appraisal of methodological quality: The quality of the evidence for a theme (i.e. across studies) will be assessed using GRADE-CERQual, a process like GRADE that is adapted for qualitative information. Synthesis of data: Thematic content analysis will be used to synthesise the qualitative data. It is a qualitative analytic method that identifies and reports recurrent themes. Thematic analysis is used in qualitative research to focus on examining themes within data and goes beyond counting phrases or words to identifying implicit and explicit ideas within the data. A theme map may also be presented if there is sufficient information identified in the search.
Meta-bias assessment – publication bias, selective reporting bias	Not applicable.
Assessment of confidence in cumulative evidence	For details please see sections 6.4 and 9.1 of Developing NICE guidelines: the manual
Rationale/context – Current management	For details please see the introduction to the evidence review.
Describe contributions of authors and guarantor	A multidisciplinary committee developed the guideline. The committee was convened by The National Guideline Alliance and chaired by Peter Hoskin in line with section 3 of Developing NICE guidelines: the manual. Staff from The National Guideline Alliance undertook systematic literature searches, appraised the evidence, conducted meta-analysis and cost-effectiveness analysis where appropriate, and drafted the guideline in collaboration with the committee. . For details please see Supplement 1.
Sources of funding/support	The NGA is funded by NICE and hosted by the Royal College of Obstetricians and Gynaecologists
Name of sponsor	The NGA is funded by NICE and hosted by the Royal College of Obstetricians and Gynaecologists
Roles of sponsor	NICE funds the NGA to develop guidelines for those working in the NHS, public health, and social care in England
PROSPERO registration number	Not registered

ASSIA: Applied Social Sciences Index and Abstracts; CASP: Critical Appraisal Skills Programme; CCTR: Cochrane Central Register of Controlled Trials; CDSR: Cochrane Database of Systematic Reviews; CERQual; Confidence in the Evidence from Reviews of Qualitative Research; CINAHL: Cumulative Index to Nursing and Allied Health Literature; DARE: Database of Abstracts of Reviews of Effects; GRADE: Grading of Recommendations Assessment, Development and Evaluation; HTA: Health Technology Assessment; NGA: National Guideline Alliance; NHS: National Health Service; NICE: National Institute for Health and Care Excellence

Appendix B – Literature search strategies

Literature search strategies for review question: What are the information needs of people prior, during and after treatment for colorectal cancer?

Database: Embase/Medline/PsycInfo

Last searched on: 14/02/2018

#	Search
1	exp colorectal cancer/ or exp colon tumor/ or exp rectum tumor/
2	1 use oemezd
3	exp Colorectal Neoplasms/ or exp Colonic Neoplasms/ or exp Rectal Neoplasms/
4	3 use prmz
5	((colorect* or colo rect*) adj3 (cancer* or neoplas* or oncolog* or malignan* or tumo?r* or carcinoma* or adenocarcinoma*)).ti,ab.
6	((colon or colonic) adj3 (cancer* or neoplas* or oncolog* or malignan* or tumo?r* or carcinoma* or adenocarcinoma*)).ti,ab.
7	((rectal* or rectum*) adj3 (cancer* or neoplas* or oncolog* or malignan* or tumo?r* or carcinoma* or adenocarcinoma*)).ti,ab.
8	or/2,4-7
9	exp health information management/mt, og, st or exp information services/mt, og, st or exp Focus Groups/ or exp Social Support/ or exp comprehension/ or exp Consumer Advocacy/ or Pamphlets/ or exp Audiovisual Aids/ or exp Internet/ or communication/ or exp patient education as topic/ or exp Self-Help Groups/ or exp Choice Behavior/ or exp Decision Making/ or exp Clinical Decision-Making/ or exp decision support techniques/ or exp Patient Participation/ or exp "Referral and Consultation"/ or exp "Surveys and Questionnaires"/ or exp Patient Satisfaction/ or exp Patient Preference/ or exp Preoperative Care/mt [Methods]
10	9 use prmz
11	exp publication/ or exp information processing/ or exp social support/ or exp comprehension/ or exp consumer advocacy/ or exp audiovisual aid/ or exp Internet/ or exp interpersonal communication/ or exp patient education/ or exp self help/ or exp decision making/ or exp clinical decision making/ or exp decision support system/ or exp nurse patient relationship/ or exp patient participation/ or exp patient care planning/ or exp patient referral/ or exp questionnaire/ or exp health care survey/ or exp patient satisfaction/ or exp patient preference/ or exp patient attitude/ or exp preoperative care/ or exp information service/ or exp information seeking/ or exp medical information/ or exp visual information/ or exp patient information/ or exp information dissemination/ or exp consumer health information/ or exp access to information/ or exp information/ or exp information center/
12	11 use oemezd
13	exp health information management/ or exp Social Support/ or exp comprehension/ or exp Consumer Behavior/ or exp Consumer Attitudes/ or exp Advocacy/ or exp Consumer Satisfaction/ or exp information services/ or exp Health Education/ or exp Health Care Utilization/ or exp Help Seeking Behavior/ or exp Health Care Seeking Behavior/ or exp Client Education/ or exp Health Promotion/ or exp Reading Materials/ or exp Health Care Services/ or exp Educational Audiovisual Aids/ or exp Films/ or exp internet/ or exp written communication/ or exp verbal communication/ or exp interpersonal communication/ or exp communication/ or exp Support Groups/ or exp Self-Help Techniques/ or exp Choice Behavior/ or exp Clinical Practice/ or exp Decision Support Systems/ or exp Decision Making/ or exp Client Participation/ or exp Professional Referral/ or exp Professional Consultation/ or exp Questionnaires/ or exp Surveys/ or exp Client Satisfaction/ or exp Treatment Compliance/ or exp Client Attitudes/ or exp Preferences/
14	13 use psyh
15	(pamphlet* or leaflet* or diary or diaries or focus group* or booklet* or guidebook*or guidance or sheet* or prompt* or coach* or check?list* or written or write* or question* or survey* or card* or helpcard* or video* or tape* or cd* or film* or dvd* or telephone* or phone* or computer* or internet or electronic or communicat* or consult* or information material* or information deliver* or interactive session* or time* or timing* or post?consultation* or pre?treatment* or (face* adj1 face*)).ti,ab.
16	((patient* or consumer* or care*or personal or interpersonal or individual) adj (educat* or skill* or teach* or train* or coach* or information or pathway* or decision* or choice* or prefer* or participat* or value* or involve*)).ti,ab.
17	((inform* or support* or decision*) adj (need* or web*1 or electronic* or print* or tool* or method* or group* or meet* or aid* or support*)).ti,ab.
18	or/10,12,14-17
19	exp body image/ or exp self concept/ or exp anxiety/ or exp depression/ or exp postoperative complications/pc or exp stents/ae or exp constipation/pc or exp diarrhea/pc or exp fecal incontinence/pc or exp urinary incontinence/pc or exp "diet, food, and nutrition"/ or exp peripheral nervous system diseases/pc or exp pregnancy/ph or exp fertility/ph or exp sexual dysfunction, physiological/ or exp sexual dysfunctions, psychological/ or exp life style/ or exp employment/ or exp exercise/ or exp "quality of life"/
20	19 use prmz
21	exp body image/ or exp self concept/ or exp postoperative complication/ or exp stent/am or exp constipation/pc, rh or exp diarrhea/pc, rh or exp feces incontinence/pc, rh or exp urine incontinence/pc, rh or exp diet/ or exp food/ or exp nutrition education/ or exp nutrition/ or exp neuropathy/ or exp pregnancy/ or exp fertility/ or exp sexual dysfunction/ or exp lifestyle/ or exp employment/ or exp exercise/ or exp "quality of life"/
22	21 use oemezd

#	Search
23	exp body image/ or exp self-concept/ or exp postsurgical complications/ or exp "side effects (treatment)"/ or exp anxiety/ or exp "depression (emotion)"/ or exp medical therapeutic devices/ or exp constipation/ or exp diarrhea/ or exp urinary incontinence/ or exp fecal incontinence/ or exp diets/ or exp food/ or exp nutrition/ or exp neuropathy/ or exp pregnancy/ or exp fertility/ or exp female sexual dysfunction/ or exp sexual function disturbances/ or exp erectile dysfunction/ or exp sexuality/ or exp lifestyle/ or exp employment status/ or exp exercise/ or exp Physical Activity/ or exp "quality of life"/
24	23 use psyh
25	(bowel function or stoma care or stress* or distress* or body image or sexual function* or self?esteem* or diarr?hea* or bloat* or wind or gas or flatulence or complicat* or neuropath* or incontinen* or pregnan* or fertility or life style or employ* or exercise* or sport* or social).ti,ab.
26	((nutrition* adj advi?e*) or (diet* adj advi?e*)).ti,ab.
27	(stoma* adj (reversal* or removal*)).ti,ab.
28	(stent* adj insert*).ti,ab.
29	temporar* ileostomy*.ti,ab.
30	or/20,22,24-29
31	8 and 18 and 30
32	(conference abstract or letter).pt. or letter/ or editorial.pt. or note.pt. or case report/ or case study/ use oemezd
33	Letter/ or editorial/ or news/ or historical article/ or anecdotes as topic/ or comment/ or case report/ use prmz
34	(letter or comment* or abstracts).ti.
35	or/32-34
36	randomized controlled trial/ use prmz
37	randomized controlled trial/ use oemezd
38	random*.ti,ab.
39	or/36-38
40	35 not 39
41	(animals/ not humans/) or exp animals, laboratory/ or exp animal experimentation/ or exp models, animal/ or exp rodentia/ use prmz
42	(animal/ not human/) or nonhuman/ or exp animal experiment/ or exp experimental animal/ or animal model/ or exp rodent/ use oemezd
43	exp animals/ or exp Animal Models/ or exp Rodents/ or exp Mice/ or exp RATS/
44	43 use psyh
45	(rat or rats or mouse or mice).ti.
46	40 or 41 or 42 or 44 or 45
47	31 not 46
48	(interview* or experience*).mp.
49	48 use prmz
50	exp HEALTH CARE ORGANIZATION/ use oemezd
51	(interview* or experience* or qualitative*).tw.
52	49 or 50 or 51
53	47 and 52
54	limit 53 to english language
55	limit 54 to yr="2008 -Current"

Database: Cochrane Library

Last searched on: 14/02/2018

#	Search
1	MeSH descriptor: [Colorectal Neoplasms] explode all trees
2	MeSH descriptor: [Health Information Management] explode all trees
3	MeSH descriptor: [Information Services] explode all trees
4	MeSH descriptor: [Focus Groups] explode all trees
5	MeSH descriptor: [Social Support] explode all trees
6	MeSH descriptor: [Comprehension] explode all trees
7	MeSH descriptor: [Consumer Advocacy] explode all trees
8	MeSH descriptor: [Pamphlets] explode all trees
9	MeSH descriptor: [Audiovisual Aids] explode all trees
10	MeSH descriptor: [Internet] explode all trees
11	MeSH descriptor: [Communication] explode all trees
12	MeSH descriptor: [Patient Education as Topic] explode all trees
13	MeSH descriptor: [Self-Help Groups] explode all trees
14	MeSH descriptor: [Choice Behavior] explode all trees
15	MeSH descriptor: [Decision Making] explode all trees
16	MeSH descriptor: [Clinical Decision-Making] explode all trees
17	MeSH descriptor: [Decision Support Techniques] explode all trees
18	MeSH descriptor: [Patient Participation] explode all trees
19	MeSH descriptor: [Referral and Consultation] explode all trees
20	MeSH descriptor: [Surveys and Questionnaires] explode all trees
21	MeSH descriptor: [Patient Satisfaction] explode all trees

#	Search
22	MeSH descriptor: [Patient Preference] explode all trees
23	MeSH descriptor: [Preoperative Care] explode all trees and with qualifier(s): [Methods - MT]
24	pamphlet* or leaflet* or diary or diaries or focus group* or booklet* or guidebook* or guidance or sheet* or prompt* or coach* or check?list* or written or write* or question* or survey* or card* or helpcard* or video* or tape* or cd* or film* or dvd* or telephone* or phone* or computer* or internet or electronic or communicat* or consult* or information material* or information deliver* or interactive session* or time* or timing* or post?consultation* or pre?treatment* or inform* or support* or decision* or pathway* or choice* or prefer* or participat* or value* or involve*
25	bowel function* or stoma or stent* or body image or sexual function* or self?esteem* or diarr?hea* or bloat* or wind or gas or flatulence or complicat* or neuropath* or incontinen* or pregnan* or fertility or life style or employ* or exercise* or sport* or social or sexualit* or diet* or food or nutrition*
26	#2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24 or #25
27	#1 and #26 Publication Year from 2008 to 2018

Database: Cinahl

Last searched on: 19/02/2018

S4	S1 AND S2	Limiters – Publication Year: 2008-2018 Narrow by Language0: -english
S3		S1 AND S2
S2		colorectal cancer patients
S1		health information management OR information services OR Social Support OR patient education OR Self-Help Groups OR Choice Behavior OR Decision Making OR decision support techniques OR Patient Participation OR Patient Satisfaction OR Patient Preference or Internet

