National Institute for Health and Care Excellence

Draft for consultation

Barrett's oesophagus

8.1 Evidence reviews for Patient information for Barrett's oesophagus or stage 1 adenocarcinoma

NICE guideline <number>

Evidence reviews underpinning recommendations 1.8.1 to 1.8.4 in the NICE guideline

August 2022

Draft for consultation

These evidence reviews were developed by Guideline Development Team NGC

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Contents

1 Patient information for Barrett's oesophagus or stage 1 adenocarcinoma

1.1 Review question

What information and support should be provided to patients (or carers or families) who are having or considering follow-up or treatment for Barrett's oesophagus or stage 1 adenocarcinoma?

1.1.1 Introduction

Barrett's oesophagus occurs as a result of injury to the mucosa of the oesophagus caused by chronic gastro oesophageal reflux. Characterised by replacement of the normal squamous epithelium with an intestinal columnar epithelium, it is a potentially premalignant condition.

The psychological impact on patients of being diagnosed with a condition that may or may not progress to cancer cannot be underestimated.

Good communication between healthcare professionals and patients is an essential part of ongoing management, considering the needs and preferences of patients carefully. The information should be both verbal and written, in simple language and should include details of the treatments available and the potential outcomes of the various treatments. Patients should also be given details of any Patient Support Groups where known.

1.1.2 Summary of the protocol

For full details see the review protocol in Appendix A.

Table 1: PICO characteristics of review question

Objective	To determine what information and support is needed by people (or carers and families) who are or considering having treatment or follow-up for Barrett's Oesophagus or Stage 1 oesophageal adenocarcinoma
Population and setting	Inclusion: Adults, 18 years and over, with Barrett's Oesophagus or Stage oesophageal 1 adenocarcinoma Exclusion: Adults with Barrett's Oesophagus beyond Stage 1 adenocarcinoma.
Context	Barrett's Oesophagus is associated with significant sequelae and can have a notable effect on the person's life. Adequate information provision for a person with Barrett's and their family and/or carer can aid care planning and management, improve understanding and accuracy of expectations, and can influence quality of life. This information for a person with Barrett's and their family and/or carer provided both within the immediate care setting and in the community following discharge can be invaluable.
Review strategy	The synthesis of qualitative data will follow a thematic analysis approach. Information will be synthesised into main review findings. Results will be presented in a detailed narrative and in table format with summary statements of main review findings. GRADE CERQual will be used to synthesise the qualitative data and assess the certainty of evidence for each review finding.

	Quantitative data from surveys reporting patient information preferences will be reported narratively and presented alongside thematic analysis. Risk of bias will be assessed to ascertain outcome quality.

1.1.3 Methods and process

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

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

1.1.4 Qualitative evidence

1.1.4.1 Included studies

Six studies were included in the review; [1-6] these are summarised in Table 2 below. Key findings from these studies are summarised in the clinical evidence summary below (Table 3). See also the study selection flow chart – Appendix C, study evidence tables in Appendix D, and excluded studies lists in– Excluded studies Appendix F.

Studies included four qualitative studies and two questionnaire studies reporting quantitative data about the information and support needs of people with Barrett's oesophagus. This information has been extracted and included in the qualitative synthesis to help illustrate the themes emerging from the qualitative studies.

Included studies were on people with Barrett's oesophagus. No relevant studies including families or carers of people with Barrett's oesophagus were identified.

Most studies were conducted in the UK with one study being conducted in the USA.

1.1.4.2 Excluded studies

A table of excluded studies can be found in – Excluded studies F.

1.1.5 Summary of studies included in the qualitative evidence

Table 2: Summary of studies included in the evidence review

Study	Design	Population	Research aim	Comments
Arney 2014 [1]	Structured, in-depth qualitative interviews with framework analysis methodology.	Barrett's oesophagus patients (n=20) who had received at least one surveillance esophagogastroduodenoscopy (EGD). Mean age (SD): 62.9 (7.32) years; n=9 were diagnosed with no dysplasia, n=10 with low-grade dysplasia and n=1	To define the patient experience of EGD from in-depth qualitative interviews with patients who recently underwent surveillance EGD.	35% completed five or more surveillance EGDs; 25% completed only 1 prior EGD. Mean number (range) of completed EGDs: 4.3 (1-20). None of the EGD procedures were performed using propofol or monitored anaesthesia care;

Study	Design	Population	Research aim	Comments
		with high-grade dysplasia. USA		90% were performed under conscious sedation combined with topical anaesthesia to the back of the throat.
Bailey 2009[2]	Semi-structured interviews with thematic analysis	Patients enrolled on a Barrett's surveillance programme in a large teaching hospital. (N=15) Median age: 59 years (36-77) UK	To assess patients' perceptions, experience, and informational needs about Barrett's oesophagus to improve the understanding of health professionals and therefore their ability to provide the best care for their patients.	Participants had been on a surveillance programme for a combined total of 92 years, with a mean of 6 years (ranging from 1–21 years). Eleven participants (73%) were receiving 2-yearly surveillance endoscopies.
Britton 2019[3]	Exploratory qualitative research, part of a concurrent mixed-methods study involving semi-structured interviews with thematic analysis	Patients with Barrett's oesophagus, enrolled in surveillance at a single general NHS hospital (N=20) Median age= 63 years (42-77 y) UK	To identify and explore factors impacting BO patients' HRQOL, the follow-up needs of BO patients and patients' perceptions and attitudes to new models of follow-up care	Participant's demographics and disease-specific information were also collected from their medical notes and endoscopy reports. Field notes were taken at the time of each interview.
Cooper 2009[4]	Questionnaire study with quantitative analysis	Barrett's oesophagus patients undergoing surveillance (n=151) Median age (range): 66 (41-79). No dysplasia 90%, indefinite dysplasia 3%, low-grade	To examine the experience of patients undergoing endoscopic surveillance for BO, their levels of anxiety and depression, and quality of life and how the relationship with their physicians influences these factors.	The questionnaire included seven questions on patients' attitudes towards Barrett's oesophagus and endoscopic surveillance, and perceptions of cancer risk in Barrett's oesophagus.

Study	Design	Population	Research aim	Comments
		dysplasia 7%, high-grade dysplasia 0% UK		
Gough 2003[5]	Postal questionnaire with quantitative analysis	Barrett's oesophagus patients identified via the 'Endoscribe' database (n=195). Characteristics not specified. UK	To assess the sources of information for a group of patients with Barrett's oesophagus; the availability of Internet access for the patients and their views on the future availability and delivery of information.	People with oesophageal adenocarcinoma were excluded.
Griffiths 2011[6]	Qualitative semi-structured interviews with framework for content analysis.	People at high risk of malignant progression from Barrett's columnar lined oesophagus enrolled in endoscopic surveillance program (N=22) Aged 50-70 years UK	To explore patients' knowledge and understanding of Barrett's oesophagus and how the information forming the basis of that knowledge and understanding influenced their self-management.	Those with serious concomitant disease such as cancer, those who were unable to give valid consent, non-English speaking patients and those unable to read or write were excluded.

1 See Appendix D for full evidence tables.

2 1.1.6 Summary of the qualitative evidence

3 **Table 3: Review findings**

Main findings	Statement of finding
Information needs	
Information about surveillance endoscopy (Arney 2014; Bailey 2009; Cooper 2009) [1, 2, 4]	People need clear and detailed information about endoscopic surveillance, the procedure, its purpose, the risks involved as this can improve the patient's experience during the procedure and their relationship with their doctor.
Information about the risk of cancer (Bailey 2009; Britton 2019, Cooper 2009, Griffiths 2011) [2-4, 6]	There is often a lack of information about the risk of cancer in Barrett's oesophagus that is often a source of anxiety for patients resulting in their over or under estimation of their cancer risk.
Information about symptom management (Bailey 2009)[2]	Patients lack information about symptom management and potential lifestyle changes that may reduce the burden of their symptoms.

Main findings	Statement of finding
Easier to understand information (Cooper 2009, Gough 2003, Griffiths 2011)[4-6]	Information available about Barrett's oesophagus was perceived by many to be difficult to understand and this was partly due to the reported usage of medical terminology.
Information about Barrett's oesophagus (Britton 2019; Gough 2003) [3, 5]	People required further information about their condition, with some having inaccurate views about what Barrett's oesophagus; their lack of knowledge enhanced cancer worry and impacted their ability to manage symptom flares.
Other types of information (Gough 2003) [5]	Other types of information people considered useful included information about current treatments and new therapeutic developments, alternative therapies and clinical trials.
Sources of information (Bailey 2009; Britton 2019; Gough 2003) [2, 3, 5]	In addition to the information they had been given, people appeared to seek further information mostly from the internet, the hospital doctor or GP and less frequently from nurses, newspapers, NHS direct, family or friends.
Amount of information (Bailey 2009)[2]	People undergoing surveillance felt too much information was not necessary unless the condition was found to progress.
Support needs	
Support and respect from the physician during endoscopy (Arney 2014; Britton 2019) [1, 3]	Perceived lack of support and respect from their physician or GP led patients to have negative experiences of endoscopic surveillance and often to a lack of trust in their doctor, whereas effective communication helped cope with anxiety related to surveillance endoscopy.
Need for surveillance (Arney 2014)[1]	Barrett's oesophagus patients expressed that surveillance allows monitoring the progression of Barrett's oesophagus, providing a sense of control.
Post-diagnosis information and support (Britton 2019)[3]	After undergoing endoscopy, people experienced a lack of attention to their needs and a lack of information about their diagnosis with many expressing the need for a face-to-face consultation after diagnosis.

See Appendix E for full GRADE-CERQual tables.

Narrative summary of review findings

Review finding 1: Information about surveillance endoscopy

In describing their experiences with endoscopy, some patients recalled their physician explaining details about the surveillance esophagogastroduodenoscopy (EGD) instrument, mechanics of the procedure, specific risks, and likelihood of encountering problems. They were aware of the risks of having an endoscopy with some commenting that they received an information leaflet each time with their appointment letter. On the other hand, several patients mentioned that they did not recall detailed conversations with a physician about endoscopy and were left with many questions about what to expect. They discussed their uncertainty about the endoscopy instrument, the purpose of the procedure, and what to expect after the EGD. Patients who felt informed, respected, and experienced little or no discomfort during an EGD often discussed having a high degree of trust in their doctors and in the endoscopy centre more generally. On the other hand, patients who felt under-informed, disrespected, or experienced pain during an EGD often discussed a loss of trust in their doctors. People reporting positive experiences of endoscopy, reported having received clear explanation of the procedure and the risks involved. People reporting negative experiences reported a lack of information for example about biopsies taking place or details of the procedure. Some patients voiced concerns about the risks of EGD, including the fear that the endoscopy could cause “punctures of the tissue by the instrument” or more generally, one patient worried about “somebody screwing the procedure up”.

A survey of 151 Barrett’s oesophagus patients supported the need for information about endoscopic surveillance with 43 patients (29%) reporting receiving too little information concerning surveillance of Barrett’s oesophagus and 33 (22%) no information at all. The information was reported to be difficult to understand by 24%, with 85% of responders expressing a desire for further information.

Explanation of quality assessment: Minor concerns over methodological limitations with minor concerns across three studies (due to the relationship between researcher and participants not having been considered in two studies, due to sample size not having been based on pre-study considerations of statistical power in the survey); minor concerns about coherence with some people expressing they had received sufficient information and not requiring further information in two studies; no concerns over relevance; no concerns over adequacy with sufficient information from three studies supporting the theme. Overall assessment of confidence was moderate due to minor concerns over methodological limitations and coherence.