Database: Web of Science

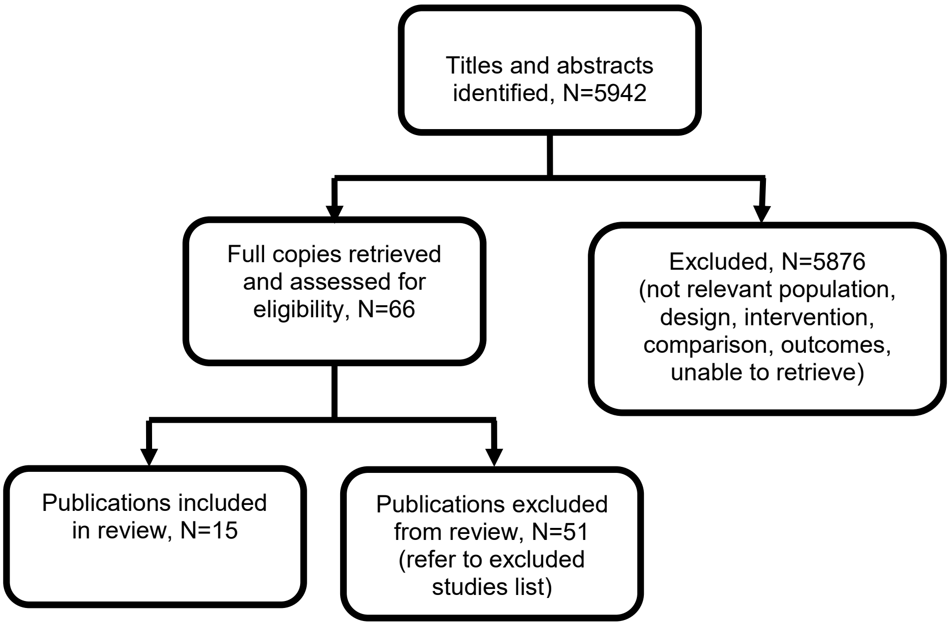
Last searched on: 19/02/2018

#	
6	(#5) AND LANGUAGE: (English)
5	#4 AND #3
4	ts=interview* or ts=experience* or ts=qualitative stud*
3	#2 AND #1
2	ts=health information management OR ts=information services OR ts=Social Support OR ts=patient education OR ts=Self-Help Group* OR ts=Choice Behavior OR ts=Decision Making OR ts=decision support techniques OR ts=Patient Participation OR ts=Patient Satisfaction OR ts=Patient Preference* or ts=Internet or ts=Focus Group* or ts=Comprehension or ts=Consumer Advocacy or ts=Pamphlet* or ts=Audiovisual aid* or ts=Communication or ts=Survey* or ts=Questionnaire* or ts=unmet need* or ts=distress* or ts=psychological stress* or ts="quality of life"
1	ts=colorectal cancer or ts=colon* cancer or ts=rectal cancer

1 Appendix C – Clinical evidence study selection

2 Clinical study selection for: What are the information needs of people prior, 3 during and after treatment for colorectal cancer?

Figure 4: Study selection flow chart



4

1 Appendix D – Clinical evidence tables

2 Clinical evidence tables for review question: What are the information needs of people prior, during and after treatment for 3 colorectal cancer?

4 **Table 4: Clinical evidence tables**

Study details	Participants	Methods	Themes	Quality assessment
Full citation Anderson, A. S., Steele, R., Coyle, J., Lifestyle issues for colorectal cancer survivors--perceived needs, beliefs and opportunities, Supportive Care in Cancer, 21, 35-42, 2013 **Ref Id** 789222 **Country/ies where the study was carried out** UK **Study type** Focus groups **Aim of the study** The aim of the study was to explore patients' perceptions of their needs in regard to advice diet, activity and beliefs about the role of lifestyle for reducing disease recurrence.	**Sample size** N= 40 **Characteristics** Male, n (%)= 20 (50) Age, years, mean (SD)= 60 (12.16) BMI, mean (SD)= 26.2 (4.85) White British, n (%)= 40 (100) **Inclusion criteria** Colorectal cancer survivors who were not undergoing active cancer-related treatment **Exclusion criteria** Not reported **Interventions** Not applicable	**Details** **Sampling** Purposive sampling through Bowel Cancer UK and local colorectal cancer nurse specialists **Setting** Six community locations in Scotland and England. **Data collection** All participants completed a short questionnaire on demographic background, health behaviours, height and weight. Focus groups lasted 1.5-2 hours each and were moderated by an experienced qualitative researcher with a topic guide developed to steer the discussion, but new topics were allowed to emerge from the participants. Data collection and analysis occurred at the same time so that new concepts could be fed	**Results** After treatment • Lifestyle ○ Diet ○ Managing bodily functions	**Limitations reported by study authors** Participants were sampled purposively and thus were not representative of the wider population. Many of the participants were from a college/university level of education and may not truly reflect the views of more disadvantaged people. **Other information** The assessment of the quality of the study was performed using the CASP checklist for qualitative studies 1. Was there a clear statement of the aims of the research? Yes 2. Is a qualitative methodology appropriate? Yes 3. Was the research design appropriate to address the aims of the research? Not clear - the authors did not justify the research design. 4. Was the recruitment strategy

Study details	Participants	Methods	Themes	Quality assessment
Study dates Not reported **Source of funding** Bowel Cancer UK		into subsequent focus groups and further explored. Data collection continued until thematic saturation was reached and new data did not add to the development of theories. **Data analysis** The focus groups were audio-recorded and transcribed. The transcripts were assessed using framework analysis, which involved the researchers first becoming familiar with the first 5 transcripts and performing a first round of coding. These codes were then compared with concepts from the literature. A thematic framework was developed to reference the remaining data. Thematic maps were created to link categories and concepts to generate new meanings. These new meanings were mapped and interpreted.		appropriate to the aims of the research? Yes 5. Was the data collected in a way that addressed the research issue? Yes 6. Has the relationship between researcher and participants been adequately considered? No (authors did not critically examine their own role, potential bias and influence during formulation of the research question or data collection). 7. Have ethical issues been taken into consideration? Can't tell (Approval was sought from the ethics committee and participants received information sheets 1 week prior to the focus groups, but the study did not provide information on how the research was explained to participants or how the researchers managed the effects of the study on the participants during and after the focus groups) 8. Was the data analysis sufficiently rigorous? Yes 9. Is there a clear statement of findings? Can't tell (Researchers did not discuss the credibility of their findings [e.g. triangulation, respondent validation, more than one

Study details	Participants	Methods	Themes	Quality assessment
				analyst]). 10. How valuable is the research? Authors consider the findings in relation to current research-based literature; identify new areas where research is necessary
Full citation Beaver, K., Latif, S., Williamson, S., Procter, D., Sheridan, J., Heath, J., Susnerwala, S., Luker, K., An exploratory study of the follow-up care needs of patients treated for colorectal cancer, Journal of clinical nursing, 19, 3291-3300, 2010 **Ref Id** 789423 **Country/ies where the study was carried out** UK **Study type** Exploratory qualitative study through in depth interviews **Aim of the study**	**Sample size** N=27 **Characteristics** Male, n (%)= 14 (51.9) Age, years 59-64, n (%)= 4 (14.8) 65-74, n (%)= 14 (51.9) 75+, n (%) 9 (33.3) Surgery, n (%)= 27 (100) Radiotherapy, n (%)= 4 (14.8) Chemotherapy, n (%)= 7 (25.9) Never had a stoma, n (%)= 13 (48.1) Permanent stoma, n (%)= 11 (40.7) Stoma temporary/reversed, n (%)= 3 (11.1) **Inclusion criteria** Patients who completed active treatment and had no current clinical problems who were attending surgical outpatient clinics at a large district general hospital in the north-west of England. **Exclusion criteria**	**Details** Eligible patients were approached by clinicians following consultation appointments. Those who expressed interest were introduced to a nurse researcher who discussed the study and provided a study information sheet and consent form. Patients who agreed to participate verbally agreed and signed the consent form. Before commencement of interviews, consent was re-established to audio-record interviews and ensured the confidentiality of interview data. **Sampling** Purposive sampling of patients who had been discharged from hospital wards and/or oncology departments and were returning to hospital clinics for routine monitoring of their condition. **Setting** In patients' homes	**Results** Prior • Surgery ○ What to expect during surgery ○ What to expect after surgery • Timing and delivery of information After • Lifestyle ○ Diet • Medical information ○ Stoma care	**Limitations reported by study authors** The qualitative methodology used in this study does not allow for generalisations to the wider population of patients with colorectal cancer or to other patient groups. As the study was conducted in a part of the north-west of England that has a predominantly white British population, this was reflected in the sample of participants recruited. **Other information** The assessment of the quality of the study was performed using the CASP checklist for qualitative studies 1. Was there a clear statement of the aims of the research? Yes 2. Is a qualitative methodology appropriate? Yes 3. Was the research design appropriate to address the aims of the research? Yes

Study details	Participants	Methods	Themes	Quality assessment
The aim of the study was to assess patients' perceptions of their experiences of follow-up care after treatment for colorectal cancer. **Study dates** Not reported **Source of funding** Cancer Research UK	Patients who had not completed treatment or who demonstrated signs of recurrent disease. **Interventions** Not applicable	**Data collection** The interview guide consisted of open-ended questions related to the aims of the study and a short survey of participants' demographic information. Participants were allocated an identification number and all identifying features were removed from interview transcripts. **Data analysis** Interviews were transcribed verbatim and coded manually. Authors used thematic analysis to identify themes. The research team collaborated to verify, confirm, and qualify themes. Transcripts were read and re-read independently by 5 research staff. Researchers then made a list of all the themes and eliminated duplicates and refined themes until a final list of themes was formed.		4. Was the recruitment strategy appropriate to the aims of the research? Yes 5. Was the data collected in a way that addressed the research issue? Yes 6. Has the relationship between researcher and participants been adequately considered? Can't tell (researchers did not state whether they critically examined their own role in the research). 7. Have ethical issues been taken into consideration? Yes 8. Was the data analysis sufficiently rigorous? Yes 9. Is there a clear statement of findings? Yes 10. How valuable is the research? Researchers discuss the contribution the study makes to existing literature; and identify new areas where research is necessary

Study details	Participants	Methods	Themes	Quality assessment
Full citation Brown, S., Greenfield, D., Thompson, J., Knowledge and awareness of long-term and late treatment consequences amongst colorectal cancer survivors: A qualitative study, European journal of oncology nursing : the official journal of European Oncology Nursing Society, 20, 191-198, 2016 **Ref Id** 789624 **Country/ies where the study was carried out** UK **Study type** Semi-structured interviews **Aim of the study** The aim of the study was to assess patient knowledge and awareness of long-term and late onset treatment consequences amongst	**Sample size** N=19 **Characteristics** Male, n (%)= 11 (57.9) Age, years, mean (SD)= White British, n (%)= 18 (94.7) Polish, n (%)= 1 (5.3) No stoma, n (%)= 9 (47.4) Temporary stoma, n (%)= 6 (31.6) Permanent stoma, n (%)= 4 (21.1) Surgery, n (%)= 19 (100) Chemotherapy, n (%)= 10 (52.6) Radiotherapy, n (%)= 5 (26.3) **Inclusion criteria** At least 12 months post treatment, 18 years of age or older, able to communicate in English, no terminal diagnosis or dementia **Exclusion criteria** Not reported **Interventions** Not applicable	**Details** Patients attending the nurse-led colorectal surgical clinic were made aware of the study. Interested patients were introduced to the researcher who gave them information about the study. Patients completed the consent process in the clinic or at the beginning of their interview. **Sampling** Convenience sampling **Setting** Participants' homes **Data collection** Interviews were audio-recorded and were based on a topic guide derived from a literature review that focused on treatment impact, awareness and understanding of treatment and its consequences, risk and support services. Interviews were 20-60 minutes in length and were transcribed verbatim with identification numbers used to preserve anonymity. **Data analysis** The researchers used framework analysis with interviews transcribed into NVivo 10 software for familiarisation	**Results** Prior • Surgery ○ What to expect after surgery • Recovery ○ Diet	**Limitations reported by study authors** Potential participation bias from patients self-selecting to enter the study. Nursing staff's awareness of study may have influenced their treatment of the participants. Participants were from one clinic and therefore participants from different locations would be needed to gain a truer understanding of knowledge and awareness across the whole colorectal cancer population. **Other information** The assessment of the quality of the study was performed using the CASP checklist for qualitative studies 1. Was there a clear statement of the aims of the research? Yes 2. Is a qualitative methodology appropriate? Yes 3. Was the research design appropriate to address the aims of the research? Yes 4. Was the recruitment strategy appropriate to the aims of the research? Yes 5. Was the data collected in a way that addressed the research issue? Yes 6. Has the relationship between

Study details	Participants	Methods	Themes	Quality assessment
colorectal cancer survivors **Study dates** January-April 2014 **Source of funding** None reported		and organisation, identification of initial themes and coding. Data was organised using the themes and framework heading to show links between the data.		researcher and participants been adequately considered? Yes 7. Have ethical issues been taken into consideration? Yes 8. Was the data analysis sufficiently rigorous? Yes 9. Is there a clear statement of findings? Yes 10. How valuable is the research? Researchers discuss the contribution the study makes to existing literature; and identify new areas where research is necessary
Full citation Dowswell, G., Ismail, T., Greenfield, S., Clifford, S., Hancock, B., Wilson, S., Men's experience of erectile dysfunction after treatment for colorectal cancer: qualitative interview study, British Medical Journal, 343, 2011 **Ref Id** 790123 **Country/ies where the study was carried out** UK	**Sample size** N=28 **Characteristics** Male, n (%)= 28 (100) Age, years, mean (SD)= 59.4 (10) Surgery for colorectal cancer, n (%)= 24 (89) White, n (%)= 24 (89) In a sexual relationship, n (%)= 17 (61) **Inclusion criteria** Men who had received treatment for colorectal cancer **Exclusion criteria** Not reported **Interventions**	**Details** Participants who had been diagnosed with colorectal cancer in a West Midlands hospital and participated in a prevalence study of erectile dysfunction were invited to take part in the qualitative study. **Sampling** Purposive sampling was used to select participants with a broad range of views and experiences **Setting** Participants' homes or healthcare location **Data collection** The authors used semi-structured interviews that	**Results** Prior • Recovery ○ Effect of treatment on sexual function After • Medical information ○ Sex specific issues	**Limitations reported by study authors** Unfamiliarity or discomfort may have resulted in men failing to be coherent or explicit when discussing their experiences or preferences. **Other information** The assessment of the quality of the study was performed using the CASP checklist for qualitative studies 1. Was there a clear statement of the aims of the research? Yes 2. Is a qualitative methodology appropriate? Yes 3. Was the research design appropriate to address the aims

Study details	Participants	Methods	Themes	Quality assessment
Study type Semi-structured interviews **Aim of the study** The aim of the study was to assess the experiences of men after treatment for colorectal cancer and identify barriers to accessing services. **Study dates** March-June 2009 **Source of funding** National Institute for Health Research	Not applicable	focused on beliefs about erectile dysfunction, impact on self-perception and relationships, satisfaction with information, and experience of treatment. Interviews were audio-recorded and transcribed verbatim. **Data analysis** Analysis occurred concurrently with data collection so that emergent themes could be explored in later interviews. Analysis was performed using framework analysis by three researchers using NVivo8 software to code and review themes. The research team discussed the coding, which led to the development of a thematic framework that included manifest and latent themes.		of the research? Yes 4. Was the recruitment strategy appropriate to the aims of the research? Yes 5. Was the data collected in a way that addressed the research issue? Yes 6. Has the relationship between researcher and participants been adequately considered? Can't tell (researchers did not state whether they critically examined their own role in the research). 7. Have ethical issues been taken into consideration? Can't tell (insufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained). 8. Was the data analysis sufficiently rigorous? Can't tell (Researchers did not critically examine their own role during the analysis and selection of data for presentation). 9. Is there a clear statement of findings? Yes 10. How valuable is the research? Researchers discuss the contribution the study makes to existing literature; and identify new areas where research is necessary

Study details	Participants	Methods	Themes	Quality assessment
Full citation Gillis, C., Gill, M., Marlett, N., MacKean, G., GermAnn, K., Gilmour, L., Nelson, G., Wasylak, T., Nguyen, S., Araujo, E., Zelinsky, S., Gramlich, L., Patients as partners in Enhanced Recovery After Surgery: A qualitative patient-led study, BMJ Open, 7, 2017 **Ref Id** 790502 **Country/ies where the study was carried out** Canada **Study type** Focus groups **Aim of the study** The aim of the study was to explore the experiences of patients undergoing colorectal surgery within an Enhanced Recovery After Surgery (ERAS) program.	**Sample size** N=27 **Characteristics** Male, n (%)= 17 (63.0) Age, years, range= 29-89 **Inclusion criteria** Patients identified by their surgeons as participants in the ERAS program, > 18 years of age, spoke English **Exclusion criteria** Not reported **Interventions** Not applicable	**Details** Patients were provided with a consent form at the surgeon's office or during their primary hospital admission for surgery. Interested patients were then contacted by the researcher who provided study details. All of the participants sign an informed consent form prior to being interviewed or participating in a focus group. A 5-hour focus group was held in a university with 7 participants for the purpose of guiding data collection. **Sampling** Purposive sampling aimed at recruiting a sample representative of varied postoperative lengths and experiences **Setting** In a university or in hospital in the patient's hospital room **Data collection** Data collection and analysis were performed iteratively. With open coding used to identify emerging themes and guide the direction of recruitment and data collection strategies. Participants were encouraged to tell their story of surgery	**Results** Prior • Surgery ○ What to expect during surgery • Recovery ○ Accessing resources and services • Treatment decision making ○ Medical information • Timing and delivery of information During • Diet • Cancer prognosis After • Medical information ○ Medical issues	**Limitations reported by study authors** Limited generalisability **Other information** The assessment of the quality of the study was performed using the CASP checklist for qualitative studies 1. Was there a clear statement of the aims of the research? Yes 2. Is a qualitative methodology appropriate? Yes 3. Was the research design appropriate to address the aims of the research? Yes 4. Was the recruitment strategy appropriate to the aims of the research? Yes 5. Was the data collected in a way that addressed the research issue? Yes 6. Has the relationship between researcher and participants been adequately considered? Can't tell (researchers did not state whether they critically examined their own role in the research). 7. Have ethical issues been taken into consideration? Yes 8. Was the data analysis sufficiently rigorous? Yes 9. Is there a clear statement of findings? Yes

Study details	Participants	Methods	Themes	Quality assessment
Study dates July 2015 to September 2016 **Source of funding** Canadian Institutes of Health Research-Strategy for Patient-Oriented Research (SPOR)-Patient Engagement-Collaboration Grants		experience, followed by open ended questions to test emerging themes. Interviews were audio recorded and transcribed. Data saturation was achieved after 10 interviews. **Data analysis** Analysis was performed with grounded theory methods. Data was triangulated through two methods (focus groups and interviews), three phases of research, and data sources (5 hospitals and in-patient, follow-up interviews). Research colleagues were asked to review and discuss coding and themes to confirm findings and achieve investigator triangulation.		10. How valuable is the research? Researchers discuss the contribution the study makes to existing literature; and identify new areas where research is necessary
Full citation Hall, S., Gray, N., Browne, S., Ziebland, S., Campbell, N. C., Hall, Susan, Gray, Nicola, Browne, Susan, Ziebland, Sue, Campbell, Neil C., A qualitative exploration of the role of primary care in supporting colorectal cancer patients, Supportive Care in Cancer, 20, 3071-3078, 2012	**Sample size** N=30 A separate secondary analysis of 39 Healthtalkonline interviews 2001-2002 was done – but is not included in this review. **Characteristics** Male, n (%)= 17 (57) Age, years, median (IQR)= NR (37-85) **Inclusion criteria**	**Details** Participants were recruited at different stages after completion of initial treatment up to 5 years after diagnosis and efforts made to ensure representation from people with different disease stage and treatment. **Sampling** A purposive (non-probability) maximum variation sample of colorectal cancer patients resident in Northeast Scotland and Glasgow were recruited	**Results** This study contributed to the following themes: Prior • Recovery ○ Effect of treatment on sexual function After • Lifestyle ○ Diet • Medical information ○ Stoma care ○ Medical issues	**Limitations reported by study authors** None reported. **Other information** The assessment of the quality of the study was performed using the CASP checklist for qualitative studies 1. Was there a clear statement of the aims of the research? Yes 2. Is a qualitative methodology appropriate? Yes 3. Was the research design

Study details	Participants	Methods	Themes	Quality assessment
Ref Id 790630 **Country/ies where the study was carried out** UK **Study type** Semi-structured interview **Aim of the study** To explore experiences and support needs of people with colorectal cancer, to identify opportunities for primary care interventions. **Study dates** Interviews done 2001-2002, and in 2009 **Source of funding** Cancer Research UK, programme grant number C542/A6502	Not reported – participants with colorectal cancer recruited via a colorectal clinical nurse specialist in North East Scotland. **Exclusion criteria** Not reported. **Interventions** Not applicable	when attending colorectal cancer clinics and via a colorectal clinical nurse specialist. Recruitment continued until new interview data no longer added new themes or codes to the analysis. **Setting** Interviews were conducted in locations selected by the participants, usually their own home, although one participant selected a café **Data collection** A semi-structured interview schedule covered information needs, support for patients and their families and support from primary care and other professionals (themes identified from analysis of the Healthtalkonline interviews). **Data analysis** Full transcripts of the interviews were read multiple times to facilitate familiarisation with the data, and QSR NVivo software was used to code, sort and retrieve data. Themes were identified via inductive analysis.		appropriate to address the aims of the research? Yes 4. Was the recruitment strategy appropriate to the aims of the research? Yes 5. Was the data collected in a way that addressed the research issue? Yes 6. Has the relationship between researcher and participants been adequately considered? Yes – some consideration 7. Have ethical issues been taken into consideration? Yes 8. Was the data analysis sufficiently rigorous? Unclear exactly how themes were derived. 9. Is there a clear statement of findings? Yes 10. How valuable is the research? Researchers discuss the contribution the study makes to existing literature; and identify new areas where research is necessary

Study details	Participants	Methods	Themes	Quality assessment
Full citation Ho, M. Y., McBride, M. L., Gotay, C., Grunfeld, E., Earle, C. C., Relova, S., Tsonis, M., Ruan, J. Y., Chang, J. T., Cheung, W. Y., A qualitative focus group study to identify the needs of survivors of stage II and III colorectal cancer, Psycho-Oncology, 25, 1470-1476, 2016 **Ref Id** 790801 **Country/ies where the study was carried out** Canada **Study type** Focus groups **Aim of the study** The aim of the study was to identify colorectal cancer survivors' concerns in regard to physical functioning, psychological wellbeing, and social relationships.	**Sample size** N= 30 **Characteristics** Male, n (%)= 16 (53) Age, years, median (IQR)= 60 (41-75) Diagnosis of colon cancer, n (%)= 17 (57) Diagnosis of rectal cancer, n (%)= 13 (43) Stage III disease, n (%)= 28 (93) **Inclusion criteria** English-speaking patients 18 years of age or older who were diagnosed with stage II or III colorectal cancer from January 2010 to December 2011. Patients had to have completed their curative treatment in the Vancouver lower mainland, and still be alive without a documented cancer recurrence based on their ongoing attendance in follow-up clinics. **Exclusion criteria** Not reported **Interventions** Not applicable	**Details** Potential participants were mailed an invitation to participate in the study. Participants who contacted the study team were screened for eligibility. Two consent forms were provided, with participants instructed to return one to the investigators. **Sampling** Participants were identified through the British Columbia Cancer Registry. **Setting** British Columbia Cancer Agency Vancouver Centre **Data collection** The focus groups were held on weekdays and weekdays during the day and evening to accommodate participants. Each focus group had 4-8 participants and lasted 90-120 minutes at the British Columbia Cancer Agency Vancouver Centre. All sessions were audio-recorded and transcribed verbatim. **Data analysis** Analysis was performed through an iterative process that involved coding, categorising, and theme identification. Firstly,	**Results** Prior • Surgery ○ What to expect during surgery • Treatment decision making ○ Cost of care • Timing and delivery of information After • Medical information ○ Medical issues ○ Sex specific issues	**Limitations reported by study authors** Study's findings were based on retrospective patient narratives, which could have been subject to recall bias. The small sample size limits generalisability of findings. The participants were limited to having Stage II or III colorectal cancer, so results may not be generalisable to patients with different stages or other tumours. **Other information** The assessment of the quality of the study was performed using the CASP checklist for qualitative studies 1. Was there a clear statement of the aims of the research? Yes 2. Is a qualitative methodology appropriate? Yes 3. Was the research design appropriate to address the aims of the research? Yes 4. Was the recruitment strategy appropriate to the aims of the research? Yes 5. Was the data collected in a way that addressed the research issue? Yes 6. Has the relationship between researcher and participants been adequately considered?