Review finding 2: Information about the risk of cancer

People tended to over or underestimated their risk of cancer with some perceiving their risk of developing cancer to be low and not to be anxious or concerned about it. Many expressed there was a lack of information about the risk of cancer but had mixed views regarding how they dealt with the uncertainty and perceived threat of cancer. Inadequate knowledge appeared to enhance cancer worry or reduce the ability to self-manage symptom flares for some, while others reacted positively and took control over their lifestyle. Overestimation of cancer risk was also linked with higher anxiety and worry about cancer whereas people who correctly viewed their risk as low, generally, appeared to have less worry.

A survey of 151 Barrett’s oesophagus patients supported the need for information about the risk of cancer. Respondents tended to underestimate the risk of cancer in Barrett’s oesophagus with 58% estimating that the risk of developing cancer over 10 years was 2% or less. 109 patients (74%) felt that surveillance would reduce the risk of developing oesophageal cancer, with seven (5%) believing that the risk was completely negated and 72 (49%) that the risk was greatly reduced.

Explanation of quality assessment: Minor concerns over methodological limitations with minor concerns across three studies (due to the relationship between researcher and participants not having been considered in two studies and due to the sample size not having been based on pre-study considerations of statistical power in the survey); no concerns in the fourth contributing study; no concerns about coherence; no concerns about relevance; no concerns about adequacy with information from four studies supporting the theme. Overall assessment of confidence was moderate due to concerns over methodological limitations.

Review finding 3: Information about symptom management

Barrett’s oesophagus patients lacked general information regarding managing their symptoms. A small number of the patients stated that they would have liked some additional information with regards to lifestyle changes and tips on how to manage the symptoms that some of them still found troublesome occasionally.

Explanation of quality assessment: Minor concerns over methodological limitations in the contributing study due to the relationship between researcher and participants not having been considered; no concerns about coherence; no concerns about relevance; serious concerns about adequacy due to limited information from one study supporting the theme.

Overall assessment of confidence was low due to the concerns over methodological limitations and adequacy.

Review finding 4: Easier to understand information

People at high risk of malignant progression reported usage of medical terminology by doctors as one of the reasons of low health literacy and lack of understanding amongst them.

Information received regarding Barrett’s oesophagus was reported to be difficult to understand by 24% of people undergoing surveillance who responded to a questionnaire survey and 41.5% of people with Barrett’s oesophagus responding to a different survey.

Explanation of quality assessment: Minor concerns over methodological limitations with no concerns in the qualitative study contributing to the theme but minor concerns over one contributing survey (due to sample size not having been based on pre-study considerations of statistical power) and moderate concerns in the other contributing survey (due to lack of information on the analysis and sample); minor concerns about coherence with the majority of participants in one of the contributing surveys reporting the information they had found was easy to understand (n=104; 54.4%); moderate concerns over applicability with no concerns in the qualitative study, but moderate concerns in one survey (due to the closed questionnaire design, the questions of which may have limited the patient views expressed and the lack of information about participant characteristics) and due to the views expressed in the other contributing survey most likely being about information participants had found themselves, rather than the information provided to them by healthcare professionals; minor concerns about adequacy with limited information from three studies supporting the theme. Overall assessment of confidence was very low due to the concerns identified across elements of quality assessment.

Review finding 5: Information about Barrett’s oesophagus

Some people with Barrett’s oesophagus undergoing surveillance held inaccurate views of exactly what Barrett’s oesophagus is, with some over or underestimating their cancer risk. Misleading or inadequate knowledge appeared to have detrimental effects such as enhancing cancer worry or reducing their ability to self-manage symptom flares.

The vast majority (78.5%) of people with Barrett’s oesophagus responding to a questionnaire survey reported they wanted more information about their condition, with only 17.9% reporting they did not want further information.

Explanation of quality assessment: moderate concerns over methodological limitations with minor concerns in one study (due to the relationship between researcher and participants not being considered) and moderate concerns in the contributing survey (due to lack of information on the analysis and sample); no concerns about coherence; minor concerns over relevance with no concerns in one study and moderate concerns in the other study (given the close-questionnaire design, the questions of which may have limited the patient views expressed and the lack of information about participant characteristics); moderate concerns about adequacy with limited information from two studies supporting the theme. Overall assessment of confidence was very low due to moderate concerns over methodological limitation and adequacy and minor concerns over relevance.

Review finding 6: Other types of information

Barrett’s oesophagus patients were questioned about what information would be useful on a Web site. 119 (61%) responded ‘Yes’ to information about current treatment, 96(49.2%) to information about new therapeutic developments, 86 (44.1%) to information about alternative therapies, 80 (41%) to information about clinical trials, 76 (39%) to information about Investigations, 18 (9.2) responded ‘Yes’ to ‘Other’ type of information.

Explanation of quality assessment: Moderate concerns over methodological limitations (due to lack of information on the analysis and sample); no concerns about coherence; moderate concerns over relevance given the close-questionnaire design, the questions of which may have limited the patient views expressed and the lack of information about participant characteristics; serious concerns about adequacy with information supporting the theme limited to one survey. Overall assessment of confidence was very low due to the concerns over methodological limitations, relevance and adequacy.

Review finding 7: Sources of information

Barrett's oesophagus patients undergoing surveillance reported that they were given information verbally. Nearly all sought further information and were predominantly self-educated via the Internet, newspaper articles, books, or radio shows with the Internet being by far the most common resource used; however, participants expressed concerns and fears over obtaining inaccurate information with no clear guidance on where to find trusted sources online. People who were aware of the risks of having an endoscopy specified that they received an information leaflet each time with their appointment letter.

Survey responders sought information most frequently from the Hospital Doctor (n=137, 70.3%), their GP (n=119; 61%) and less frequently from leaflets (n=23; 11.8%), the Internet (n=18; 9.2%), nurses (n=11; 5.6%), magazine/newspaper (n=11; 5.6%), Family/friends (n=9; 4.6%), NHS Direct (n=8; 4.1%). 105 (53.8%) patients stated that they would use an Internet site if access was available. 79 (40.5%) stated they would not use an Internet site.

Explanation of quality assessment: minor concerns over methodological limitations with minor concerns in two studies (due to the relationship between researcher and participants not being considered) and moderate concerns in the contributing survey (due to lack of information on the analysis and sample); minor concerns about coherence with different views emerging about the use of the internet as a source of information; minor concerns over applicability with no concerns in two contributing studies but moderate concerns in the contributing survey (given the close-questionnaire design, the questions of which may have limited the patient views expressed and the lack of information about participant characteristics); moderate concerns about adequacy with limited information from three studies illustrating the theme. Overall assessment of confidence was low due to the concerns over methodological limitations, coherence, relevance, and adequacy.

Review finding 8: Amount of information

Most people undergoing surveillance for Barrett's oesophagus expressed that too much information was not a good thing unless the condition was found to have progressed. They were satisfied with the level of information they had received. Although very few seemed to be aware of the major surgical treatment required should the disease progressed, many chose not to explore this further despite being aware that further information was available. Only a small number of people sought further information either themselves or through their partner or friend.

Explanation of quality assessment: Minor concerns over methodological limitations in the contributing study (due to the relationship between researcher and participants not being discussed and the researcher having personally conducted the interviews); no concerns about coherence; no concerns about relevance; moderate concerns about adequacy with relatively limited information from one study supporting the theme. Overall assessment of confidence was low due to the concerns over methodological limitations and adequacy.

Review finding 9: Support and respect from the physician during endoscopy

Effective communication from health-care professionals in the procedure room appears vitally important in counteracting and helping cope anxiety related to surveillance endoscopy.

A few Barrett’s oesophagus patients undergoing surveillance discussed how well they were treated by their physician, for instance, describing how a physician eased their anxiety upon arriving for the endoscopy procedure and comforted them during the procedure. On the other hand, several participants’ salient memories of surveillance involved feelings of not being treated well or feeling disrespected. Such mentions of “disrespect” often involved patients’ requests being “ignored,” and others reported they were incapable of movement during the procedure because they were “strapped down”. Participants with supportive and caring GPs appeared to have more satisfaction and trust in their GP’s abilities to deal with their Barrett’s oesophagus. Some participants felt their GP was dismissive or lacked knowledge regarding their condition.

Explanation of quality assessment: Minor concerns over methodological limitations with minor concerns in two studies (due to relationship between researcher and participants not having been considered); no concerns about coherence; no concerns about relevance; minor concerns about adequacy due to relatively limited information from two studies supporting the theme. Overall assessment of confidence was moderate due to the concerns over methodological limitations and adequacy.

Review finding 10: Need for surveillance

Patients acknowledged that surveillance allows them to monitor progression of Barrett’s oesophagus to cancer and increases the likelihood of identifying problems in their early stages. Other patients acknowledged that while they may tend to worry about Barrett’s oesophagus, surveillance gives them a sense of control over it. Thus, for many patients, the most salient aspect of the surveillance experience is the sense of control they receive from having Barrett’s oesophagus monitored.

Explanation of quality assessment: minor concerns over methodological limitations in the contributing study (due to the relationship between the researcher and participants not having been considered); no concerns about coherence; no concerns over relevance; moderate concerns over adequacy with relatively limited information from one study supporting the theme. Overall assessment of confidence was low due to the concerns over methodological limitations and adequacy.

Review finding 11: Post-diagnosis information and support

People reported inadequate attention to their needs and information regarding Barrett’s oesophagus post endoscopy procedure. Some were unaware of their diagnosis until they were asked to attend the next surveillance endoscopy. Many preferred a face-to-face consultation after diagnosis to allow for questions and reported knowledge gaps and key uncertainties at the time of diagnosis.

Explanation of quality assessment: minor concerns over methodological limitations in the contributing study (due to the relationship between the researcher and participants not having been considered); no concerns about coherence; no concerns over relevance; serious concerns over adequacy with limited information from one study supporting the theme. Overall assessment of confidence was low due to the concerns over methodological limitations and adequacy.

1.1.7 Economic evidence

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

1.1.9 The committee's discussion and interpretation of the evidence

1.1.9.2 The outcomes that matter most

This review looked at the information and support needs of people with Barrett's oesophagus or stage 1 oesophageal adenocarcinoma, and their families or carers by analysis of views, opinions and experiences reported. Information emerging from qualitative studies as well as quantitative data, such as incidence rate or frequencies of information preference from questionnaires, were summarised into different themes. Themes were derived from the evidence identified and were not prespecified by the committee. Evidence from four qualitative studies and two quantitative studies were identified for people with Barrett's oesophagus. No evidence was identified for people with stage 1 oesophageal adenocarcinoma, or for families or carers.

1.1.9.2 The quality of the evidence

Confidence in the evidence base informing the review ranged from very low to moderate. Confidence in the evidence for 3 out of 11 themes was moderate, confidence for 5 out of 11 themes was low, and confidence for a further 3 themes was very low. The primary reasons for downgrading review findings were due to methodological limitations in the contributing studies. These included the relationship between the researcher and the participants not having been explored, concerns about the adequacy of information to support each theme, or limited information supporting the emergent theme. Evidence was occasionally downgraded due to concerns over coherence, with participants within or across studies expressing opposing views about their information and support needs. Also due to concerns over relevance that were due to a lack of information on participant characteristics, or the use of closed questionnaire limiting the views expressed by participants.

1.1.9.3 Findings identified in the evidence synthesis

The committee agreed the findings emerging from the evidence were consistent with the views and needs expressed by people with Barrett's oesophagus that they see in clinical practice. In particular general information about Barrett's oesophagus, information about surveillance endoscopy, and risk of cancer.

In the evidence, people with Barrett's oesophagus reported that a lot of information about the condition was not helpful unless their condition was to progress. In the committee's experience, people differ in regard to the amount of information they wish to have, with some wanting as much information as possible and others not wishing to have too much. They agreed the amount of information that is given to patients should be assessed on a case-by-case basis by the clinician and should be tailored based on the patients' individual circumstances and needs.