Study details	Participants	Methods	Themes	Quality assessment
Study dates January 2010 to December 2011 **Source of funding** Not reported		short segments of the transcripts tests were coded independently using NVivo 9 software. Related codes were grouped and relating meanings and ideas were re-examined. After half of the total transcripts were analysed, three investigators convened to discuss the findings and ensure face validity. The remaining interviews were then analysed and audited by another member of the research team. The research team believed that thematic saturation had been met by the end of the analysis and additional information was not needed.		Can't tell (researchers did not state whether they critically examined their own role in the research) 7. Have ethical issues been taken into consideration? Yes 8. Was the data analysis sufficiently rigorous? Yes 9. Is there a clear statement of findings? Yes 10. How valuable is the research? Researchers discuss the contribution the study makes to existing literature; and identify new areas where research is necessary
Full citation Hoedjes, M., De Kruif, A., Mols, F., Bours, M., Beijer, S., Winkels, R., Westerman, M. J., Seidell, J. C., Kampman, E., An exploration of needs and preferences for dietary support in colorectal cancer survivors: A mixed-methods study, PLoS ONE, 12 (12) (no pagination), 2017 **Ref Id**	**Sample size** N= 16 **Characteristics** Male, n (%)= 10 (62.5) Age, years, mean (SD)= BMI classification - overweight, n (%)= 8 (50) BMI classification - obese, n (%), n (%)= 8 (50) Stage I colorectal cancer, n (%)= 3 (18.8) Stage II colorectal cancer, n (%)= 11 (68.8) Stage III colorectal cancer, n (%)= 2 (12.5)	**Details** **Sampling** Eligible participants from the COLON-study were invited to participate in one of three focus groups. **Setting** Not reported **Data collection** The focus groups were guided by a topic list based on sensitising concepts, including: the perception of a healthy lifestyle, determinants of a healthy lifestyle, and lifestyle change. Focus groups were	**Results** After • Lifestyle ○ Diet • Medical information ○ Stoma care ○ Medical issues	**Limitations reported by study authors** There was an under-representation of stage IV colorectal survivors. The need for dietary support may have been under-expressed due to the tendency towards socially desirable answers. **Other information** The assessment of the quality of the study was performed using the CASP checklist for qualitative studies 1. Was there a clear statement of the aims of the research? Yes

Study details	Participants	Methods	Themes	Quality assessment
790811 **Country/ies where the study was carried out** the Netherlands **Study type** Focus groups **Aim of the study** The aim of the study was to assess colorectal cancer survivors' needs and preferences in regard to lifestyle support **Study dates** July and December 2014 **Source of funding** Not reported	**Inclusion criteria** Colorectal cancer survivors who were part of the COLON-study and had a BMI of ≥ $27 kg/m^2$ at 6 months after diagnosis. **Exclusion criteria** Patients who were diagnosed > 1 year prior to study commencement **Interventions** Not applicable	moderated by a qualitative researcher and observed by another researcher. Focus groups were transcribed verbatim and transcripts were supplemented by field notes taken by the observer. **Data analysis** The researchers used a thematic analysis to analyse the data by performing several phases of coding. Firstly, data were openly coded. Secondly, axial coding focused on describing and ordering the codes. Thirdly, main themes were determined and categorised. Emergent themes were identified and overlapping clusters were combined so that themes were refined and linked to the research question. To increase validity, the codes were verified by another researcher until consensus was attained. Analysis took place concurrently with data collection so that results from the earlier focus groups could inform prompts in the later groups.		2. Is a qualitative methodology appropriate? Yes 3. Was the research design appropriate to address the aims of the research? Yes 4. Was the recruitment strategy appropriate to the aims of the research? Yes 5. Was the data collected in a way that addressed the research issue? Yes 6. Has the relationship between researcher and participants been adequately considered? Can't tell (researchers did not state whether they critically examined their own role in the research) 7. Have ethical issues been taken into consideration? Can't tell (insufficient details of how the research was explained to participants, did not discuss informed consent) 8. Was the data analysis sufficiently rigorous? Yes 9. Is there a clear statement of findings? Yes 10. How valuable is the research? Researchers discuss the contribution the study makes to existing literature; and identify new areas where research is necessary
Full citation	**Sample size** N= 24	**Details**	**Results** After	**Limitations reported by study authors**

Study details	Participants	Methods	Themes	Quality assessment
Maxwell-Smith, C., Zeps, N., Hagger, M. S., Platell, C., Hardcastle, S. J., Barriers to physical activity participation in colorectal cancer survivors at high risk of cardiovascular disease, Psycho-Oncology, 26, 808-814, 2017 **Ref Id** 791869 **Country/ies where the study was carried out** Australia **Study type** Semi-structured interviews **Aim of the study** The aim of the study was to identify barriers to physical activity for colorectal cancer survivors. **Study dates** Not reported **Source of funding** Not reported	**Characteristics** Male, n (%)= 11 (45.8) Age, years, mean (SD)= 69.38 (4.19) American Society for Anesthesiologists (ASA) score 2, n (%)= 15 (62.5) ASA score 3, n (%)= 9 (37.5) **Inclusion criteria** Participants were eligible if they had completed active treatment for colorectal cancer in the past 2 years and had existing morbidities that increased their cardiovascular disease risk. **Exclusion criteria** Not reported **Interventions** Not applicable	Colorectal cancer consultants at the St. John of God Subiaco Hospital sent letters to eligible participants. Participants phoned or emailed the consultant to confirm participation and were then contacted by the researcher. Participants provided written informed consent and consented to being audio-recorded. They were informed that pseudonyms would be used in reporting the data to protect their identity. **Sampling** Convenience sampling **Setting** Participants' homes or another suitable location **Data collection** Semi-structured interviews were performed by 3 interviewers to explore current physical activity levels, and motives and barriers to increasing physical activity levels. **Data analysis** Analysis was performed using an inductive thematic analysis. Interviews were audio-recorded and transcribed verbatim. Firstly, transcripts were read several	• Lifestyle ○ Physical activity	Participants were at an increased risk for cardiovascular disease and therefore potentially not generalisable to a wider population of survivors of colorectal cancer survivors **Other information** The assessment of the quality of the study was performed using the CASP checklist for qualitative studies 1. Was there a clear statement of the aims of the research? Yes 2. Is a qualitative methodology appropriate? Yes 3. Was the research design appropriate to address the aims of the research? Yes 4. Was the recruitment strategy appropriate to the aims of the research? Yes 5. Was the data collected in a way that addressed the research issue? Yes 6. Has the relationship between researcher and participants been adequately considered? Yes 7. Have ethical issues been taken into consideration? Yes 8. Was the data analysis sufficiently rigorous? Yes 9. Is there a clear statement of findings? Yes 10. How valuable is the

Study details	Participants	Methods	Themes	Quality assessment
		times to establish meanings and experiences. Secondly, codes were assigned to text segments across the entire data set and were then combined to define overarching themes. Themes were created with a focus of linking to participants' barriers around physical activity and health changes. Lastly, themes were reviewed to eliminate overlap in content and an independent expert reviewed interviews to ensure consistency across interviewers.		research? Researchers discuss the contribution the study makes to existing literature; and identify new areas where research is necessary
Full citation McCaughan, E., Parahoo, K., Prue, G., Comparing cancer experiences among people with colorectal cancer: A qualitative study, Journal of advanced nursing, 67, 2686-2695, 2011 **Ref Id** 791888 **Country/ies where the study was carried out** UK **Study type**	**Sample size** N= 38 **Characteristics** Male, n (%)=24 (63.2) Married, n (%)= 32 (84) **Inclusion criteria** Participants were English-speaking, were over 18 years of age, and had a first diagnosis of colorectal cancer in the Northern Ireland Cancer Centre. **Exclusion criteria** Not reported **Interventions** Not applicable	**Details** Written informed consent was obtained prior to the interview. **Sampling** Nurses identified potential participants at their first oncology appointment. A researcher contacted those who agreed and explained the study and its implications, and also sought the patient's consent to participate. **Setting** Participants' venue of choice (their own home) **Data collection** In-person, in-depth were performed by the study authors.	**Results** During • Cancer prognosis	**Limitations reported by study authors** None reported **Other information** The assessment of the quality of the study was performed using the CASP checklist for qualitative studies 1. Was there a clear statement of the aims of the research? Yes 2. Is a qualitative methodology appropriate? Yes 3. Was the research design appropriate to address the aims of the research? Can't tell (researchers did not justify the research design) 4. Was the recruitment strategy appropriate to the aims of the

Study details	Participants	Methods	Themes	Quality assessment
In depth interviews **Aim of the study** The aim of the study is to assess how people with colorectal cancer compare experiences, what comparison meant to them, and the context in which it took place. **Study dates** November 2006- June 2007 **Source of funding** No funding received		Interviews lasted 1 hour and were audio-recorded with the permission of the participants. Participants were asked to tell their story of what they experienced and how they coped from diagnosis to the time of the interview. **Data analysis** The interviews were transcribed and uploaded to NVivo. Codes were generated and catalogued into tree nodes. Nodes were compared and further categorised until saturation of codes and categories was reached.		research? Yes 5. Was the data collected in a way that addressed the research issue? Yes 6. Has the relationship between researcher and participants been adequately considered? Can't tell (researchers did not state whether they critically examined their own role in the research) 7. Have ethical issues been taken into consideration? Yes 8. Was the data analysis sufficiently rigorous? Yes 9. Is there a clear statement of findings? Yes 10. How valuable is the research? Researchers discuss the contribution the study makes to existing literature; and identify new areas where research is necessary
Full citation Steel, E. J., Trainer, A. H., Heriot, A. G., Lynch, C., Parry, S., Win, A. K., Keogh, L. A., The Experience of Extended Bowel Resection in Individuals With a High Metachronous Colorectal Cancer Risk: A Qualitative Study, Oncology nursing	**Sample size** N= 18 **Characteristics** Male, n (%)= 12 (66.7) Age at interview, 30-49 years, n (%)= 8 (44.4) Age at interview, 50-69 years, n (%)= 10 (55.6) Temporary stoma, n (%)= 1 (5.6) Permanent stoma, n (%)= 2 (11.1)	**Details** Before the interview participants received a written and verbal explanation of the purpose of the interviews, what participation would involve and their rights as a participant. Informed consent was obtained verbally if over the phone or written if in person. **Sampling** Patients were contacted by an ACCFR representative or one of	**Results** Prior • Surgery ○ Preparation for surgery ○ What to expect during surgery ○ What to expect after surgery	**Limitations reported by study authors** Participants were a subset of individuals who were at risk for high metachronous colorectal cancer. **Other information** The assessment of the quality of the study was performed using the CASP checklist for qualitative studies 1. Was there a clear statement

Study details	Participants	Methods	Themes	Quality assessment
forum, 43, 444-452, 2016 **Ref Id** 793192 **Country/ies where the study was carried out** Australia **Study type** Semi-structured interviews **Aim of the study** The aim of the study was to explore experiences of extended bowel resection as treatment for colorectal cancer, including the self-reported adequacy of information received at different times throughout treatment and recovery. **Study dates** Not reported **Source of funding** Victorian Cancer Agency; National Cancer Institute and National Institutes of Health	No stoma, n (%)= 15 (83.3) **Inclusion criteria** 18 years of age or older, spoke English, were contactable within Australia, had an extended bowel resection following a diagnosis of colorectal cancer between 6 months to 12 years prior to the interview. **Exclusion criteria** Significant ill health **Interventions** Not applicable	their treating specialists. Those who agreed to receive additional information were sent a participant information sheet and then contacted by the first author to arrange an interview. Recruitment ceased once thematic saturation was reached. **Setting** Not reported **Data collection** Interviews took place in person or over the phone. Interviews were semi-structured and designed to obtain information about participants' experiences being diagnosed with colorectal cancer. Interviews were on average 50 minutes and were audio recorded and transcribed verbatim. The transcripts were de-identified. **Data analysis** Thematic analysis was used. Firstly, the transcripts were read several times. Transcripts were coded in NVivo software with double coding used to ensure that any bias in interpretation was clarified.	After • Lifestyle ○ Managing bodily functions	of the aims of the research? Yes 2. Is a qualitative methodology appropriate? Yes 3. Was the research design appropriate to address the aims of the research? Yes 4. Was the recruitment strategy appropriate to the aims of the research? Yes 5. Was the data collected in a way that addressed the research issue? 6. Has the relationship between researcher and participants been adequately considered? Can't tell (researchers did not state whether they critically examined their own role in the research) 7. Have ethical issues been taken into consideration? Yes 8. Was the data analysis sufficiently rigorous? Yes 9. Is there a clear statement of findings? Yes 10. How valuable is the research? Researchers discuss the contribution the study makes to existing literature; and identify new areas where research is necessary

Study details	Participants	Methods	Themes	Quality assessment
Full citation Taylor, C., Bradshaw, E., Tied to the Toilet: Lived Experiences of Altered Bowel Function (Anterior Resection Syndrome) After Temporary Stoma Reversal, Journal of Wound Ostomy and Continence Nursing, 40, 415-421, 2013 **Ref Id** 793375 **Country/ies where the study was carried out** UK **Study type** Semi-structured interview. **Aim of the study** To explore the experiences of patients with anterior resection syndrome after rectal cancer treatment **Study dates** March to June 2011	**Sample size** N= 8 **Characteristics** Male, n (%)= 5 (63%) Age at interview: median age was 66.5 years (range, 63-76 years). Time from stoma reversal at interview, 4- 6 weeks **Inclusion criteria** People treated with curative surgery for rectal cancer (with or without chemotherapy & radiotherapy), with self-reported changes in bowel function post rectal cancer treatment, from 4 to 6 weeks post temporary stoma closure, fluent in English, over 18 years of age, living within 20-mile radius of hospital **Exclusion criteria** Not able to give consent, palliative treatment (e.g. metastatic disease) **Interventions** Not applicable.	**Details** Twenty potential respondents were identified during a 4-month period and all participants were sent an information sheet that explained the study. Eight patients telephoned the researcher, stating that they were interested in participating. **Sampling** A purposive sampling technique was used to identify a sample group of patients with anterior resection syndrome. **Setting** Not reported. **Data collection** Data were collected using in-depth, semi-structured face-to-face interviews. The interview schedule was designed with open-ended questions to allow discussion on those areas of interest (identified from an initial review of the literature), which addressed study aims. Interviews were recorded and transcribed, and field notes were also taken. **Data analysis**	**Results** This study contributed to the following themes: After • Lifestyle ○ Managing bodily functions	**Limitations reported by study authors** Study data were obtained from a single interview within a few weeks of experiencing anterior resection syndrome. The results from this study are applicable only to those experiencing acute changes in bowel function following stoma surgery reversal **Other information** The assessment of the quality of the study was performed using the CASP checklist for qualitative studies 1. Was there a clear statement of the aims of the research? Yes 2. Is a qualitative methodology appropriate? Yes 3. Was the research design appropriate to address the aims of the research? Yes 4. Was the recruitment strategy appropriate to the aims of the research? Yes 5. Was the data collected in a way that addressed the research issue? Yes 6. Has the relationship between researcher and participants

Study details	Participants	Methods	Themes	Quality assessment
Source of funding National Cancer Survivorship Initiative		Framework analysis was used. The conceptual framework aimed to show pieces of data that had been isolated and placed with other pieces of data in order to determine relationships among pertinent constructs. The data were analysed as units of participant description under the following headings: Index Code; Statement; Context; and Meaning to formulate overall themes. A list of statements was indexed, then refined and mapped onto the main themes.		been adequately considered? Yes – some consideration 7. Have ethical issues been taken into consideration? Yes 8. Was the data analysis sufficiently rigorous? Yes 9. Is there a clear statement of findings? Yes 10. How valuable is the research? Researchers discuss the contribution the study makes to existing literature; and identify new areas where research is necessary
Full citation Veitch, C., Crossland, L., Steeghs, M., Ho, Y. H., Hanks, H., Patients' Experiences of Colorectal Cancer and Oncology Services in North Queensland, Australian Journal of Primary Health, 14, 93-100, 2008 **Ref Id** 793629	**Sample size** N= 117 N focus group= 30 N interviews= 18 N postal surveys= 69 **Characteristics** Focus groups, n=30 Male, n (%)= 12 (40) Age range= not reported Interviews, n=18 Male, n (%)= 10 (56) Age, years, median (range)= 64 (50-79) Postal survey, n=69 Male, n (%)= 38 (55) Age, years, median (range)= 65 (38-80)	**Details** Participants had previously consented to being approached for other related surveys when joining the database. Additional ethics approval was sought for this study. **Sampling** For the focus groups and interviews, participants were purposively sampled to include age range, gender and residence, treatment modalities, treatment stages, and disease stages. In the survey, all non-terminal living patients in the	**Results** Prior • Surgery ○ Preparation for surgery • Treatment decision making ○ Awareness of colorectal cancer	**Limitations reported by study authors** None reported **Other information** The assessment of the quality of the study was performed using the CASP checklist for qualitative studies 1. Was there a clear statement of the aims of the research? Yes 2. Is a qualitative methodology appropriate? Yes 3. Was the research design appropriate to address the aims of the research? Yes

Study details	Participants	Methods	Themes	Quality assessment
Country/ies where the study was carried out Australia **Study type** Focus groups, interviews, and postal surveys **Aim of the study** The aim of the study was to explore participants' experiences with and attitudes to colorectal cancer. **Study dates** Not reported **Source of funding** Cancer Council of Queensland and the Rural Health Research Unit, JCU School of Medicine	**Inclusion criteria** Were part of the North Queensland Centre for Cancer Research colorectal cancer database **Exclusion criteria** Terminally ill **Interventions** Not applicable	database were invited to participate. **Setting** Focus groups: cities in Australia **Data collection** Focus groups: There were 4 focus group sessions with patients and their supporters (spouse or other relative). Each group contained 6 to 10 participants. Participants were asked to record three aspects of their care which were good and three which were not, participants considered clinical and non-clinical aspects of the cancer experience, their entry and pathway through the health system. Interviews: Interviews were audio-recorded and were guided by a semi-structured topic schedule devised from the focus group sessions. Participants were recruited until thematic saturation was reached. Postal survey: Participants completed a self-completed questionnaire that included open-ended questions derived from the focus groups and interviews with several validated health attitudes and belief instruments. Participants received questionnaires via posed, and were followed up by		4. Was the recruitment strategy appropriate to the aims of the research? Yes 5. Was the data collected in a way that addressed the research issue? Can't tell (researchers did not explain why using three methods was needed 6. Has the relationship between researcher and participants been adequately considered? Can't tell (researchers did not state whether they critically examined their own role in the research) 7. Have ethical issues been taken into consideration? Yes 8. Was the data analysis sufficiently rigorous? Yes 9. Is there a clear statement of findings? Yes 10. How valuable is the research? Researchers discuss the contribution the study makes to existing literature; and identify new areas where research is necessary

Study details	Participants	Methods	Themes	Quality assessment
		telephone to consent to participate. **Data analysis** Analysis of the focus group and interview data was performed using QSR N7 software. Researchers noted recurrent themes and differences in viewpoints. Reliability was ensured through respondent validation during the focus groups, participants' review of their interview transcripts, and the transcripts being independently reviewed by 2 other team members. Analysis of the open-ended questions from the questionnaires were collated and reviewed in a similar process that was used with the focus group and interview data. No new themes were identified.		
Full citation Wilson, T. R., Birks, Y. F., Alexander, D. J., A qualitative study of patient perspectives of health-related quality of life in colorectal cancer: comparison with disease-specific evaluation tools, Colorectal Disease, 12, 2010	**Sample size** N= 20 **Characteristics** Male, n (%)= 13 (65) Age, years, mean= 62.3 Temporary stoma, n (%)= 9 (45) No stoma, n (%)= 6 (30) Permanent stoma, n (%)= 5 (20) **Inclusion criteria**	**Details** See below **Sampling** Participants were prospectively sampled to ensure adequate representation of demographic and medical factors that might impact on HrQoL. Recruitment took place until thematic saturation was achieved. **Setting**	**Results** Prior • Surgery ○ What to expect during surgery • Treatment decision making ○ Medical information	**Limitations reported by study authors** Lack of generalisability due to participants all being white and English speaking. **Other information** The assessment of the quality of the study was performed using the CASP checklist for qualitative studies 1. Was there a clear statement of the aims of the research?

Study details	Participants	Methods	Themes	Quality assessment
Ref Id 536795 **Country/ies where the study was carried out** UK **Study type** Semi-structured interviews **Aim of the study** The aim of the study was to determine which areas of the health-related quality of life scale are important to patients with colorectal cancer. **Study dates** Not reported **Source of funding** Roche PLC and ConvaTec	Colorectal cancer patients with potentially curable disease who were part of a cohort of patients taking part in a survey on HrQoL. **Exclusion criteria** Not reported **Interventions** Not applicable	Participant's home or in a private university room. **Data collection** Semi-structured interviews were recorded and transcribed. Participants talked about their experiences of being diagnosed and treated for colorectal cancer. Interviews were structured around a topic guide. The sequencing of topics was adapted for each interview to allow the individual to dictate the structure of the interview. **Data analysis** Framework analysis was used to analyse the transcripts. Thematic analysis was used to create an appropriate coding scheme. The reliability of the final coding scheme was determined by double coding a random sample of the transcript data. Transcribed data were coded in ATLAS/ti. Themes were graphically mapped to explore relationships between themes. Once the thematic analysis was complete, the themes were compared with the item content of QLQ-C30/CR38 and FACT-C.		Yes 2. Is a qualitative methodology appropriate? Yes 3. Was the research design appropriate to address the aims of the research? Yes 4. Was the recruitment strategy appropriate to the aims of the research? Yes 5. Was the data collected in a way that addressed the research issue? Yes 6. Has the relationship between researcher and participants been adequately considered? Can't tell (researchers did not state whether they critically examined their own role in the research) 7. Have ethical issues been taken into consideration? No (Researchers did not state whether ethical approval was received or how information provided to ascertain whether ethical standards were maintained) 8. Was the data analysis sufficiently rigorous? Yes 9. Is there a clear statement of findings? Yes 10. How valuable is the research? Researchers discuss the contribution the study makes to existing literature; and identify new areas where research is necessary

Study details	Participants	Methods	Themes	Quality assessment
Full citation Abelson, Jonathan S., Chait, Alanna, Shen, Megan J., Charlson, Mary, Dickerman, Anna, Yeo, Heather L., Sources of distress among patients undergoing surgery for colorectal cancer: a qualitative study, Journal of Surgical Research, 226, 140-149, 2018 **Ref Id** 866904 **Country/ies where the study was carried out** US **Study type** Semi-structured interviews **Aim of the study** The aim of the study was to assess sources of distress among colorectal cancer patients undergoing surgery. **Study dates**	**Sample size** N=24 **Characteristics** Female sex, n (%)= 16 (67) White, %= 75 Black, %= 13 Hispanic, %= 8 Rectal cancer, n (%)= 15 (62) Colon cancer, n (%)= 9 (38) **Inclusion criteria** Had pathology-confirmed diagnosis of colorectal cancer and had recently undergone (postoperative) or were about to undergo (preoperative) curative resection for colorectal cancer **Exclusion criteria** Not reported **Interventions** Not applicable	**Details** Postoperative patients were recruited no less than 2 weeks after discharge so that the interview could probe for sources of distress related to the discharge process and transition to home. Postoperative patients were recruited up until 6 months after surgery to ensure capture of potential sources of distress related to recovery at home. Interviews were not conducted beyond 6 months after surgery, so the memory of the surgical process was not too old. Participants completed informed consent after recruitment. **Sampling** Purposive sampling with emphasis on pre-operative and postoperative patients to obtain their perceptions of sources of distress around the surgical experience. **Setting** Not reported **Data collection** Participants completed one on one, semi-structured, open ended interviews with a study researcher. Interviews were performed until data saturation was reached and were audio recorded and transcribed.	**Results** Prior • Surgery ○ Preparation for surgery ○ What to expect during surgery ○ What to expect after surgery • Treatment decision making ○ Awareness of colorectal cancer and treatments ○ Preoperative assessments During • Cancer prognosis	**Limitations reported by study authors** Higher proportion of women **Other information** The assessment of the quality of the study was performed using the CASP checklist for qualitative studies 1. Was there a clear statement of the aims of the research? Yes 2. Is a qualitative methodology appropriate? Yes 3. Was the research design appropriate to address the aims of the research? Yes 4. Was the recruitment strategy appropriate to the aims of the research? Yes 5. Was the data collected in a way that addressed the research issue? Yes 6. Has the relationship between researcher and participants been adequately considered? Can't tell (researchers did not state whether they critically examined their own role in the research) 7. Have ethical issues been taken into consideration? Can't tell (not enough details provided to determine whether ethical standards were maintained) 8. Was the data analysis sufficiently rigorous? Yes

Study details	Participants	Methods	Themes	Quality assessment
Not reported **Source of funding** Not reported		**Data analysis** All 3 researchers coded the transcripts and then compared discrepancies. Themes were organised.		9. Is there a clear statement of findings? Yes 10. How valuable is the research? Researchers discuss the contribution the study makes to existing literature; and identify new areas where research is necessary.

ACCFR: Australasian Colorectal Cancer Family Registry; ASA: American Society of Anesthesiologists; BMI: body mass index; CASP: Critical Appraisal Skills Programme; EORTC QLQ-C30: European Organisation for Re-search and Treatment of Cancer Quality of Life Questionnaire Core 30 Items; EORTC QLQ-CR38: European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire colorectal cancer module (38 items); ERAS: Enhanced recovery after surgery; FACT-C: Functional Assessment of Cancer Therapy questionnaire (colorectal cancer); HrQoL: health-related quality of life; IQR: inter-quartile range; N: number; SD: standard deviation

Appendix E – Forest plots

Forest plots for review question: What are the information needs of people prior, during and after treatment for colorectal cancer?

Not applicable for this qualitative review.

Appendix F – GRADE CERQual tables

GRADE CERQual tables for review question: What are the information needs of people prior, during and after treatment for colorectal cancer?

Information needs prior to treatment

Table 5: Qualitative evidence profile for theme 1. Surgery

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Assessment of Concerns**	**Overall Confidence**
Sub theme 1: Preparation for surgery					
2 (Abelson 2018; Steel 2016)	2 semi-structured interviews	2 studies conducted in different countries (Australia, and the USA) among 42 people with colorectal cancer found that people wanted to know what preparation was required prior to surgery. People wanted more thorough explanations, as receiving too much information at once regarding scheduling the surgery, colon preparation and reviewing test results could be overwhelming.	Methodological limitations	No concerns	Moderate
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	Minor concerns[1]	
Sub theme 2: What to expect during surgery					
6 (Abelson 2018; Beaver 2010; Gillis 2017; Ho 2016; Steel 2016; Wilson 2010)	4 semi-structured interviews; 2 focus group	6 studies conducted in different countries (Australia, Canada, the UK, and the US) among 146 people with colorectal cancer reported that participants wanted more information about what to expect during treatment, such as pain from inflating the abdomen for laparoscopic surgery, to feel better prepared for possible treatment side-effects. Participants wanted an explicit discussion prior to treatment about the possibility of changes to the treatment plan during the operation, such as the unexpected removal of additional organs, so as to not be taken by surprise.	Methodological limitations	No concerns	High
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	No concerns	
Sub theme 3: What to expect after surgery					
4 (Abelson 2018; Beaver 2010; Brown 2016; Steel 2016)	4 semi-structured interviews	4 studies conducted in different countries (Australia, the UK, and the US) among 88 people with colorectal cancer reported that participants wanted to be informed about what to expect after surgery, including altered bowel function, potential treatment symptoms, other physical and mental	Methodological limitations	No concerns	High
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	No concerns	

Study information			CERQual assessment of the evidence		
Number of studies	Design	Description of theme or finding	Criteria	Assessment of Concerns	Overall Confidence
		changes, the presence of tubes and connections, and the length of the recovery process.			