The evidence also highlighted a need for information and support following their diagnosis of Barrett's oesophagus. Many people reported knowledge gaps and uncertainties at the time of diagnosis that were not resolved until the next surveillance endoscopy. The committee agreed there is a need for discussion at the time of diagnosis as information and support during this time can lead to a better understanding and less anxiety. Within this context the committee agreed people would be offered a clinical consultation to discuss their diagnosis and any concerns they may have at the initial stages of their treatment.

People reported difficulty understanding the information they were given, that was largely attributed to the use of medical terminology by health-care professionals. The committee agreed on the importance of providing people with information that is easy to understand. They noted that in clinical practice, people are given a copy of their endoscopy report that is not written in easy-to-understand language and will include medical terminology. There was consensus amongst the committee that the endoscopy report should be adapted to be more useful for people, by containing a lay summary of the endoscopic findings in addition to the technical data included in the report. The committee emphasised that surveillance endoscopy appointments should not be limited to the endoscopic procedure. They also provide an opportunity for clinicians to offer people information and support as well as to discuss the endoscopy findings. The committee was aware that including a lay summary in the endoscopy report and explaining the endoscopy findings during the medical consultation is likely to be more time consuming but agreed this was a very important modification that can improve the understanding of patients.

The evidence highlighted that people with Barrett's oesophagus often lack information about symptom management. The committee thought that symptom control is an important area that people should receive information about. They agreed there is a need for additional time during Barrett's surveillance appointments to allow health-professionals to give people information about symptom control.

People also raised their experience with different sources of information, including verbal information by health-care professionals, leaflets, and the internet. Findings reported some expressing concerns about obtaining inaccurate information and a lack of guidance on trusted online sources. The committee emphasised the importance of providing people with written information in the form of leaflets that they can turn to when needed rather than relying on their recollection of information provided verbally.

1.1.9.4 Cost effectiveness and resource use

Cost effectiveness evidence was not sought as this was a qualitative review. The recommendations generally provide guidance regarding the content of information and support specific to people with Barrett's oesophagus in line with the general principles of provision of information already established in the existing NICE Patient Experience Guideline. However, the committee acknowledged that practice among clinicians in dispensing specific support was not universal and that any move towards standardisation would incur some increase in health care professional time, most likely during the initial endoscopic surveillance appointment. The magnitude of this increase required is not clear.

1.1.9.5 Other factors the committee took into account

The committee considered that the recommendations on communication, information and shared decision making within the Patient experience in adult NHS services guideline were applicable and agreed to cross reference to this.

1.1.10 Recommendations supported by this evidence review

This evidence review supports recommendations 1.8.1, 1.8.2, 1.8.3 and 1.8.4.

1.1.11 References

1. Arney J, Hinojosa-Lindsey M, Street RL, Jr., Hou J, El-Serag HB, Naik AD. Patient experiences with surveillance endoscopy: A qualitative study. Digestive Diseases and Sciences. 2014; 59(7):1378-1385

2. Bailey K. Barrett's oesophagus, part 3: A study into patients' perceptions of surveillance. Gastrointestinal Nursing. 2009; 7(10):34-42

3. Britton J, Hamdy S, McLaughlin J, Horne M, Ang Y. Barrett's oesophagus: A qualitative study of patient burden, care delivery experience and follow-up needs. Health Expectations. 2019; 22(1):21-33

4. Cooper SC, El-agib A, Dar S, Mohammed I, Nightingale P, Murray IA et al. Endoscopic surveillance for Barrett's oesophagus: The patients' perspective. European Journal of Gastroenterology and Hepatology. 2009; 21(8):850-854

5. Gough MD, Gilliam AD, Stoddard CJ, Ackroyd R. Barrett's esophagus: Patient information and the internet. The patient's perspective. Diseases of the Esophagus. 2003; 16(2):57-59

6. Griffiths H, Davies R. Understanding Barrett's columnar lined oesophagus from the patients' perspective: Qualitative analysis of semistructured interviews with patients. Frontline Gastroenterology. 2011; 2(3):168-175

7. National Institute for Health and Care Excellence. Developing NICE guidelines: the manual [updated January 2022]. London. National Institute for Health and Care Excellence, 2014. Available from: http://www.nice.org.uk/article/PMG20/chapter/1%20Introduction%20and%20overview

Appendices

Appendix A – Review protocols

Review protocol for patients with Barrett's oesophagus or stage 1 adenocarcinoma

ID	Field	Content
0.	PROSPERO registration number	CRD42022340515
1.	Review title	Information and support for patients (or carers or families) who are having or considering follow-up or treatment for Barrett's oesophagus or stage 1 oesophageal adenocarcinoma
2.	Review question	What information and support should be provided to patients (or carers or families) who are having or considering follow-up or treatment for Barrett's oesophagus or stage 1 oesophageal adenocarcinoma?
3.	Objective	To determine what information, support and follow up people (or carers and families) need who are or considering having treatment for Barrett's Oesophagus or Stage 1 adenocarcinoma
4.	Searches	The following databases (from inception) will be searched: • Cochrane Database of Systematic Reviews (CDSR) • Embase • MEDLINE • CINAHL • PsychInfo Searches will be restricted by: • English language studies • Human studies

		• Letters and comments are excluded Other searches: • Inclusion lists of systematic reviews will be checked by the reviewers The searches may be re-run 6 weeks before the final committee meeting and further studies retrieved for inclusion if relevant. The full search strategies will be published in the final review. Medline search strategy to be quality assured using the PRESS evidence-based checklist (see methods chapter for full details).
5.	Condition or domain being studied	Barrett's Oesophagus
6.	Population	Inclusion: Adults, 18 years and over, with Barrett's Oesophagus or Stage 1 adenocarcinoma Exclusion: Adults with Barrett's Oesophagus beyond Stage 1 adenocarcinoma.
7.	Setting	Views, opinions and experiences relating to any information, education or support specified in studies Including but not limited to duration of treatment, follow-up, complication/adverse events, success rate, risk of recurrence of disease
8.	Comparator	N/A

9.	Types of study to be included	Qualitative studies such as interview and focus group studies (including studies using grounded theory, phenomenology or other appropriate qualitative approaches); quantitative data such as incidence rate or frequencies of information preference from questionnaires will also be considered alongside qualitative evidence.
10.	Other exclusion criteria	Non-English language studies. Quantitative studies with no relevant data Conference abstracts will be excluded as it is expected there will be sufficient full text published studies available.
11.	Context	Barrett's Oesophagus is associated with significant sequelae and can have a notable effect on the person's life. Adequate information provision for a person with Barrett's and their family and/or carer can aid care planning and management, improve understanding and accuracy of expectations, and can influence quality of life. This information for a person with Barrett's and their family and/or carer provided both within the immediate care setting and in the community following discharge can be invaluable.
12.	Primary outcomes (critical outcomes)	Themes will be derived from the evidence identified for this review and not pre-specified. Quantitative data such as incidence rate or frequencies of reported information preference will be extracted and presented alongside the themes identified from qualitative analysis.
13.	Data extraction (selection and coding)	All references identified by the searches and from other sources will be uploaded into EPPI reviewer and de-duplicated. This review will make use of the priority screening functionality within the EPPI-reviewer software. 10% of the abstracts will be reviewed by two reviewers, with any disagreements resolved by discussion or, if necessary, a third independent reviewer. The full text of potentially eligible studies will be retrieved and will be assessed in line with the criteria outlined above. A standardised form will be used to extract data from studies (see Developing NICE guidelines: the manual section 6.4). 10% of all evidence reviews are quality assured by a senior research fellow. This includes checking:

		• papers were included /excluded appropriately • a sample of the data extractions • correct methods are used to synthesise data • a sample of the risk of bias assessments Disagreements between the review authors over the risk of bias in particular studies will be resolved by discussion, with involvement of a third review author where necessary. Study investigators may be contacted for missing data where time and resources allow.
14.	Risk of bias (quality) assessment	Risk of bias will be assessed using the appropriate checklist as described in Developing NICE guidelines: the manual. Critical Appraisal Skills Programme (CASP) qualitative checklist with be used to assess included qualitative studies. Risk of bias for quantitative data will be employed depending on the design of the study: • Randomised Controlled Trial: Cochrane RoB (2.0) • Non randomised study, including cohort studies: Cochrane ROBINS-I • Case control study: CASP case control checklist • Controlled before-and-after study or Interrupted time series: Effective Practice and Organisation of Care (EPOC) RoB Tool Cross sectional study: JBI checklist for cross sectional study
15.	Strategy for data synthesis	The synthesis of qualitative data will follow a thematic analysis approach. Information will be synthesised into main review findings. Results will be presented in a detailed narrative and in table format with summary statements of main review findings. GRADE CERQual will be used to synthesise the qualitative data and assess the certainty of evidence for each review finding. Quantitative data from surveys reporting patient information preferences will be reported narratively and presented alongside thematic analysis. Risk of bias will be assessed to ascertain outcome quality.

16.	Analysis of sub-groups	General surveillance vs endoscopic intervention Age: elderly (cut-off at 75 years) vs non-elderly) Health inequalities		
17.	Type and method of review	☐	Intervention	
		☐	Diagnostic	
		☐	Prognostic	
		☒	Qualitative	
		☐	Epidemiologic	
		☐	Service Delivery	
		☐	Other (please specify)	
18.	Language	English		
19.	Country	England		
20.	Anticipated or actual start date			
21.	Anticipated completion date			
22.	Stage of review at time of this submission	Review stage	Started	Completed
		Preliminary searches	☐	☐
		Piloting of the study selection process	☐	☐
		Formal screening of search results	☐	☐

		against eligibility criteria		
		Data extraction	☐	☐
		Risk of bias (quality) assessment	☐	☐
		Data analysis	☐	☐
23.	Named contact	5a. Named contact National Guideline Centre 5b Named contact e-mail @nice.org.uk 5e Organisational affiliation of the review National Institute for Health and Care Excellence (NICE) and National Guideline Centre		
24.	Review team members	From the National Guideline Centre: Gill Ritchie Amy Crisp Lina Gulhane Stephen Deed Vimal Bedia Muksitur Rahman Melina Vasileiou		

25.	Funding sources/sponsor	This systematic review is being completed by the National Guideline Centre which receives funding from NICE.
26.	Conflicts of interest	All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must declare any potential conflicts of interest in line with NICE's code of practice for declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a member's declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.
27.	Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of Developing NICE guidelines: the manual. Members of the guideline committee are available on the NICE website: [NICE guideline webpage].
28.	Other registration details	
29.	Reference/URL for published protocol	
30.	Dissemination plans	NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as: • notifying registered stakeholders of publication • publicising the guideline through NICE's newsletter and alerts • issuing a press release or briefing as appropriate, posting news articles on the NICE website, using social media channels, and publicising the guideline within NICE.
31.	Keywords	Barrett’s Oesophagus
32.	Details of existing review of same topic by same authors	

33.	Current review status	☒	Ongoing
		☐	Completed but not published
		☐	Completed and published
		☐	Completed, published and being updated
		☐	Discontinued
34.	Additional information		
35.	Details of final publication	www.nice.org.uk	

Appendix B – Literature search strategies

The literature searches for this review are detailed below and complied with the methodology outlined in Developing NICE guidelines: the manual. [7]

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

B.1 Clinical search literature search strategy

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

Table 4: Database parameters, filters and limits applied

Database	Dates searched	Search filters and limits applied
Medline (OVID)	1946 – 29 April 2022	Qualitative studies Exclusions (animal studies, letters, comments, editorials, case studies/reports, children) English language
Embase (OVID)	1974 – 29 April 2022	Qualitative studies Exclusions (animal studies, letters, comments, editorials, case studies/reports, conference abstracts, children) English language
Current Nursing and Allied Health Literature (CINAHL) (EBSCO)	Inception – 29 April 2022	Human Exclusions (Medline records) English Language
PsycINFO (OVID)	Inception – 29 April 2022	Qualitative studies English language

Medline (Ovid) search terms

1.	exp Barrett esophagus/
2.	barrett*.ti,ab.
3.	(speciali* adj3 (epithel* or oesophag* or esophag* or mucos*)).ti,ab.
4.	(column* adj3 (epithel* or oesophag* or esophag* or mucos* or lined or lining or metaplas*)).ti,ab.
5.	(intestin* adj2 metaplas*).ti,ab.

6.	or/1-5
7.	Precancerous conditions/
8.	(dysplasia* or precancer* or pre-cancer* or premalign* or pre-malign* or preneoplast* or pre-neoplastic* or preneoplasia* or pre-neoplasia* or neoplasm* or cancer* or carcinoma* or adenocarcinom* or adenoma* or tumour* or tumor* or malignan* or metaplas* or metast* or nodul* or node* or lump* or lymphoma*).ti,ab.
9.	7 or 8
10.	exp Esophagus/
11.	Esophageal Mucosa/
12.	(oesophag* or esophag* or intramucosal* or intra-mucosal*).ti,ab.
13.	or/10-12
14.	9 and 13
15.	exp Esophageal Neoplasms/
16.	6 or 14 or 15
17.	letter/
18.	editorial/
19.	news/
20.	exp historical article/
21.	Anecdotes as Topic/
22.	comment/
23.	case report/
24.	(letter or comment*).ti.
25.	or/17-24
26.	randomized controlled trial/ or random*.ti,ab.
27.	25 not 26
28.	animals/ not humans/
29.	exp Animals, Laboratory/
30.	exp Animal Experimentation/
31.	exp Models, Animal/
32.	exp Rodentia/
33.	(rat or rats or mouse or mice or rodent*).ti.
34.	or/27-33
35.	16 not 34
36.	limit 35 to English language
37.	exp Patients/ or exp Family/ or Caregivers/
38.	Consumer Health Information/ or Needs Assessment/ or Patient Education as Topic/ or Patient Education Handout/ or Health Communication/ or Information Dissemination/
39.	((patient* or inpatient* or outpatient* or carer* or client* or user* or customer* or consumer* or caregiver* or care giver* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or next of kin or significant other* or partner* or guardian* or relative* or sibling* or sister* or brother* or grandparent* or grandfather* or grandmother*) adj3 (information* or advice or advis* or need* or requirement* or support* or access* or service* or educat* or learn* or teach* or train*)).ti,ab,kf.
40.	((information* or educat*) adj3 (need* or requirement* or support* or seek* or access* or disseminat* or barrier* or service*)).ti,ab,kf.
41.	(support* adj3 (need* or requirement* or assess* or seek* or access* or barrier* or service*)).ti,ab,kf.
42.	"Patient Acceptance of Health Care"/ or exp Patient Satisfaction/

43.	((patient* or inpatient* or outpatient* or carer* or client* or user* or customer* or consumer* or caregiver* or care giver* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or next of kin or significant other* or partner* or guardian* or relative* or sibling* or sister* or brother* or grandparent* or grandfather* or grandmother*) adj3 (belief* or attitud* or priorit* or perception* or preferen* or expectation* or choice* or perspective* or view* or satisfact* or experience* or opinion* or preference* or feedback*)).ti,ab,kf.
44.	or/37-43
45.	36 and 44
46.	Qualitative research/ or Narration/ or exp Interviews as Topic/ or exp "Surveys and Questionnaires"/ or Health care surveys/
47.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
48.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* adj3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).ti,ab.
49.	or/46-48
50.	45 and 49

Embase (Ovid) search terms

1.	exp Barrett esophagus/
2.	barrett*.ti,ab.
3.	(speciali* adj3 (epithel* or oesophag* or esophag* or mucos*)).ti,ab.
4.	(column* adj3 (epithel* or oesophag* or esophag* or mucos* or lined or lining or metaplas*)).ti,ab.
5.	(intestin* adj2 metaplas*).ti,ab.
6.	or/1-5
7.	Precancer/
8.	(dysplasia* or precancer* or pre-cancer* or premalign* or pre-malign* or preneoplast* or pre-neoplastic* or preneoplasia* or pre-neoplasia* or neoplasm* or cancer* or carcinoma* or adenocarcinom* or adenoma* or tumour* or tumor* or malignan* or metaplas* or metast* or nodul* or node* or lump* or lymphoma*).ti,ab.
9.	7 or 8
10.	exp Esophagus/
11.	Esophagus Mucosa/
12.	(oesophag* or esophag*).ti,ab.
13.	or/10-12
14.	9 and 13
15.	exp Esophagus Tumor/
16.	6 or 14 or 15
17.	letter.pt. or letter/
18.	note.pt.
19.	editorial.pt.
20.	case report/ or case study/
21.	(letter or comment*).ti.
22.	(conference abstract or conference paper).pt.
23.	or/17-22
24.	randomized controlled trial/ or random*.ti,ab.

25.	23 not 24
26.	animal/ not human/
27.	nonhuman/
28.	exp Animal Experiment/
29.	exp Experimental Animal/
30.	animal model/
31.	exp Rodent/
32.	(rat or rats or mouse or mice or rodent*).ti.
33.	or/25-32
34.	16 not 33
35.	limit 34 to English language
36.	patient/ or family/ or caregivers/
37.	consumer health information/ or needs assessment/ or communication barrier/ or patient education/ or medical information/ or information dissemination/
38.	((patient* or inpatient* or outpatient* or carer* or client* or user* or customer* or consumer* or caregiver* or care giver* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or next of kin or significant other* or partner* or guardian* or relative* or sibling* or sister* or brother* or grandparent* or grandfather* or grandmother*) adj3 (information* or advice or advis* or need* or requirement* or support* or access* or service* or educat* or learn* or teach* or train*)).ti,ab,kf.
39.	((information* or educat*) adj3 (need* or requirement* or support* or seek* or access* or disseminat* or barrier* or service*)).ti,ab,kf.
40.	(support* adj3 (need* or requirement* or assess* or seek* or access* or barrier* or service*)).ti,ab,kf.
41.	patient preference/ or patient satisfaction/ or consumer attitude/ or patient attitude/
42.	((patient* or inpatient* or outpatient* or carer* or client* or user* or customer* or consumer* or caregiver* or care giver* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or next of kin or significant other* or partner* or guardian* or relative* or sibling* or sister* or brother* or grandparent* or grandfather* or grandmother*) adj3 (belief* or attitud* or priorit* or perception* or preferen* or expectation* or choice* or perspective* or view* or satisfact* or experience* or opinion* or preference* or feedback*)).ti,ab,kf.
43.	or/36-42
44.	35 and 43
45.	health survey/ or exp questionnaire/ or exp interview/ or qualitative research/ or narrative/
46.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
47.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* adj3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).ti,ab.
48.	or/45-47
49.	44 and 48

CINAHL (EBSCO) search terms

S1.	(MH "Barrett Esophagus")
S2.	(TI barrett* OR AB barrett*)
S3.	((TI speciali* OR AB speciali*) N3 ((TI epithel* OR AB epithel*) OR (TI oesophag* OR AB oesophag*) OR (TI esophag* OR AB esophag*) OR (TI mucos* OR AB mucos*)))

S4.	((TI column* OR AB column*) N3 ((TI epithel* OR AB epithel*) OR (TI oesophag* OR AB oesophag*) OR (TI esophag* OR AB esophag*) OR (TI mucos* OR AB mucos*) OR (TI lined OR AB lined) OR (TI lining OR AB lining) OR (TI metaplas* OR AB metaplas*)))
S5.	((TI intestin* OR AB intestin*) N2 (TI metaplas* OR AB metaplas*))
S6.	S1 OR S2 OR S3 OR S4 OR S5
S7.	(MH "Precancerous Conditions+")
S8.	((TI dysplasia* OR AB dysplasia*) OR (TI precancer* OR AB precancer*) OR (TI pre-cancer* OR AB pre-cancer*) OR (TI premalign* OR AB premalign*) OR (TI pre-malign* OR AB pre-malign*) OR (TI preneoplast* OR AB preneoplast*) OR (TI pre-neoplastic* OR AB pre-neoplastic*) OR (TI preneoplasia* OR AB preneoplasia*) OR (TI pre-neoplasia* OR AB pre-neoplasia*) OR (TI neoplasm* OR AB neoplasm*) OR (TI cancer* OR AB cancer*) OR (TI carcinoma* OR AB carcinoma*) OR (TI adenocarcinom* OR AB adenocarcinom*) OR (TI adenoma* OR AB adenoma*) OR (TI tumour* OR AB tumour*) OR (TI tumor* OR AB tumor*) OR (TI malignan* OR AB malignan*) OR (TI metaplas* OR AB metaplas*) OR (TI metast* OR AB metast*) OR (TI nodul* OR AB nodul*) OR (TI node* OR AB node*) OR (TI lump* OR AB lump*) OR (TI lymphoma* OR AB lymphoma*))
S9.	S7 OR S8
S10.	(MH "Esophagus+")
S11.	(MH "Esophageal Mucosa")
S12.	((TI oesophag* OR AB oesophag*) OR (TI esophag* OR AB esophag*) OR (TI intramucosal* OR AB intramucosal*) OR (TI intra-mucosal* OR AB intra-mucosal*))
S13.	S10 OR S11 OR S12
S14.	S9 AND S13
S15.	(MH "Esophageal Neoplasms+")
S16.	S6 OR S14 OR S15
S17.	(MH Patients+) OR (MH Family+) OR (MH Caregivers)
S18.	(MH "Consumer Health Information") OR (MH "Needs Assessment") OR (MH "Patient Education as Topic") OR (MH "Patient Education Handout") OR (MH "Health Communication") OR (MH "Information Dissemination")
S19.	(((TI patient* OR AB patient* OR SU patient*) OR (TI inpatient* OR AB inpatient* OR SU inpatient*) OR (TI outpatient* OR AB outpatient* OR SU outpatient*) OR (TI carer* OR AB carer* OR SU carer*) OR (TI client* OR AB client* OR SU client*) OR (TI user* OR AB user* OR SU user*) OR (TI customer* OR AB customer* OR SU customer*) OR (TI consumer* OR AB consumer* OR SU consumer*) OR (TI caregiver* OR AB caregiver* OR SU caregiver*) OR (TI "care giver*" OR AB "care giver*" OR SU "care giver*") OR (TI famil* OR AB famil* OR SU famil*) OR (TI parent* OR AB parent* OR SU parent*) OR (TI father* OR AB father* OR SU father*) OR (TI mother* OR AB mother* OR SU mother*) OR (TI spouse* OR AB spouse* OR SU spouse*) OR (TI wife OR AB wife OR SU wife) OR (TI wives OR AB wives OR SU wives) OR (TI husband* OR AB husband* OR SU husband*) OR (TI "of kin" OR AB "of kin" OR SU "of kin") OR (TI "significant other*" OR AB "significant other*" OR SU "significant other*") OR (TI partner* OR AB partner* OR SU partner*) OR (TI guardian* OR AB guardian* OR SU guardian*) OR (TI relative* OR AB relative* OR SU relative*) OR (TI sibling* OR AB sibling* OR SU sibling*) OR (TI sister* OR AB sister* OR SU sister*) OR (TI brother* OR AB brother* OR SU brother*) OR (TI grandparent* OR AB grandparent* OR SU grandparent*) OR (TI grandfather* OR AB grandfather* OR SU grandfather*) OR (TI grandmother* OR AB grandmother* OR SU grandmother*)) N3 ((TI information* OR AB information* OR SU information*) OR (TI advice OR AB advice OR SU advice) OR (TI advis* OR AB advis* OR SU advis*) OR (TI need* OR AB need* OR SU need*) OR (TI requirement* OR AB requirement* OR SU requirement*) OR (TI support* OR AB support* OR SU support*) OR (TI access* OR AB access* OR SU access*) OR (TI service* OR AB service* OR SU service*) OR (TI educat* OR AB educat* OR SU