Table 6: Qualitative evidence profile for theme 2. Recovery

Study information			CERQual assessment of confidence in the evidence		
Number of studies	Design	Description of theme or finding	Criteria	Assessment of Concerns	Overall Confidence
Sub-theme 1: Diet					
1 (Brown 2016)	1 semi-structured interview	1 study conducted in the UK among 19 people with colorectal cancer reported that prior to surgery, participants wanted to know about what adaptations to their diet would be required after surgery.	Methodological limitations	No concerns	Moderate
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	Minor concerns[1]	
Sub-theme 2: Accessing resources and services					
1 (Gillis 2017)	1 focus group	1 study conducted in Canada among 27 people with colorectal cancer reported that participants were unaware of the resources available to them, therefore guidance on how to access the appropriate services could help reduce patients' anxiety during the period prior to surgery.	Methodological limitations	No concerns	Moderate
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	Minor concerns[1]	
Sub-theme 3: Effect of treatment on sexual function					
2 (Dowswell 2011; Hall 2012)	2 semi-structured interviews	2 studies conducted in the UK among 58 people with colorectal cancer reported that they did not think that they were adequately warned about the potential for sexual dysfunction post-surgery. When clinicians did provide information about the potential for altered sexual function, it was biased towards younger men and sometimes misleading. Most understood the importance of information about sexual matters being available to those that needed it.	Methodological limitations	No concerns	High
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	No concerns	

[1] *The confidence in the adequacy of the evidence was downgraded by 1 due to data saturation not being reached. Themes were under-developed and analysing further data would likely reveal new data and concepts.*

Table 7: Qualitative evidence profile for theme 3. Treatment decision making

Study information			CERQual assessment of confidence in the evidence		
Number of studies	Design	Description of theme or finding	Criteria	Assessment of Concerns	Overall Confidence
Sub theme 1: Awareness of colorectal cancer and treatments					
			Methodological limitations	Minor concerns[1]	Moderate

Study information			CERQual assessment of confidence in the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Assessment of Concerns**	**Overall Confidence**
3 (Abelson 2018; Veitch 2008; Wilson 2010)	1 focus group + semi-structured interview; 2 semi-structured interviews	3 studies conducted in different countries (Australia, the UK, and the US) among 92 people with colorectal cancer reported that they had limited knowledge on colorectal cancer prior to diagnosis and would have acted faster and sooner had they known more about the signs and symptoms. Additionally, ambiguous information about the efficacy of some treatments, such as adjuvant chemotherapy, made it difficult to make decisions. Participants noted the need to educate relatives on their need to be screened.	Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	No concerns	
Sub theme 2: Cost of care					
1 (Ho 2016)	1 focus group	1 study conducted in Canada among 30 people with colorectal cancer reported that participants wanted to be informed about which supportive care medications were covered by the public healthcare system or private insurance, as the need to pay for medications out of pocket would affect their decision about whether to proceed with a medication.	Methodological limitations	No concerns	Low
			Relevance of findings	Minor concerns[3]	
			Coherence of findings	No concerns	
			Adequacy of evidence	Minor concerns[2]	
Sub theme 3: Preoperative assessments					
2 (Abelson 2018; Gillis 2017)	1 focus group; 1 semi-structured interview	2 studies conducted in different countries (Canada, and the US) among 51 people with colorectal cancer reported that unawareness of the time needed to review and report preoperative assessments and results, such as biopsy results, caused undue preoperative stress. Receiving insufficient information could result in people regretting treatment decisions.	Methodological limitations	No concerns	Moderate
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	Minor concerns[2]	

[1] *The confidence in the quality of the evidence was downgraded by 1 due to studies not critically reflecting on the researchers' roles in the research and did not describe methods used to maintain ethical standards (Wilson 2010)*

[2] *The confidence in the adequacy of the evidence was downgraded by 1 due to data saturation not being reached. Themes were under-developed and analysing further data would likely reveal new data and concepts.*

[3] *Downgraded by 1 as healthcare funding arrangements are different in Canada and the UK.*

Table 8: Qualitative evidence profile for theme 4. Timing and delivery of information

Study information			CERQual assessment of confidence in the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Assessment of Concerns**	**Overall Confidence**
4 (Beaver 2010; Gillis 2017; Ho 2016; Hoedjes 2017)	1 semi-structured interview; 3 focus groups	4 studies conducted in different countries (Canada, the UK, and the Netherlands) among 100 people with colorectal cancer reported that	Methodological limitations	No concerns	High
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	

Study information			CERQual assessment of confidence in the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Assessment of Concerns**	**Overall Confidence**
		many participants spoke of 'information overload' during the first consultation appointment and would have preferred that preoperative information be conveyed later when they were better able to absorb information, along with a binder or resource that they could consult. Participants also wanted to receive information updates directly after surgery, on the first hospital visit post-discharge, and during the follow-up period.	Adequacy of evidence	No concerns	

Information needs of colorectal cancer patients during treatment

Table 9: Qualitative evidence profile for theme 1. Diet

Study information			CERQual assessment of confidence in the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Assessment of Concerns**	**Overall Confidence**
1 (Gillis 2017)	1 semi-structured interview	1 study conducted in the UK among 27 people with colorectal cancer reported that participants would have liked some guidance while they were in hospital as to the type of food that relatives could bring for them from home.	Methodological limitations	No concerns	Moderate
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	Minor concerns[2]	

[1] The confidence in the adequacy of the evidence was downgraded by 1 due to data saturation not being reached. Themes were under-developed and analysing further data would likely reveal new data and concepts.

Table 10: Qualitative evidence profile for theme 2. Other's experiences

Study information			CERQual assessment of confidence in the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Assessment of Concerns**	**Overall Confidence**
1 (McCaughan 2011)	1 semi-structured interview	1 study conducted in the UK among 38 people with colorectal cancer reported that during treatment participants wanted to have the opportunity to learn from people who had similar experiences and to learn about possible treatment effects, such as chemotherapy side effects, from other patients.	Methodological limitations	No concerns	Moderate
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	Minor concerns[2]	

[1] The confidence in the adequacy of the evidence was downgraded by 1 due to data saturation not being reached. Themes were under-developed and analysing further data would likely reveal new data and concepts.

Table 11: Qualitative evidence profile for theme 3. Cancer prognosis

Study information			**CERQual assessment of confidence in the evidence**		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Assessment of Concerns**	**Overall Confidence**
3 (Abelson 2018; Gillis 2017; McCaughan 2011)	1 focus group; 2 semi-structured interviews	3 studies conducted in different countries (Canada, the UK, and the US) among 89 people with colorectal cancer reported that lack of information regarding biopsy results and inaccessibility of surgeons caused anxiety during patients' hospital stays. While some participants wanted to know how long they were likely to live with cancer and how long they could expect to be disease-free, others found that too much information about complication risks was unhelpful and caused more anxiety.	Methodological limitations	No concerns	Moderate
			Relevance of findings	No concerns	
			Coherence of findings	Minor concerns[1]	
			Adequacy of evidence	No concerns	

[1] The confidence in the coherence of the data was downgraded by 1 due to inconsistency in study results

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Table 12: Qualitative evidence profile for theme 1. Lifestyle

Study information			**CERQual assessment of the evidence**		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Assessment of Concerns**	**Overall Confidence**
Sub theme 1: Diet					
5 (Anderson 2013; Beaver 2010; Brown 2017; Hall 2012; Hoedjes 2017)	3 semi-structured interviews; 2 focus groups	5 studies conducted in different countries (the Netherlands, and the UK) among 132 people with colorectal cancer reported that prior to hospital discharge, participants needed information on practical advice on dietary adaptations required following the removal of part of the bowel and on foods to avoid to prevent diarrhoea and flatulence. Participants also felt that it was important to have access to a dietician or support person to be able to ask questions and receive individually-tailored advice relating to appropriate nutrition and dietary supplements. Many interviewees reported the availability of leaflets or diet sheets from the dieticians whilst in hospital.	Methodological limitations	No concerns	High
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	No concerns	
Sub theme 2: Physical activity					
1 (Maxwell-Smith 2017)	1 semi-structured interview	1 study conducted in Australia among 24 people with colorectal cancer reported that many participants were unaware of government guidelines and did not receive adequate advice regarding physical activity and would have liked information from medical professionals about the recommended duration, intensity, and frequency of exercising.	Methodological limitations	No concerns	Moderate
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	Minor concerns[1]	

Study information		**Description of theme or finding**	**CERQual assessment of the evidence**		
Number of studies	**Design**		**Criteria**	**Assessment of Concerns**	**Overall Confidence**
Sub theme 3: Managing bodily functions					
3 (Anderson 2013; Steel 2016; Taylor 2013)	1 focus group; 2 semi-structured interviews	3 studies conducted in Australia and the UK among 66 people with colorectal cancer reported that after treatment, many participants struggled with changes in bowel function, diarrhoea and weight gain and would have liked more information on how to manage symptoms to facilitate adjusting to life post-surgery and return-to-work.	Methodological limitations	No concerns	High
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	No concerns	

[1] The confidence in the adequacy of the evidence was downgraded by 1 due to data saturation not being reached. Themes were under-developed and analysing further data would likely reveal new data and concepts.

Table 13: Qualitative evidence profile for theme 2. Medical information

Study information		**Description of theme or finding**	**CERQual assessment of the evidence**		
Number of studies	**Design**		**Criteria**	**Assessment of Concerns**	**Overall Confidence**
Sub theme 1: Stoma care					
3 (Beaver 2010; Hall 2012; Hoedjes 2017)	1 focus group; 2 semi-structured interviews	3 studies conducted in different countries (the Netherlands, and the UK) among 73 people with colorectal cancer reported that participants with a stoma received insufficient information on the provision of stoma bags and care. Participants needed practical information on how to dress with a stoma bag and how to adapt their lifestyles and died in order to reduce the noise and odours caused by certain foods.	Methodological limitations	No concerns	High
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	No concerns	
Sub theme 2: Medical issues					
5 (Brown 2016; Gillis 2017; Hall 2012; Ho 2016; Hoedjes 2017)	3 focus groups; 2 semi-structured interviews	5 studies conducted in different countries (Canada, the Netherlands, and the UK) among 122 people with colorectal cancer reported that many participants were unaware of medical issues, such as bleeding from the rectum or pain from radiotherapy that could arise as a result of treatment. Participants sought advice in regard to treatment-related issues, including lack of strength or energy, and lymphedema.	Methodological limitations	No concerns	High
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	No concerns	
Sub theme 3: Sex-specific issues					
2 (Dowswell 2011; Ho 2016)	1 focus group; 1 semi-structured interview	2 studies conducted in different countries (Canada, UK) among 58 people with colorectal cancer reported that they received insufficient sex-related advice and support after surgery. Many men did not know how or where to seek support for erectile dysfunction. Men sought information	Methodological limitations	No concerns	Moderate
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	Minor concerns[1]	

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Assessment of Concerns**	**Overall Confidence**
		on how to ask for help and to gain a sense of new norms might be. Women reported that male health care providers appeared uncomfortable discussing gynaecological side effects and would have preferred access to a gynaecologist.			

[1] The confidence in the adequacy of the evidence was downgraded by 1 due to data saturation not being reached. Themes were under-developed and analysing further data would likely reveal new data and concepts.

Appendix G – Economic evidence study selection

Economic evidence study selection for review question: What are the information needs of people prior, during and after treatment for colorectal cancer?

A global search of economic evidence was undertaken for all review questions in this guideline. See Supplement 2 for further information.

Appendix H – Economic evidence tables

Economic evidence tables for review question: What are the information needs of people prior, during and after treatment for colorectal cancer?

No economic evidence was identified which was applicable to this review question.

Appendix I – Economic evidence profiles

Economic evidence profiles for review question: What are the information needs of people prior, during and after treatment for colorectal cancer?

No economic evidence was identified which was applicable to this review question.

Appendix J – Economic analysis

Economic evidence analysis for review question: What are the information needs of people prior, during and after treatment for colorectal cancer?

No economic analysis was conducted for this review question.

Appendix K – Excluded studies

Excluded clinical studies for review question: What are the information needs of people prior, during and after treatment for colorectal cancer?