	educat*) OR (TI learn* OR AB learn* OR SU learn*) OR (TI teach* OR AB teach* OR SU teach*) OR (TI train* OR AB train* OR SU train*)))
S20.	(((TI information* OR AB information* OR SU information*) OR (TI educat* OR AB educat* OR SU educat*)) N3 ((TI need* OR AB need* OR SU need*) OR (TI requirement* OR AB requirement* OR SU requirement*) OR (TI support* OR AB support* OR SU support*) OR (TI seek* OR AB seek* OR SU seek*) OR (TI access* OR AB access* OR SU access*) OR (TI disseminat* OR AB disseminat* OR SU disseminat*) OR (TI barrier* OR AB barrier* OR SU barrier*) OR (TI service* OR AB service* OR SU service*)))
S21.	((TI support* OR AB support* OR SU support*) N3 ((TI need* OR AB need* OR SU need*) OR (TI requirement* OR AB requirement* OR SU requirement*) OR (TI assess* OR AB assess* OR SU assess*) OR (TI seek* OR AB seek* OR SU seek*) OR (TI access* OR AB access* OR SU access*) OR (TI barrier* OR AB barrier* OR SU barrier*) OR (TI service* OR AB service* OR SU service*)))
S22.	(MH "Patient Satisfaction+")
S23.	(((TI patient* OR AB patient* OR SU patient*) OR (TI inpatient* OR AB inpatient* OR SU inpatient*) OR (TI outpatient* OR AB outpatient* OR SU outpatient*) OR (TI carer* OR AB carer* OR SU carer*) OR (TI client* OR AB client* OR SU client*) OR (TI user* OR AB user* OR SU user*) OR (TI customer* OR AB customer* OR SU customer*) OR (TI consumer* OR AB consumer* OR SU consumer*) OR (TI caregiver* OR AB caregiver* OR SU caregiver*) OR (TI "care giver*" OR AB "care giver*" OR SU "care giver*") OR (TI famil* OR AB famil* OR SU famil*) OR (TI parent* OR AB parent* OR SU parent*) OR (TI father* OR AB father* OR SU father*) OR (TI mother* OR AB mother* OR SU mother*) OR (TI spouse* OR AB spouse* OR SU spouse*) OR (TI wife OR AB wife OR SU wife) OR (TI wives OR AB wives OR SU wives) OR (TI husband* OR AB husband* OR SU husband*) OR W1 (TI "of kin" OR AB "of kin" OR SU "of kin") OR (TI "significant other*" OR AB "significant other*" OR SU "significant other*") OR (TI partner* OR AB partner* OR SU partner*) OR (TI guardian* OR AB guardian* OR SU guardian*) OR (TI relative* OR AB relative* OR SU relative*) OR (TI sibling* OR AB sibling* OR SU sibling*) OR (TI sister* OR AB sister* OR SU sister*) OR (TI brother* OR AB brother* OR SU brother*) OR (TI grandparent* OR AB grandparent* OR SU grandparent*) OR (TI grandfather* OR AB grandfather* OR SU grandfather*) OR (TI grandmother* OR AB grandmother* OR SU grandmother*)) N3 ((TI belief* OR AB belief* OR SU belief*) OR (TI attitud* OR AB attitud* OR SU attitud*) OR (TI priorit* OR AB priorit* OR SU priorit*) OR (TI perception* OR AB perception* OR SU perception*) OR (TI preferen* OR AB preferen* OR SU preferen*) OR (TI expectation* OR AB expectation* OR SU expectation*) OR (TI choice* OR AB choice* OR SU choice*) OR (TI perspective* OR AB perspective* OR SU perspective*) OR (TI view* OR AB view* OR SU view*) OR (TI satisfact* OR AB satisfact* OR SU satisfact*) OR (TI experience* OR AB experience* OR SU experience*) OR (TI opinion* OR AB opinion* OR SU opinion*) OR (TI preference* OR AB preference* OR SU preference*) OR (TI feedback* OR AB feedback* OR SU feedback*) OR (TI questionnaire* OR AB questionnaire* OR SU questionnaire*)))
S24.	S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23
S25.	S16 AND S24

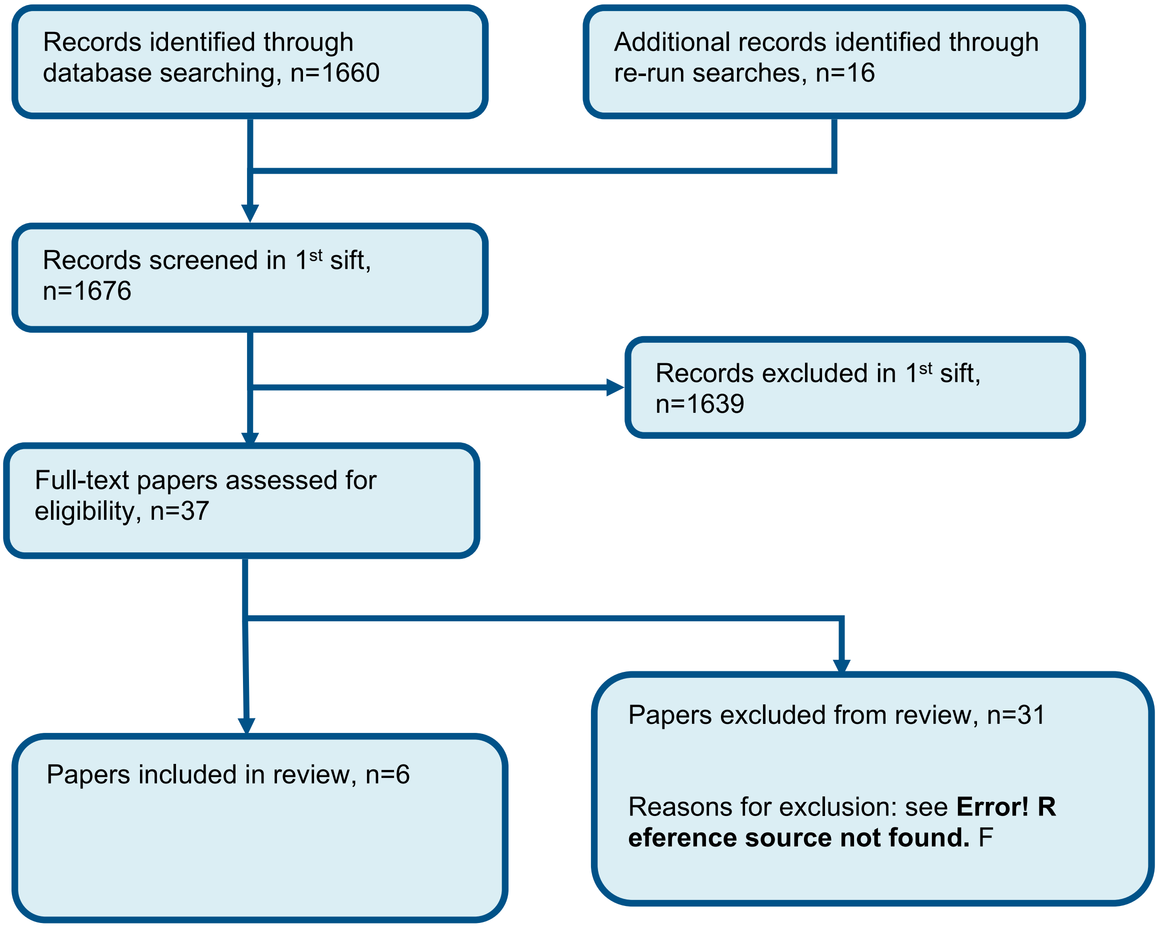
PsycINFO (ProQuest) search terms

1.	barrett*.ti,ab.
2.	(speciali* adj3 (epithel* or oesophag* or esophag* or mucos*)).ti,ab.
3.	(column* adj3 (epithel* or oesophag* or esophag* or mucos* or lined or lining or metaplas*)).ti,ab.
4.	(intestin* adj2 metaplas*).ti,ab.
5.	or/1-4
6.	(dysplasia* or precancer* or pre-cancer* or premalign* or pre-malign* or preneoplast* or pre-neoplastic* or preneoplasia* or pre-neoplasia* or neoplasm* or cancer* or

	carcinoma* or adenocarcinom* or adenoma* or tumour* or tumor* or malignan* or metaplas* or metast* or nodul* or node* or lump* or lymphoma*).ti,ab.
7.	exp Esophagus/
8.	(oesophag* or esophag* or intramucosal* or intra-mucosal*).ti,ab.
9.	or/7-8
10.	6 and 9
11.	5 or 10
12.	Letter/
13.	Case report/
14.	exp Rodents/
15.	or/12-14
16.	11 not 15
17.	limit 16 to English language
18.	exp Patients/ or Family/ or exp Caregivers/
19.	Health Information/ or exp Needs Assessment/ or Client Education/ or Communication barriers/
20.	((patient* or inpatient* or outpatient* or carer* or client* or user* or customer* or consumer* or caregiver* or care giver* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or next of kin or significant other* or partner* or guardian* or relative* or sibling* or sister* or brother* or grandparent* or grandfather* or grandmother*) adj3 (information* or advice or advis* or need* or requirement* or support* or access* or service* or educat* or learn* or teach* or train*)).ti,ab.
21.	((information* or educat*) adj3 (need* or requirement* or support* or seek* or access* or disseminat* or barrier* or service*)).ti,ab.
22.	(support* adj3 (need* or requirement* or assess* or seek* or access* or barrier* or service*)).ti,ab.
23.	Client Satisfaction/ or Client Attitudes/
24.	((patient* or inpatient* or outpatient* or carer* or client* or user* or customer* or consumer* or caregiver* or care giver* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or next of kin or significant other* or partner* or guardian* or relative* or sibling* or sister* or brother* or grandparent* or grandfather* or grandmother*) adj3 (belief* or attitud* or priorit* or perception* or preferen* or expectation* or choice* or perspective* or view* or satisfact* or experience* or opinion* or preference* or feedback*)).ti,ab.
25.	or/18-24
26.	qualitative methods/ or exp interviews/ or exp questionnaires/
27.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
28.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* adj3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).ti,ab.
29.	or/26-28
30.	17 and 25
31.	17 and 29
32.	30 or 31

Appendix C –Qualitative evidence study selection

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



Appendix D – Qualitative evidence

Study	**Arney 2014** [1]
Aim	To define the patient experience of EGD from in-depth qualitative interviews with patients who recently underwent surveillance EGD
Population	Participants was recruited from a regional Department of Veterans Affairs Medical Center. Potential participants were identified using a clinical Barrett's oesophagus (BE) registry augmented by a detailed electronic medical record review to confirm BE diagnosis. Recruitment and data collection occurred between March 2011 and July 2012. Patients were considered for inclusion if they: 1) were between the ages of 18-80 years of age; 2) had non-dysplastic BE and received at least one surveillance EGD; or 3) had dysplastic BE (low-grade or high-grade dysplasia). Patients were excluded from the study if their records indicated that they: 1) had a severe medical or psychiatric co-morbidity; 2) were hospitalized at the time of recruitment; 3) had a gastroesophageal disorder requiring endoscopy for reasons other than BE surveillance (i.e. esophageal cancer, gastroduodenal cancer, gastroduodenal ulcers, radiation, caustic ingestion, infectious esophagitis, or HIV); or 4) had anemia, bleeding, cirrhosis, or metastatic cancer. Characteristics: n=20; all male; mean age (SD): 62.9 years; n=9 were diagnosed with BE with no dysplasia, n=10 with low-grade dysplasia and n=1 with high-grade dysplasia; 35% completed five or more surveillance EGDs, 25% completed only 1 prior EGD. Mean number (range) of completed EGDs: 4.3 (1-20). None of these EGD procedures were performed using propofol or monitored anaesthesia care; most procedures (90%) were performed under conscious sedation with midazolam (2-4mg IV) and/ or mepiridine (25-75mg IV), combined with topical anaesthesia to the back of the throat. Only two patients received no systemic sedation during their most recent EGD because of patient preference or lack of a designated driver following the EGD.
Setting	Department of Veterans Affairs Medical Centre
Study design	Qualitative interview study
Methods and analysis	Structured, in-depth qualitative interviews were conducted in-person or via telephone. Interviews lasted approximately one hour. Interviews were designed to elicit information about patients' experiences with EGD, their expectations and perceptions of their physicians and the endoscopy experience, risk of developing oesophageal cancer, necessity of EGD, and their intentions to adhere to future EGDs. The interview guide was pilot tested and revised prior to initiating data collection. Interviews were recorded, transcribed, and analysed for content using Atlas.ti 6.2 to facilitate data analysis and management. Data were analysed using framework analysis methodology.
Findings	**Detailed information about the endoscopic procedure, its purpose and what to expect**
	In describing their EGD experiences, some patients recalled their physician explaining details about EGD instrument, mechanics of the

Study	Arney 2014 [1]
	procedure, specific risks, and likelihood of encountering problems during the procedure. On the other hand, several patients mentioned that they did not recall detailed conversations with a physician about endoscopy, and were left with many questions about what to expect. They discussed their uncertainty about the endoscopy instrument, the purpose of the procedure, and what to expect after the EGD. Patients who felt informed, respected, and experienced little or no discomfort during an EGD often discussed having a high degree of trust in their doctors and in the endoscopy centre more generally. On the other hand, patients who felt under-informed, disrespected, or experienced pain during an EGD often discussed a loss of trust in their doctors. People reporting positive experiences of endoscopy, reported having received clear explanation of the procedure and the risks involved. People reporting negative experiences reported a lack of information for example about biopsies taking place or details of the procedure.
	Information about the risks of endoscopy
	Some patients voiced concerns about the risks of EGD, including the fear that the endoscopy could cause “punctures of the tissue by the instrument” or more generally, one patient worried about “somebody screwing the procedure up”.
	Support/Respect by the physician during endoscopy
	A few patients discussed how well they were treated by their physician, for instance, describing how a physician eased their anxiety upon arriving for the procedure and comforted them during the procedure. On the other hand, several participants’ salient memories of EGD involved feelings of not being treated well or feeling disrespected. Such mentions of “disrespect” often involved patients’ requests being “ignored,” and others reported they were incapable of movement during the procedure because they were “strapped down”.
	Need for surveillance
	Many patients acknowledged that EGD allows them to monitor progression of BE to cancer, and increases the likelihood of identifying problems in their early stages. Other patients acknowledged that while they may tend to worry about BE, EGD gives them a sense of control over BE. Thus, for many patients, the most salient aspect of the EGD experience is the sense of control they receive from having the BE monitored.
Funding	NIH grant RC4CA155844
Limitations and applicability of evidence	Minor limitations due to relationship between researcher and participants not having been adequately considered (no evidence to suggest it was taken into account). No concerns over applicability.

Study	Bailey 2009[2]
Aim	To assess patients’ perceptions, experience, and informational needs about Barrett’s oesophagus to improve the understanding of health professionals and therefore their ability to provide the best care for their patients.

Study	**Bailey 2009**[2]
Population	Patients who were currently enrolled on a Barrett's surveillance programme in a large teaching hospital. Patients were sent letters requesting they phone for a pre-assessment interview before their appointment. N=15; Male: 14 (93%), Female: 1 (7%); Mean age: 59 (range 36-77 years);
Setting	Teaching hospital
Study design	Qualitative interview study
Methods and analysis	Semi structured interviews. The researcher personally conducted all the interviews, which were tape-recorded. Some general information about the participants was taken from their medical records. This included some demographic data and more specific information regarding their age, length of time on surveillance and frequency of procedure. Thematic analysis was used to analyse data using qualitative analysis package called NVivo 7 to help organize and manage the data more effectively. Themes emerged were 1) Acceptance and knowledge of Barrett's oesophagus; 2) Informational needs and getting the right balance, 3) The importance of professional input, 4) Belief that surveillance offers reassurance.
Findings	**Information regarding cancer risk and endoscopy**
	All the participants were aware of the risk of developing cancer being low and were not anxious or concerned about it.
	The participants were also aware of the risks of having an endoscopy commenting that they received an information leaflet each time with their appointment letter.
	Amount and level of information
	53% of the participants expressed that too much information was not a good thing unless the condition was found to have progressed.
	The participants in this study were satisfied with the level of information they had received.
	Less than half of the participants (n =5) seemed to be aware of the major surgical treatment needed should their disease progress. Although they were aware that further information was available, but many chose not to explore this further.
	Five participants (33%) sought further information either themselves or through their partner or friend
	Lack of information about symptom management
	The study participants lacked general information regarding managing their symptoms. Small number of the patients stated that they would have liked some additional information with regards to lifestyle changes and tips on how to manage the symptoms that some of them still found troublesome occasionally.
	There was lack of information within the hospital as to how many patients have dropped out of surveillance and how many were and still are receiving surveillance endoscopies.
	27% could not quite remember if they had received any form of written information on Barrett's oesophagus at the time of diagnosis.
	Support from GP

Study	Bailey 2009[2]
	Participants were generally happy with the care and support they had received from the clinical team. They did not really see the need to discuss things further with their GP.
	Two of the participants had gone back to their GP surgery only to discuss issues around their medication and general advice regarding diet and general lifestyle measures
	One participant shared the support received by the GP to not to cancel the surveillance appointment.
Funding	Not specified
Limitations and applicability of evidence	Minor concerns regarding the relationship between researcher and participants not being discussed. The researcher personally conducted interviews which could have potentially caused bias No concerns over applicability.

Study	Britton 2019[3]
Aim	To identify and explore factors impacting BO patients' HRQOL, the follow-up needs of BO patients and patients' perceptions and attitudes to new models of follow-up care.
Population	Patients with Barrett's oesophagus, enrolled in surveillance. [Characteristics: N=20; male=15(75%); Female= 5(25%); mean age= 63 years (range 42-77y); Disease duration (median = 5.8 y, range = 1-15 y)]
Setting	general NHS hospital.
Study design	Exploratory qualitative research part of a concurrent mixed-methods study
Methods and analysis	Semi-structured, in-depth, one-to-one interviews were undertaken by JB (average time of 40 minutes, range 21-76 minutes). Interviews focused on the impact of surveillance, physical and psychological symptoms, experiences of follow-up care, follow-up needs and new models of follow-up. A thematic analysis was conducted on all data, using a framework approach29 supported by NVivo Pro 11
Findings	**GPs' knowledge, ability, and attitude**
	Participants with supportive and caring GP appeared to have more satisfaction and trust in their GP's abilities to deal with their BO. Some participants felt their GP was dismissive or lacked knowledge regarding BO with a heavier focus on medication changes rather than on lifestyle interventions.
	Misleading or inadequate knowledge
	Some participants held inaccurate views of exactly what BO is, while others over- or underestimate their cancer risk.
	Misleading or inadequate knowledge have detrimental effects such as enhancing cancer worry or reduce their ability to self-manage symptom flares.
	over estimators of cancer risk were linked to heightened anxieties and worries of cancer, whereas those who correctly viewed their risk as low, generally, appeared to have less worry.
	Source of information
	Participants reported that they were given information verbally. Nearly all the participants sought further information and are predominantly self-educated via the Internet, newspaper articles, books, or radio shows.
	The Internet was by far the most common resource used; however, participants expressed concerns and fears over obtaining inaccurate worrisome information with no clear guidance on where to find trusted sources online
	Inadequate post- endoscopy support
	Participants reported inadequate attention on their needs and information regarding Barrett's oesophagus post endoscopy procedure. Some of the participants were unaware of their diagnosis until they were asked to attend next surveillance endoscopy.

Study	Britton 2019[3]
	Nearly all patients ideally preferred a face-to-face consultation after diagnosis to allow questions. Participants reported knowledge gaps and key uncertainties at the time of diagnosis.
	Effective communication
	Effective communication from health-care professionals in the procedure room appears vitally important in counteracting and helping cope anxiety related to surveillance endoscopy.
Funding	Medtronic, Grant/Award Number: ISR-2016- 10773
Limitations and applicability of evidence	Minor concerns on relationship between researcher and participants. The study does not report any detail regarding it. No concerns over applicability.

Study	Cooper 2009[4]
Aim	To examine the experience of patients undergoing endoscopic surveillance for BO, their levels of anxiety and depression, and quality of life and how the relationship with their physicians influences these factors.
Population	All patients who were undergoing surveillance for BO from three English hospitals were invited to participate in a postal survey that was conducted at a time independent of their gastroscopy. All patients had evidence of red columnar lined oesophagus above the proximal margins of the gastric folds and intestinal metaplasia on biopsy. 250 Patients were invited to take part. Response rate was 71% (n=178) with 60% (n=151) completing the questionnaire sufficiently for analysis Characteristics: n=151; 67% male; median age (range): 66 (41-79); median number of gastroscopies (range): 3 (1-18); median length of Barrett's segment (range): 5 (1-19) cm; no dysplasia 90%, indefinite dysplasia 3%, low-grade dysplasia 7%, high-grade dysplasia 0%
Setting	The Royal Cornwall Hospital, Sandwell General Hospital and City Hospital Birmingham
Study design	Quantitatively analysed survey
Methods and analysis	The questionnaire consisted of seven questions on patients' attitudes towards BO and endoscopic surveillance, and perceptions of cancer risk in BO, the Hospital Anxiety and Depression Scale (HADS), the Short Form-36 (SF-36) and the Trust in Physician Scale (TIPS). The following seven questions were asked: whether they had received no, too little, about the right amount or too much information to explain the need for monitoring endoscopies; whether they had some difficulty, or were not able to understand the information they received; whether they would like further information; whether having endoscopies to monitor for detection of early cancerous changes reassures or increases their anxiety (reassured/anxious); whether they worry about developing cancer as a result of BO (5 point scale from not at all to all the time); them to estimate their chance of developing oesophageal cancer in the next 10 years (1, 2,

Study	**Cooper 2009**[4]
	5, 10, 20, 50, 100%); how much do they think monitoring by endoscopy reduces their chance of developing oesophageal cancer (5 point scale from does not to completely removes their risk). Quantitative analysis involving comparative analysis of SF-36 data performed as described by Hobbs et al. and by using their general population values derived in the West Midlands, the same setting as patients from Sandwell and City Hospitals. Correlations were drawn between patients' attitudes towards endoscopic surveillance and anxiety and depression scores (HADS), quality of life scores (SF-36) and TIPS using the Spearman's correlation coefficient, unless the responses were of a dichotomous nature, when Kendall's tau-b correlation coefficient was used. Comparison between the individual SF-36 dimensions and TIPS, utilized Pearson's correlation coefficient. All statistical analyses were performed using SPSS 12.0.1.
Findings	**Information about surveillance**
	43 patients (29%) reported receiving too little information concerning surveillance of Barrett's oesophagus and 33 (22%) no information at all. The information was reported to be difficult to understand by 24%, with 85% of responders expressing a desire for further information.
	Information about the risk of cancer
	Patients tended to underestimate the risk of cancer in Barrett's oesophagus with 58% estimating that the risk of developing cancer over 10 years was 2% or less. One hundred and nine patients (74%) felt that surveillance would reduce the risk of developing oesophageal cancer, with seven (5%) believing that the risk was completely negated and 72 (49%) that the risk was greatly reduced.
Funding	Not specified
Limitations and applicability of evidence	Minor concerns over methodological limitations due to sample size not having been based on pre-study considerations of statistical power. No concerns over applicability

Study	**Gough 2003**[5]
Aim	To assess the sources of information for a group of patients with Barrett's oesophagus; the availability of Internet access for the patients and their views on the future availability and delivery of information.
Population	Endoscribe database was used to generate a list of patients, from those under the care of the four consultant surgeons involved in the study, with Barrett's oesophagus diagnosed at endoscopy during a study period from December 1999 to December 2001. The database provided a list of 301 patients. The endoscopy reports were then retrieved and studied. Patients with an oesophageal adenocarcinoma at the initial endoscopy were excluded (n = 32). The remaining 268 patients form the basis for the present study.