Table 14: Excluded studies and reasons for their exclusion

Study	Reason for exclusion
Alawadi, Z. M., Leal, I., Phatak, U. R., Flores-Gonzalez, J. R., Holihan, J. L., Karanjawala, B. E., Minas, S. G., Kao, L. S., Facilitators and barriers of implementing enhanced recovery in colorectal surgery at a safety net hospital: A provider and patient perspective, Surgery, 159, 700-712, 2016	Study did not pertain to patients' information needs
Appleton, Lynda, Goodlad, Sue, Irvine, Fiona, Poole, Helen, Wall, Christine, Patients' experiences of living beyond colorectal cancer: A qualitative study, European Journal of Oncology Nursing, 17, 610-617, 2013	Study not relevant to patients' information needs
Appleyard, S., Gilbert, D., Moynihan, C., Patient expectations of treatment in metastatic colorectal cancer. A qualitative study exploring the endpoints which are important to patients and their perceptions of decision-making process, Psycho-Oncology, 26, 18-18, 2017	Abstract
Asiedu, G. B., Eustace, R. W., Eton, D. T., Radecki Breitkopf, C., Coping with colorectal cancer: a qualitative exploration with patients and their family members, Family Practice, 31, 598-606, 2014	Mixed population - patients and family members
Bergin, R., Emery, J., Bollard, R., White, V., How rural and urban patients in Australia with colorectal or breast cancer experience choice of treatment provider: A qualitative study, European journal of cancer care, 26, 2017	Mixed population - patients had breast cancer or colorectal cancer
Bergin, R., White, V., Emery, J., Bollard, R., "If You Were Going to Have Bowel Cancer Surgery, Who Would You Choose?" How Urban and Rural Colorectal Patients Experience Decision-Making for Referral to Hospital and Specialist, Asia-Pacific Journal of Clinical Oncology, 10, 165-166, 2014	Conference abstract
Berian, J. R., Cuddy, A., Francescatti, A. B., O'Dwyer, L., You, Y. N., Volk, R. J., Chang, G. J., A systematic review of patient perspectives on surveillance after colorectal cancer treatment, Journal of Cancer hip, 11, 542-552, 2017	Systematic review - studies assessed individually
Blazeby, J. M., Soulsby, M., Winstone, K., King, P. M., Bulley, S., Kennedy, R. H., A qualitative evaluation of patients' experiences of an enhanced recovery programme for colorectal cancer, Colorectal Disease, 12, e236-e242, 2010	Study not relevant to patients' information needs
Boulton, M., Adams, E., Horne, A., Durrant, L., Rose, P., Watson, E., A qualitative study of cancer ' responses to information on the long-term and late effects of pelvic radiotherapy 1-11 years post treatment, European journal of cancer care, 24, 734-47, 2015	Population did not have colorectal cancer
Brandenbarg, D., Roorda, C., Stadlander, M., de Bock, G. H., Berger, M. Y., Berendsen, A. J., Patients' views on general practitioners' role during treatment and follow-up of colorectal cancer: a qualitative study, Family Practice, 34, 234-238, 2017	Did not pertain to information needs
Brebach, R., Rhodes, P., Sharpe, L., Butow, P., Cancer patients' reasons for acceptance or decline of psychological intervention: An interview study, Psycho-Oncology, 2), 54, 2015	Abstract

Study	Reason for exclusion
Breitkopf, C. R., Asiedu, G. B., Egginton, J., Sinicrope, P., Opyrchal, S. M. L., Howell, L. A., Patten, C., Boardman, L., An investigation of the colorectal cancer experience and receptivity to family-based cancer prevention programs, Supportive Care in Cancer, 22, 2517-2525, 2014	Mixed population (patients and family members); did not pertain to information needs
Burke, S. M., West, M. A., Grocott, M. P. W., Brunet, J., Jack, S., Exploring the experience of adhering to a prescribed pre-surgical exercise program for patients with advanced rectal cancer: A phenomenological study, Psychology of Sport and Exercise, 16, 88-95, 2015	Study not relevant to patients' information needs
Carduff, E., Kendall, M., Murray, S. A., Living and dying with metastatic bowel cancer: Serial in-depth interviews with patients, European journal of cancer care, 27, 2018	Did not pertain to information needs
Cengiz, B., Bahar, Z., Perceived Barriers and Home Care Needs When Adapting to a Fecal Ostomy: A Phenomenological Study, Journal of wound, ostomy, and continence nursing : official publication of The Wound, Ostomy and Continence Nurses Society, 44, 63-68, 2017	Study not relevant to patients' information needs
Corner, J., Wagland, R., Glaser, A., Richards, S. M., Qualitative analysis of patients' feedback from a PROMs survey of cancer patients in England, BMJ Open, 3, 2013	Mixed population - participants had either breast cancer or colorectal cancer
Cusack,M., Taylor,C., A literature review of the potential of telephone follow-up in colorectal cancer, Journal of Clinical Nursing, 19, 2394-2405, 2010	Patients did not have colorectal cancer
Dabirian, A., Yaghmaei, F., Rassouli, M., Tafreshi, M. Z., Quality of life in ostomy patients: a qualitative study, Patient Preference and Adherence, 5, 1-5, 2011	Study not relevant to patients' information needs
Damm, K., Vogel, A., Prenzler, A., Preferences of colorectal cancer patients for treatment and decision-making: a systematic literature review, European journal of cancer care, 23, 762-772, 2014	Systematic review- studies assessed individually
Danielsen, A. K., Soerensen, E. E., Burcharth, K., Rosenberg, J., Impact of a temporary stoma on patients' everyday lives: feelings of uncertainty while waiting for closure of the stoma, Journal of clinical nursing, 22, 1343-1352, 2013	Study not relevant to patients' information needs
Danielsen, A. K., Soerensen, E. E., Burcharth, K., Rosenberg, J., Learning to Live With a Permanent Intestinal Ostomy Impact on Everyday Life and Educational Needs, Journal of Wound Ostomy and Continence Nursing, 40, 407-412, 2013	1/3 of participants did not have cancer
Davidge, K. M., Eskicioglu, C., Lipa, J., Ferguson, P., Swallow, C. J., Wright, F. C., Qualitative assessment of patient experiences following sacrectomy, Journal of Surgical Oncology, 101, 447-450, 2010	Patients did not have colorectal cancer
Dowswell, G., Ryan, A., Taylor, A., Daley, A., Freemantle, N., Brookes, M., Jones, J., Haslop, R., Grimmett, C., Cheng, K. K., Sue, W., Colorectal Cancer Prevention, Group, Designing an intervention to help people with colorectal adenomas reduce their intake of red and processed meat and increase their levels of physical activity: a qualitative study, BMC Cancer, 12, 255, 2012	Population did not have colorectal cancer
Drott, J., Vilhelmsson, M., Kjellgren, K., Bertero, C., Experiences With a Self-Reported Mobile Phone-Based System Among Patients With Colorectal Cancer: A Qualitative Study, JMIR Mhealth Uhealth, 4, 182-190, 2016	Study not relevant to patients' information needs

Study	Reason for exclusion
Flora, S., Zotti, P., De Paoli, A., Rectal cancer: What patients face and express during their care experience, Neuropathological Diseases, 2, 21-30, 2013	Paper unavailable from the British Library
Hardcastle, S. J., Maxwell-Smith, C., Zeps, N., Platell, C., O'Connor, M., Hagger, M. S., A qualitative study exploring health perceptions and factors influencing participation in health behaviors in colorectal cancer , Psycho-Oncology, 26, 199-205, 2017	Study not relevant to patients' information needs
Hawkins, N. A., Berkowitz, Z., Rodriguez, J. L., Miller, J. W., Sabatino, S. A., Pollack, L. A., Examining Adherence With Recommendations for Follow-Up in the Prevention Among people with colorectal cancer Study, Oncology nursing forum, 42, 233-240, 2015	Quantitative study
Herlufsen, P., Brodsgaard, A., The Lived Experiences of Persons Hospitalized for Construction of an Urgent Fecal Ostomy, Journal of Wound, Ostomy, & Continence Nursing, 44, 557-561, 2017	50% of participants did not have colorectal cancer
Hirpara, D. H., Cleghorn, M. C., Sockalingam, S., Quereshy, F. A., Understanding the complexities of shared decision-making in cancer: a qualitative study of the perspectives of patients undergoing colorectal surgery, Canadian journal of surgery, 59, 197-204, 2016	Study not relevant to patients' information needs
Hueso-Montoro, C., Bonill-de-las-Nieves, C., Celdran-Manas, M., Hernandez-Zambrano, S. M., Amezcua-Martinez, M., Morales-Asencio, J. M., Experiences and coping with the altered body image in digestive stoma patients, Revista Latino-Americana de Enfermagem, 24, 2016	Study not in English - Spanish
Ieropoli, S. C., White, V. M., Jefford, M., Akkerman, D., What models of peer support do people with colorectal cancer prefer?, European journal of cancer care, 20, 455-465, 2011	Study not relevant to patients' information needs
Jakobsson, J., Idvall, E., Kumlien, C., The lived experience of recovery during the first 6 months after colorectal cancer surgery, Journal of clinical nursing, 26, 4498-4505, 2017	Study not relevant to patients' information needs
Kelly, K. N., Noyes, K., Dolan, J., Fleming, F., Monson, J. R. T., Gonzalez, M., Sevdalis, N., Dozier, A., Patient perspective on care transitions after colorectal surgery, Journal of Surgical Research, 203, 103-112, 2016	Study not relevant to patients' information needs
Kotronoulas, G., Papadopoulou, C., Burns-Cunningham, K., Simpson, M., Maguire, R., A systematic review of the supportive care needs of people living with and beyond cancer of the colon and/or rectum, European journal of oncology nursing : the official journal of European Oncology Nursing Society, 29, 60-70, 2017	Systematic review- studies assessed individually
Krogsgaard, M., Dreyer, P., Egerod, I., Jarden, M., Post-discharge symptoms following fast-track colonic cancer surgery: a phenomenological hermeneutic study, Springerplus, 3, 2014	Study not relevant to patients' information needs
McCaughan, E., Prue, G., Parahoo, K., McIlfatrick, S., McKenna, H., Exploring and comparing the experience and coping behaviour of men and women with colorectal cancer after chemotherapy treatment: A qualitative longitudinal study, Psycho-Oncology, 21, 64-71, 2012	Study not relevant to patients' information needs
McMullen, C. K., Hornbrook, M. C., Grant, M., Baldwin, C. M., Wendel, C. S., Mohler, M. J., Altschuler, A., Ramirez, M., Krouse, R. S., The greatest challenges reported by long-term colorectal cancer with stomas, Journal of Supportive Oncology, 6, 175-182, 2008	Study did not pertain to patients' information needs

Study	Reason for exclusion
Nazareth, I., Jones, L., Irving, A., Aslett, H., Ramsay, A., Richardson, A., Tookman, A., Mason, C., King, M., Perceived concepts of continuity of care in people with colorectal and breast cancer - a qualitative case study analysis, European journal of cancer care, 17, 569-577, 2008	Mixed population - patients had breast cancer or colorectal cancer
Ohlsson-Nevo, E., Andershed, B., Nilsson, U., Anderzen-Carlsson, A., Life is back to normal and yet not - partners' and patient's experiences of life of the first year after colorectal cancer surgery, Journal of clinical nursing, 21, 555-563, 2012	Study did not pertain to patients' information needs
Pullar, J. M., Chisholm, A., Jackson, C., Dietary information for colorectal cancer : An unmet need, New Zealand Medical Journal, 125, 27-37, 2012	Quantitative methods
Salamonsen, A., Kiil, M. A., Kristoffersen, A. E., Stub, T., Berntsen, G. R., "My cancer is not my deepest concern": life course disruption influencing patient pathways and health care needs among persons living with colorectal cancer, Patient Preference and Adherence, 10, 1591-1600, 2016	Study did not pertain to patients' information needs
Sanoff, H. K., Morris, W., Mitcheltree, A. L., Wilson, S., Lund, J. L., Lack of Support and Information Regarding Long-Term Negative Effects in of Rectal Cancer, Clinical journal of oncology nursing, 19, 444-448, 2015	Study did not pertain to patients' information needs
Sarabi, N., Navipour, H., Mohammadi, E., Relative Tranquility in Ostomy Patients' Social Life: A Qualitative Content Analysis, World journal of surgery, 41, 2136-2142, 2017	Study did not pertain to patients' information needs
Sarabi, N., Navipour, H., Mohammadi, E., Sexual Performance and Reproductive Health of Patients with an Ostomy: A Qualitative Content Analysis, Sexuality and Disability, 35, 171-183, 2017	Study did not pertain to patients' information needs
Spalding, Nicola Jane, Poland, Fiona Mary, Gregory, Sheila, McCulloch, Jane, Sargen, Kevin, Vicary, Penny, Addressing patients' colorectal cancer needs in preoperative education, Health Education (0965-4283), 113, 502-516, 2013	Did not pertain to information needs
Spence, R. R., Heesch, K. C., Brown, W. J., Colorectal cancer ' exercise experiences and preferences: Qualitative findings from an exercise rehabilitation programme immediately after chemotherapy, European journal of cancer care, 20, 257-266, 2011	Study did not pertain to patients' information needs
Sterba, K. R., Zapka, J., LaPelle, N., Armeson, K., Ford, M. E., A Formative Study of Colon Cancer Surveillance Care: Implications for Survivor-Centered Interventions, Journal of Cancer Education, 30, 719-727, 2015	Study did not pertain to patients' information needs
Stuhlfauth, S., Melby, L., Helleso, R., Everyday Life After Colon Cancer: The Visible and Invisible Challenges, Cancer Nursing., 23, 2017	Study did not pertain to patients' information needs
Urquhart, R., Folkes, A., Babineau, J., Grunfeld, E., Views of breast and colorectal cancer on their routine follow-up care, Current Oncology, 19, 294-301, 2012	Mixed population with breast cancer or colorectal cancer
van Mossel, C., Leitz, L., Scott, S., Daudt, H., Dennis, D., Watson, H., Alford, M., Mitchell, A., Payeur, N., Cosby, C., Levi-Milne, R., Purkis, M. E., Information needs across the colorectal cancer care continuum: scoping the literature, European journal of cancer care, 21, 296-320, 2012	Systematic review assessing quantitative studies
Zheng, M. C., Zhang, J. E., Qin, H. Y., Fang, Y. J., Wu, X. J., Telephone follow-up for patients returning home with	Study did not pertain to patients' information needs

Study	Reason for exclusion
colostomies: Views and experiences of patients and enterostomal nurses, European Journal of Oncology Nursing, 17, 184-189, 2013	

Appendix L – Research recommendations

Research recommendations for review question: What are the information needs of people prior, during and after treatment for colorectal cancer?

No research recommendations were made for this review question.

Appendix M – Qualitative evidence and quotes

Qualitative evidence and quotes for review question: What are the information needs of people prior, during and after treatment for colorectal cancer?