Study	**Gough 2003**[5]
	Characteristics: n=197 (73% response rate); n=43 (28%) had midazolam sedation at an average does of 4.4 mg (range: 1-8 mg); Type of follow-up requested by endoscopist: 36% Clinic, 18% endoscopy yearly, 9% endoscopy every 2 years, 10% endoscopy at other frequency, 11% Ablation trial/APC, 2% GP, 3% PH + Manometry, 11% other
Setting	Not specified; recruitment via consultant surgeons.
Study design	Survey
Methods and analysis	A postal questionnaire was devised, using simple tick boxes and limited to one side of A4 paper to maximize patient cooperation. Analysis method not specified; results reported quantitatively as frequencies.
Findings	**Sources of information**
	People reported they sought information most frequently from the Hospital Doctor (n=137, 70.3%), their GP (n=119; 61%) and less frequently from leaflets (n=23; 11.8%), the Internet (n=18; 9.2%), nurses (n=11; 5.6%), magazine/newspaper (n=11; 5.6%), Family/friends (n=9; 4.6%), NHS Direct (n=8; 4.1%). One hundred and five (53.8%) patients stated that they would use an **Internet site** if access was available. The average age of this group was 58.7 years. Seventy-nine (40.5%) stated they would not use an Internet site; their average age was 69.4 years. Eleven (5.7%) did not respond
	Quality of information
	The majority reported information they had found was **easy to understand** (n=104; 54.4%) but many had not (n=81; 41.5%). 134 (68.7%) reported there was **sufficient access to information** while 51 (26.2%) reported there was no sufficient access to information. 83 (42.6%) reported the information was detailed enough whereas 102 (52.3) reported **the information was not detailed enough**.
	Information about their condition
	Of those who responded, 153 patients (78.5%) wanted more information about their condition. Only 33 (17.9%) did not want further information, and seven (3.6%) failed to respond.
	Other types of information
	Patients were questioned about what information would be useful on a Web site. 119 (61%) responded 'Yes' to information about current treatment, 96(49.2%) to information about new therapeutic developments, 86 (44.1%) to information about alternative therapies, 80 (41%) to information about clinical trials, 76 (39%) to information about Investigations, 18 (9.2) responded 'Yes' to 'Other' type of information.
Funding	Not specified
Limitations and applicability of evidence	Moderate limitations due to lack of information on the analysis and sample. Moderate concerns over applicability given the close-questionnaire design, the questions of which may have limited the patient views expressed and the lack of information about participant characteristics.

Study	**Griffiths 2011[6]**
Aim	To explore patients' knowledge and understanding of Barrett's oesophagus and how the information forming the basis of that knowledge and understanding influenced their self-management.
Population	Caucasian men aged 50–70 years at high risk of malignant progression from Barrett's columnar lined oesophagus enrolled in endoscopic surveillance program Those with serious concomitant disease such as cancer, those who were unable to give valid consent, non-English speaking patients and those unable to read or write were excluded. (N=22) Characteristics not specified
Setting	District general hospital
Study design	Qualitative research
Methods and analysis	Semi-structured interviews were conducted. Interview questions were focused on meeting the aims of the study and explored their knowledge and understanding of Barrett's CLO. Interviews took on average an hour, were recorded digitally, and completed over 5 months. The framework for content analysis designed by Krippendorff was used to provide a prescriptive, analytical, and methodological grounding to the study.
Findings	**Lack of understanding**
	Participants reported usage of medical terminologies by doctors, hesitation to ask questions and selective/lack of information provided to them as some of the reasons of low health literacy and understanding.
	Information about cancer risk
	For some participants, lack of understanding led to uncertainty about their condition which resulted in a perceived threat to their health and well-being and affected their perception of the cancer risk.
	All the participants agreed that there was a lack of information but had mixed views regarding how they dealt with the uncertainty and perceived threat of cancer. Some participants reacted positively and took control over their lifestyle while others felt it made them anxious.
	View about surveillance
	Most of the participants perceived endoscopic surveillance as a safety net and an opportunity to take control of their condition despite of the uncomfortable experience.
Funding	Not specified

Study	**Griffiths 2011**[6]
Limitations and applicability of evidence	Directly applicable No limitations

Appendix E – GRADE-CERQual tables

Qualitative evidence summary

Table 5: Summary of evidence

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Information about surveillance endoscopy					
3	Semi-structured interviews (1 study); in-depth structured interviews (1 study); complemented by quantitative questionnaire data (1 study)	People need clear and detailed information about endoscopic surveillance, the procedure, its purpose, the risks involved as this can improve the patient's experience during the procedure and their relationship with their doctor.	Limitations	Minor concerns about methodological limitations [a]	MODERATE
			Coherence	Minor concerns about coherence [b]	
			Relevance	No concerns about relevance	
			Adequacy	No concerns about adequacy	

(a)Three studies with minor issues due to the relationship between researcher and participants not having been adequately considered in two studies [1, 2] and due to sample size not having been based on pre-study considerations of statistical power in the contributing survey [4].

(b) Minor concerns about coherence with some people expressing they had received sufficient information and not requiring further information in two studies [1, 2].

Table 6: Summary of evidence

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Findings**	**Criteria**	**Rating**	**Overall assessment of confidence**
Information about the risk of cancer					
4	Semi-structur	There is often a lack of information about the risk of cancer in Barrett's	Limitations	Minor concerns	MODERATE

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Findings	Criteria	Rating	Overall assessment of confidence
	ed interviews (3 studies); quantitative questionnaire (1 study)	oesophagus that is often a source of anxiety for patients resulting in their over or under estimation of their cancer risk.		about methodological limitations[a]	
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	No concerns about adequacy	

(a) Three studies with minor concerns over methodological limitations due to the relationship between researcher and participants not having been considered in two studies [2, 3] and due to sample size not having been based on pre-study considerations of statistical power in the included survey[4]

Table 7: Summary of evidence

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Findings	Criteria	Rating	Overall assessment of confidence
Information about symptom management					
1	Semi-structured interviews	Patients lack information about symptom management and potential lifestyle changes that may reduce the burden of their symptoms.	Limitations	Minor concerns about methodological limitations[a]	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Findings	Criteria	Rating	Overall assessment of confidence
			Adequacy	Serious concerns about adequacy [b]	

(a) One study with minor concerns over methodological limitations due the relationship between researcher and participants not having been considered [2].
(b) serious concerns about adequacy due to limited information from one study supporting the theme.

Table 8: Summary of evidence

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Findings	Criteria	Rating	Overall assessment of confidence
Easier to understand information					
3	Semi-structured interviews (1 study); quantitative questionnaire (2 studies)	Information available about Barrett's oesophagus was perceived by many to be difficult to understand and this was partly due to the reported usage of medical terminology.	Limitations	Minor concerns about methodological limitations [a]	VERY LOW
			Coherence	Minor concerns about coherence [b]	
			Relevance	Moderate concerns about relevance [c]	
			Adequacy	Minor concerns about adequacy [d]	

(a) Three studies with no to moderate limitations; minor concerns over methodological limitations with no concerns in the qualitative study contributing to the theme [6] but minor concerns over one contributing survey (due to sample size not having been based on pre-study considerations of statistical power) [4] and moderate concerns in the other contributing survey (due to lack of information on the analysis and sample [5]
(b) minor concerns about coherence with the majority of participants in one of the contributing surveys reporting the information they had found was easy to understand (n=104; 54.4%)[4]
(c) moderate concerns over relevance with no concerns in the qualitative study [6], but moderate concerns in one survey (due to the close-questionnaire design, the questions of which may have

limited the patient views expressed and the lack of information about participant characteristics) [5] *and due to the views expressed in the other contributing survey most likely being about information participants had found themselves, rather than the information provided to them by healthcare professionals* [4]*.*

(d) *minor concerns about adequacy with limited information from three studies supporting the theme.*

Table 9: Summary of evidence

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Findings**	**Criteria**	**Rating**	**Overall assessment of confidence**
Information about Barrett's oesophagus					
2	Semi-structured interviews (1 study); quantitative questionnaire (1 study)	People required further information about their condition, with some having inaccurate views about what Barrett's oesophagus; their lack of knowledge enhanced cancer worry and impacted their ability to manage symptom flares.	Limitations	Moderate concerns about methodological limitations [a]	VERY LOW
			Coherence	No concerns about coherence	
			Relevance	Minor concerns about relevance [b]	
			Adequacy	Moderate concerns about adequacy [c]	

(a) *Two studies with minor and moderate concerns; moderate concerns over methodological limitations with minor concerns in one study due to the relationship between researcher and participants not being considered* [3] *and moderate concerns in the contributing survey due to lack of information on the analysis and sample* [5]*.*

(b) *minor concerns over relevance with no concerns in one study* [3] *and moderate concerns in the other study, given the close-questionnaire design, the questions of which may have limited the patient views expressed and the lack of information about participant characteristics* [5]*.*

(c) *moderate concerns about adequacy with limited information from two studies supporting the theme.*

Table 10: Summary of evidence

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Findings**	**Criteria**	**Rating**	**Overall assessment of confidence**
Other types of information					

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Findings**	**Criteria**	**Rating**	**Overall assessment of confidence**
1	Quantitative questionnaire	Other types of information people considered useful, included: information about current treatments and new therapeutic developments, alternative therapies and clinical trials.	Limitations	Moderate concerns about methodological limitations [a]	VERY LOW
			Coherence	No concerns about coherence	
			Relevance	Moderate concerns about relevance [b]	
			Adequacy	Serious concerns about adequacy [c]	

(a) One study with moderate concerns over methodological limitations due to lack of information on the analysis and sample [5]

(b) moderate concerns over relevance given the close-questionnaire design, the questions of which may have limited the patient views expressed and the lack of information about participant characteristics

(c) serious concerns about adequacy with information supporting the theme limited to one survey.

Table 11: Summary of evidence

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Findings**	**Criteria**	**Rating**	**Overall assessment of confidence**
Sources of information					
3	Semi-structured interviews (2 studies); Quantitative questionnaire	In addition to the information they had been given, people appeared to seek further information mostly from the internet, the hospital doctor or GP and less frequently from nurses, newspapers, NHS direct, family or friends.	Limitations	Minor concerns about methodological limitations [a]	LOW
			Coherence	Minor concerns about coherence[b]	

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Findings**	**Criteria**	**Rating**	**Overall assessment of confidence**
	(1 study)		Relevance	Minor concerns about relevance [c]	
			Adequacy	Moderate concerns about adequacy [d]	

(a) Two studies with minor limitations and one study with moderate limitations; minor concerns over methodological limitations with minor concerns in two studies due to the relationship between researcher and participants not being considered [2, 3] and moderate concerns in the contributing survey due to lack of information on the analysis and sample [5].

(b) minor concerns about coherence with different views emerging about the use of the internet as a source of information.

(c) minor concerns over applicability with no concerns in two contributing studies but moderate concerns in the contributing survey given the close-questionnaire design, the questions of which may have limited the patient views expressed and the lack of information about participant characteristics [5].

(d) moderate concerns about adequacy with limited information from three studies illustrating the theme.

Table 12: Summary of evidence

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Findings**	**Criteria**	**Rating**	**Overall assessment of confidence**
Amount of information					
1	Semi-structured interviews	People undergoing surveillance felt too much information was not necessary unless the condition was found to progress.	Limitations	Minor concerns about methodological limitations [a]	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Moderate concerns about adequacy [b]	

(a) One study with minor concerns over methodological due to the relationship between researcher and participants not being discussed and the researcher having personally conducted the interviews [2]*.*

(b) moderate concerns about adequacy with relatively limited information from one study supporting the theme.

Table 13: Summary of evidence

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Findings**	**Criteria**	**Rating**	**Overall assessment of confidence**
Support and respect from the physician during endoscopy					
2	In-depth structured interviews (1 study); semi-structured interviews (1 study)	Perceived lack of support and respect from their physician or GP led patients to have negative experiences of endoscopic surveillance and often to a lack of trust in their doctor, whereas effective communication helped cope with anxiety related to surveillance endoscopy.	Limitations	Minor concerns about methodological limitations [a]	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy [b]	

(a) Two studies with minor concerns over methodological limitations; minor concerns over methodological limitations due to relationship between researcher and participants not having been considered [1, 3]

(b) Minor concerns about adequacy due to relatively limited information from two studies supporting the theme.

Table 14: Summary of evidence

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Findings**	**Criteria**	**Rating**	**Overall assessment of confidence**
Need for surveillance					
1	In-depth structured	Barrett's oesophagus patients expressed that surveillance allows monitoring the progression of Barrett's oesophagus, providing a sense of control.	Limitations	Minor concerns about methodological	LOW

Study design and sample size		Findings	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
	interviews			limitations [a]	
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Moderate concerns about adequacy [b]	

(a) One study with minor concerns over methodological limitations due the relationship between researcher and participants not having been considered [1].
(b) Moderate concerns over adequacy with relatively limited information from one study supporting the theme.

Table 15: Summary of evidence

Study design and sample size		Findings	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Post-diagnosis information and support					
1	Semi-structured interviews	After undergoing endoscopy, people experienced a lack of attention to their needs and a lack of information about their diagnosis with many expressing the need for a face-to-face consultation after diagnosis.	Limitations	Minor concerns about methodological limitations [a]	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Serious concerns	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Findings	Criteria	Rating	Overall assessment of confidence
				about adequacy [b]	

(a) *One study with minor concerns over methodological limitations due the relationship between researcher and participants not having been considered [3].*
(b) *Serious concerns over adequacy with limited information from one study supporting the theme.*

Appendix F – Excluded studies

Clinical studies

Table 16: Studies excluded from the qualitative review

Study	Exclusion reason
Ackerman, G. and Oliver, D. (1997) Psychosocial support in an outpatient clinic. Palliative Medicine 11(2): 167-168	- Conference abstract
Adamson, D., Blazeby, J., Nelson, A. et al. (2014) Palliative radiotherapy in addition to self-expanding metal stent for improving dysphagia and survival in advanced oesophageal cancer (ROCS: Radiotherapy after Oesophageal Cancer Stenting): study protocol for a randomized controlled trial. Trials [Electronic Resource] 15: 402	- No relevant information to extract
Adamson, D., Blazeby, J., Porter, C. et al. (2021) Palliative radiotherapy combined with stent insertion to reduce recurrent dysphagia in oesophageal cancer patients: the ROCS RCT. Health Technology Assessment (Winchester, England) 25(31): 1-144	- No relevant information to extract
Alberda, C., Alvadj-Korenic, T., Mayan, M. et al. (2017) Nutrition Care in Patients With Head and Neck or Esophageal Cancer: The Patient Perspective. Nutrition in Clinical Practice 32(5): 664-674	- Population not relevant to this review protocol *Mixed population of people with head and neck cancer and oesophageal cancer unclear if related to Barrett's oesophagus and what stage it was*
Andreassen, S., Randers, I., Naslund, E. et al. (2007) Information needs following a diagnosis of oesophageal cancer; self-perceived	- Population not relevant to this review protocol

Study	Exclusion reason
information needs of patients and family members compared with the perceptions of healthcare professionals: a pilot study. European Journal of Cancer Care 16(3): 277-85	*unclear if cancer was related to Barrett's oesophagus and what stage it was*
Andreassen, S., Randers, I., Naslund, E. et al. (2005) Family members' experiences, information needs and information seeking in relation to living with a patient with oesophageal cancer. European Journal of Cancer Care 14(5): 426-34	- Population not relevant to this review protocol *unclear if cancer was related to Barrett's oesophagus*
Andreassen, S., Randers, I., Naslund, E. et al. (2006) Patients' experiences of living with oesophageal cancer. Journal of Clinical Nursing 15(6): 685-95	- Population not relevant to this review protocol *unclear in cancer was related to Barrett's oesophagus*
Andreassen, Sissel (2022) Life situation, information needs, and information seeking in patients with oesophageal cancer and their family members. Dissertation Abstracts International: Section B: The Sciences and Engineering 83(3b): nopaginationspecified	- Population not relevant to this review protocol *people with oesophageal cancer unclear if related to Barrett's oesophagus*
Bennett, A. E., O'Neill, L., Connolly, D. et al. (2018) Patient experiences of a physiotherapy-led multidisciplinary rehabilitative intervention after successful treatment for oesophago-gastric cancer. Supportive Care in Cancer 26(8): 2615-2623	- Population not relevant to this review protocol *unclear if related to Barrett's oesophagus*
Bennett, A. E., O'Neill, L., Connolly, D. et al. (2020) Perspectives of Esophageal Cancer Survivors on Diagnosis, Treatment, and Recovery. Cancers 13(1): 31	- Population not relevant to this review protocol *Majority were higher than stage 1*
Blom, R. L., Nieuwkerk, P. T., van Heijl, M. et al. (2012) Patient preferences in screening for recurrent disease after potentially curative esophagectomy. Digestive Surgery 29(3): 206-12	- Population not relevant to this review protocol *Mixed population of people with adenocarcinoma and squamous cell carcinoma, majority higher than stage 1.*
Britton, J., Gadeke, L., Lovat, L. et al. (2017) Research priority setting in Barrett's oesophagus and gastro-oesophageal reflux disease. The Lancet. Gastroenterology & Hepatology 2(11): 824-831	- No relevant information to extract
Essink-Bot, Marie-Louise, Kruijshaar, Michelle E., Bac, Dirk J. et al. (2007) Different perceptions of the burden of upper GI endoscopy: An empirical study in three patient	- No relevant information to extract

Study	Exclusion reason
groups. Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation 16(8): 1309-1318	
Gilliam, A. D., Speake, W. J., Scholefield, J. H. et al. (2003) Finding the best from the rest: evaluation of the quality of patient information on the Internet. Annals of the Royal College of Surgeons of England 85(1): 44-6	- Conference abstract
Graham-Wisener, L., Collins, L., Hanna, J. et al. (2019) The need for enhanced psychological support in esophageal cancer-an exploratory study of the perception of HCPs, patients, and carers. Diseases of the Esophagus 32(5): 01	- Population not relevant to this review protocol *unclear if related to Barrett's oesophagus*
Graham-Wisener, L. and Dempster, M. (2017) Peer advice giving from posttreatment to newly diagnosed esophageal cancer patients. Diseases of the Esophagus 30(10): 1-7	- Population not relevant to this review protocol *unclear if related to Barrett's oesophagus*
Jacobs, M., Henselmans, I., Macefield, R. C. et al. (2014) Delphi survey to identify topics to be addressed at the initial follow-up consultation after oesophageal cancer surgery. British Journal of Surgery 101(13): 1692-701	- Population not relevant to this review protocol *mixed population of health care professionals and people who have had oesophageal cancer surgery, unclear if related to Barrett's oesophagus and what cancer stage.*
Jaromahum, J. and Fowler, S. (2010) Lived experiences of eating after esophagectomy: a phenomenological study. MEDSURG Nursing 19(2): 96-100	- No relevant information to extract
Koshimoto, S., Arimoto, M., Saitou, K. et al. (2019) Need and demand for nutritional counselling and their association with quality of life, nutritional status and eating-related distress among patients with cancer receiving outpatient chemotherapy: a cross-sectional study. Supportive Care in Cancer 27(9): 3385-3394	- No relevant information to extract
Kruijshaar, M. E., Kerkhof, M., Siersema, P. D. et al. (2006) The burden of upper gastrointestinal endoscopy in patients with Barrett's esophagus. Endoscopy 38(9): 873-8	- No relevant information to extract *No relevant themes*
McNair, A. G., Brookes, S. T., Kinnersley, P. et al. (2013) What surgeons should tell patients with oesophago-gastric cancer: a cross sectional study of information needs. European Journal of Surgical Oncology 39(11): 1278-86	- Population not relevant to this review protocol *People with oesophagogastric cancer not always related to the oesophagus but to the stomach and oesophagogastric junction; majority above stage I.*

Study	Exclusion reason
Mills, M. E. and Sullivan, K. (2000) Patients with operable oesophageal cancer: their experience of information-giving in a regional thoracic unit. Journal of Clinical Nursing 9(2): 236-46	- Population not relevant to this review protocol *patients with operable oesophageal cancer unclear if related to Barrett's*
Morowatisharifabad, M. A., Gerayllo, S., Jouybari, L. et al. (2021) Perceived Threats toward Esophageal Cancer among Immediate Relatives of Sufferers: a Qualitative Study. Journal of Gastrointestinal Cancer 52(2): 643-650	- Population not relevant to this review protocol *unclear if cancer was related to Barrett's*
Nagao, N., Tsuchiya, A., Ando, S. et al. (2017) The Psychosocial Influences of Waiting Periods on Patients Undergoing Endoscopic Submucosal Dissection. Gastroenterology Nursing 40(5): 373-379	- Population not relevant to this review protocol *mixed population including people with stomach and colon cancer; no relevant themes*
Nicklin, J. (2009) Gastrointestinal cancer: developing an information booklet for patients. Nursing Standard 23(33): 35-40	- Population not relevant to this review protocol *Sample of 2 men who had undergone gastrectomy unclear if for Barrett's oesophagus and their wives*
Pickering, Melissa (2009) Patient control mode and likelihood of using the Internet to seek information related to Barrett's Esophagus. Dissertation Abstracts International: Section B: The Sciences and Engineering 70(2b): 1330	- No relevant information to extract
Pucher, P. H., Coombes, A., Evans, O. et al. (2022) Patient perspectives on key symptoms and preferences for follow-up after upper gastro-intestinal cancer surgery. Supportive Care in Cancer 11: 11	- Population not relevant to this review protocol *unclear if cancer was related to Barrett's oesophagus*
Ren, J. Y., Zhong, J. D., Yuan, J. et al. (2020) Unmet supportive care needs and associated factors among Chinese discharged patients with esophageal cancer after esophagectomy: A cross-sectional study. European Journal of Oncology Nursing 46: 101767	- Population not relevant to this review protocol *People with oesophageal cancer that was dues to squamous cell carcinoma, not Barrett's oesophagus*
Ringborg, C. H., Schandl, A., Wengstrom, Y. et al. (2022) Experiences of being a family caregiver to a patient treated for oesophageal cancer-1 year after surgery. Supportive Care in Cancer 30(1): 915-921	- Population not relevant to this review protocol Caregiver of people with oesophageal cancer that most probably was higher than stage 1 and part of which was related to squamous cell carcinoma, not Barrett's oesophagus
Sjeltoft, J. R., Donsel, P. O., Vad, H. et al. (2020) A radical change: A qualitative study of	- Population not relevant to this review protocol

Study	Exclusion reason
patients' experiences of eating and daily living through the first year after oesophageal resection. European Journal of Oncology Nursing 48: 101800	*squamous cell carcinoma*
Smets, E. M., van Heijl, M., van Wijngaarden, A. K. et al. (2012) Addressing patients' information needs: a first evaluation of a question prompt sheet in the pretreatment consultation for patients with esophageal cancer. Diseases of the Esophagus 25(6): 512-9	- Population not relevant to this review protocol *Majority had stage higher than T1*