Information needs prior to treatment

Table 15: Theme 1. Surgery

Study ID	Evidence
Subtheme 1: Preparation for surgery	
Abelson 2018	A few patients described having distress while preparing for the day of surgery, for example, needing to comply with the bowel preparation.
Abelson 2018	"I wish that things were explained to me a little bit more. You know, I had a lot of information thrown at me at once; scheduling the surgery, washing myself before the surgery, having a colon prep, looking at the ileostomy. It was too much at once." (Participant 21)
Steel 2016	Preparation that was required prior to extended resection surgery.
Subtheme 2: What to expect during surgery	
Abelson 2018	"I was not pre-prepared for the risks. Now she said it was a rare thing to happen; I don't know. But it happened to me, and I was not told of, or I don't remember, we'll put it that way, that I was told of a possibility of infection and subsequent drains and ileostomy, 'cause if I had, I would've asked more questions, like what the hell is that."
Abelson 2018	Some patients were worried about the pain of the operation and the recovery process
Beaver 2010	Participants often reported not understanding whether their physical symptoms were 'normal' for patients who had experienced colorectal cancer surgery. Participants stated that they would have appreciated more information on what to expect to alleviate anxiety and concerns
Gillis 2017	The pain that surprised many participants was the high level of intraperitoneal gas pain they experienced as a result of the inflation of the abdomen for laparoscopic surgery.
Ho 2016	Have an explicit explanation at the start of treatment that the proposed management plan serves merely as a guide and that treatment may change depending on its efficacy and toxicities.
Steel 2016	Three would have liked more information prior to surgery on the possibility of a permanent ileostomy and how that would affect their lifestyle.
Steel 2016	Two participants unexpectedly had more than just their colon removed during surgery, including the removal of an ovary in one instance and the removal of a large number of lymph glands in another. Although both of these outcomes were necessary to reduce the risk of future cancers, these participants felt they should have been prepared beforehand for such an outcome.
Wilson 2010	Insufficient information could result in patients feeling ill prepared for the treatment or later regretting treatment decisions that they had been involved in.
What to expect after surgery	
Abelson 2018	For other patients, part of the concern was that they did not believe they were told of the risk of having poor control of bowel movements.
Abelson 2018	"I had moments of fear, anger, panic, resentment that nobody told me how hard it would be. That was one thing that was not brought up or discussed. They tell you if you excessive swelling, call, but they don't tell you what normally happens."
Beaver 2010	Patients frequently discussed uncertainty about their condition and not knowing what to expect after surgery for colorectal cancer
Beaver 2010	Unsure of what to expect when they returned home…particularly the case for those patients who did not have a stoma, as they did not usually receive a visit from a nurse specialist once discharged home.

Beaver 2010	Uncertain about their condition and what to expect.
Brown 2016	Some described feeling that how things might change after surgery had been less well explained than other aspects of their treatment and a number seemed unsure whether their current symptoms were related to cancer or not, asking the researcher what the implications of treatment might be and seeking affirmation as to whether other people were experiencing similar problems.
Brown 2016	Most participants expressed a preference for being ‘warned’ about the possibility of an altered bowel habit and some of the things that it might affect, prior to experiencing it.
Brown 2016	Participants felt they would have also benefited from more general information about how life might change after treatment.
Steel 2016	Issues included not knowing what to expect physically and mentally, not being prepared for how many tubes and connections would be present after surgery, and not being certain about how long the recovery process should take.
Veitch 2008	Participants reported being concerned about the severity and lack of preparation/information with respect to possible treatment side-effects. This was in addition to the treatment side-effects themselves.

Table 16: Theme 2. Recovery

Study ID	**Evidence**
Diet	
Brown 2016	The biggest gap was surrounding change in bowel habit and diet adaptation.
Accessing resources and services	
Gillis 2017	Lack of knowledge of available resources meant few patients even reached out to community services on their own.
Gillis 2017	Guidance in the access of appropriate services, would have helped them during the waiting period for surgery, and allowed them to go into surgery much calmer
Effect of treatment on sexual function	
Dowswell 2011	More than half of the men who developed erectile dysfunction after treatment for colorectal cancer believed that they had not been warned specifically about erectile dysfunction.
Dowswell 2011	There seemed to be a strong trend for clinicians to offer the most information and help to younger men and for the greatest offence to be given to patients perceived to be “too old”
Dowswell 2011	If patients asked about possible erectile dysfunction, positive (but inadvertently misleading) information was given: [the] nurse gave me the injection, I did ask the nurse will this interfere with any sexual activity and her reply to that was “oh you’ll be perfectly okay, we have tablets for that”
Hall 2012	Participants reported the issues surrounding possible impotence, sexual problems and body image being addressed by their surgeon or oncologist. Many received information booklets and some surgeons discussed the risks with patients before surgery

Table 17: Theme 3. Treatment decision making

Study ID	**Evidence**
Awareness of CRC and treatments	
Abelson 2018	“I always question myself. What did I do? Growing up during the years, did I follow the right diet? Did I do this?” (Participant 19)
Abelson 2018	“I was just really ashamed at myself when I look back at all the things that I should have done, that I didn’t get it checked out sooner.” (Participant 1)
Veitch 2008	All participants reported very limited knowledge or even awareness of CRC before their diagnosis. Many felt they may have acted sooner if they had had better knowledge about CRC signs and symptoms.
Veitch 2008	All felt there was a great need for community education about CRC, most especially the need to educate relatives of CRC patients and their need to be screened.

Veitch 2008	Some were ignorant of the potentially serious nature of the problem; thinking that the symptoms could be explained by other factors, such as lifestyle or a less threatening condition.
Wilson 2010	Some information was seen as ambiguous, for example the potential benefits of adjuvant chemotherapy.
Cost of care	
Ho 2016	They wanted to be informed if certain supportive care medications were not fully covered by the public healthcare system. With this knowledge, they felt that they would have been better able to decide whether or not they could proceed with a medication that required them to pay from out-of-pocket.
Preoperative assessments	
Abelson 2018	“The hardest part probably for me for the whole experience will have been the time waiting for the biopsy results.” (Participant 14)
Abelson 2018	“Yeah, well that was the hard part, it’s the waiting. She showed me the pictures. I can see it there. I’m like, “Is there any chance that it’s just benign?” (Participant 1)
Abelson 2018	Some patients reported distress waiting for communication of test results from a physician’s office confirming the colorectal cancer diagnosis. For other patients, the distress waiting for results stemmed from waiting for communication regarding staging results to determine if they would need chemotherapy.
Abelson 2018	“I cried with (my husband) and I got nervous like what stage is this? Is this true? Did it go to the liver, will I need chemo.” (Participant 6)
Gillis 2017	Perceived lack of information regarding the results of preoperative assessments, what the surgeon had planned to do and how long it would take to recover from the surgery were all presurgery stressors
Gillis 2017	Many patients were unaware of the necessary time required to review and report these results [biopsy or other test results], and this caused undue anxiety.

Table 18: Theme 4. Timing and delivery of information

Study ID	Evidence
Beaver 2010	Information overload was a common theme in barriers to patient education, and participants described a preference for being given information initially prior to surgery but with the addition of ‘updates’ following treatment.
Gillis 2017	Many patients perceived that the preoperative information provided came too late.
Ho 2016	The majority of CRC survivors felt overwhelmed by the amount of information presented at the initial consultation appointment. Many believe that their abilities to absorb and retain information were limited at this phase of their illness when denial and disbelief were still so pervasive.
Ho 2016	Many suggested that it would be helpful to receive all of the information in a binder or be able to access such details at a ‘central’ information resource centre where patients could seek assistance when desired.
Hoedjes 2017	They preferred to receive support both during and after treatment, but particularly after completion of treatment. Two periods were preferred in particular: the period from directly after the operation to the first visit after the operation, and the follow-up period, when the frequency of hospital visits decreases and the time between visits increases.

Information needs during treatment

Table 19: Theme 1. Diet

Study ID	Evidence
Gillis 2017	They would have preferred some guidance about appropriate food for relatives to bring from home.
Hall 2012	“Well I had very helpful information in the hospital about what applies and not applies to eating in the early stages”
Hall 2012	The majority of the 2009 interviewees reported the availability of leaflets or diet sheets from the dieticians whilst in hospital.

1 **Table 20: Theme 2. Others' experiences**

Study ID	Evidence
McCaughan 2011	Opportunity to learn about others' experiences
McCaughan 2011	There were also opportunities to hear second hand information about other people with cancer.
McCaughan 2011	Participants compared their treatment with others, and chemotherapy and its effects seemed to dominate the narratives… different types of chemotherapy and its side effects.

2 **Table 21: Theme 3. Cancer prognosis**

Study ID	Evidence
Abelson 2018	“Too much information about [complication] risks is not helpful. It gives you more stuff to worry about.” (Participant 24)
Gillis 2017	Lack of information around biopsy results, inconsistency in information sharing between providers at shift changes, perceived mismanagement of nasogastric tubes and an inability to have a conversation with their surgeon.
McCaughan 2011	Participants were interested to know how long people lived with cancer (not just colorectal), how long people were disease-free and whether they would have a similar experience.

3 Information needs after treatment

4 **Table 22: Theme 1. Lifestyle**

Study ID	Evidence
Subtheme 1: Diet	
Anderson 2013	Patients' perceived needs for advice on diet, activity and lifestyle in the immediate post-treatment period were related to a range of physical and psychological challenges, including loss of control of bodily functions, fatigue, sleep problems, sexual dysfunction, fear of recurrence and reduced mobility.
Anderson 2013	For many participants, diarrhoea and flatulence were daily problems for which they sought simple practical dietary advice on foods to avoid. Many also wanted information about the incompatibility of some foods with their medical appliances.
Anderson 2013	Indeed, some participants reported that practitioners had turned orthodox medical advice on healthy eating ‘on its head’ after surgery by recommending fatty junk food; this caused confusion and anxiety among patients.
Anderson 2013	But a ‘trial and error’ approach was often regarded as almost ‘useless’, and instead, participants wanted some kind of parameters as to what their system may now be able or unable to cope with.
Beaver 2010	A commonly expressed concern related to diet and what specific type of diet would be appropriate following removal of part of the bowel.
Beaver 2010	Participants considered that information on diet should have been provided prior to discharge from hospital.
Brown 2016	They did however highlight that as with information provision, the gap in support services is surrounding bowel function and diet and almost all participants felt that cancer specific input from a dietician would be beneficial.
Hoedjes 2017	Participants reported a need for an easily accessible contact person or information point to be able to receive answers to their questions, and to receive information and individually-tailored advice, for example on lifestyle-related issues such as appropriate nutrition, and the use of dietary supplements.
Physical activity	
Maxwell-Smith 2017	Many participants reported receiving little advice concerning physical activity from medical professionals.
Maxwell-Smith 2017	When asked whether health care professionals recommended a duration, intensity, or frequency for walking, Mary responded, “Ah no.”

Maxwell-Smith 2017	When asked about the government guidelines, participants were commonly unaware that such guidelines existed, “I don't know what you mean” (Jenny, aged 72 years).
Managing bodily functions	
Anderson 2013	In the longer term (post 6 months after treatment), many participants continued to experience problems with bodily functioning (diarrhoea), weight gain and work and therefore still wanted advice on diet, exercise, and work-life balance.
Anderson 2013	Some participants wanted to know if there were specific exercises they could do to ameliorate symptoms such as diarrhoea.
Steel 2016	How to manage bowel movements, and how to adjust to life in general following an extended resection.
Taylor 2013	Participants observed that advice about changes in bowel function from health care professionals relied heavily on pharmacological management.
Taylor 2013	“I think the fact I had studied the leaflet in detail before the reversal helped, but my experience was bad, if not worse, than what it says here.”

Table 23: Theme 2. Medical information

Study ID	Evidence
Stoma care	
Beaver 2010	Those patients with a stoma frequently commented on learning more about their stoma care through ‘trial and error’, as follow-up care did not provide sufficient information on provision of stoma bags and care.
Beaver 2010	Having a stoma presented practical problems and a potential loss of independence. Participants reported concerns about the appearance and visibility of the stoma bag through clothing.
Hall 2012	Support from stoma nurses was appreciated.
Hoedjes 2017	A need for advice on appropriate nutrition to reduce problems with their stoma, such as noise and odours caused by certain foods.
Medical issues	
Brown 2016	Overall awareness of treatment consequences…Although all were aware of recurrence as a risk, when asked how else they felt they might be affected in the future, none expressed concern about any other complications; some felt they would have encountered problems by now and others did not think there was anything else that might happen.
Brown 2016	It became apparent that many continued to be affected by implications of their own treatment and often described feeling unaware of their risk before encountering them.
Gillis 2017	Some participants raised major concerns that had not been fully explained, including bleeding from the rectum, variation in bowel movements and diet.
Gillis 2017	There was uncertainty regarding the best service to contact.
Hall 2012	Some participants reported specifically looking for information and reassurance from general practice on medical issues following treatment.
Ho 2016	Side effects to expect ex: pain from radiotherapy
Hoedjes 2017	Individually-tailored advice regarding their disease and treatment-related complaints (e.g., lack of strength, lack of energy, lymphedema, stoma-related problems, and bowel complaints such as too frequent stools and changes in the consistency of the stool).
Sex specific issues	
Dowswell 2011	Not all knew where to seek help for erectile dysfunction. Some men took part in our study specifically to ask for help and to get a sense of what the norms might be. No coordinated system of care for erectile dysfunction was apparent from accounts
Ho 2016	Frustration in terms of gynaecological side effects with many commenting that male healthcare providers appeared uncomfortable discussing these issues.