National Institute for Health and Care Excellence

Final

Thyroid cancer: assessment and management

[R] Evidence review for the information, education and support needed by people with suspected and confirmed thyroid cancer, and their families and carers

NICE guideline NG230

Evidence reviews underpinning recommendations 1.1.1 to 1.1.10 in the NICE guideline

December 2022

Final

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Contents

1 The information, education and support needed by people with suspected and confirmed thyroid cancer, and their families and carers

1.1 Review question

1.1.1 What information, education and support do people with suspected and confirmed thyroid cancer and their families and carers need?

1.1.2 Introduction

Providing information to people with suspected or confirmed thyroid cancer will help them understand and manage their condition. It is important to identify and address the unique needs of people with thyroid cancer.

When people are provided with the correct timely information and support, they can share decision-making in line with their needs and wishes, enabling them to actively participate in their own care and improve their health outcomes.

Individual hospitals may have locally written information to distribute to patients, however this will differ between centres, reflecting local practice as there are no national standards for this information.

This review seeks to determine the information, education and support that people with suspected and confirmed thyroid cancer and their families and carers need by evaluating the qualitative information on the opinions, thoughts, feelings and experiences of people with thyroid cancer.

1.1.3 Summary of the protocol

For full details see the review protocol in Appendix A.

Table 1: PICO characteristics of review question

Objective	To determine the information, education and support that people with suspected and confirmed thyroid cancer and their families and carers need
Population and setting	People aged 16 or over with suspected and confirmed thyroid cancer, and their families and carers
Context	Perceptions of patients of the information, education and support they require

1.1.4 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.

1.1.5 Qualitative evidence

1.1.5.1 Included studies

Seven qualitative studies were included in the review,[11, 16, 18, 21, 24-26] these are summarised in Table 2 below. Key findings from these studies are summarised in the clinical evidence summary below (Table 2). See also the study selection flow chart in Appendix C, quality of the evidence in Appendix D, study evidence tables in Appendix E and excluded studies lists in Appendix G.

Only studies were found for people with confirmed thyroid cancer rather than suspected thyroid cancer. No studies were identified that explicitly set out to explore the specific desires of people with thyroid cancer in relation to information, education or support, however, the qualitative nature of the study designs means that evidence falls out from the experiential findings of the seven included studies. We identified eleven relevant themes from qualitative studies on aspects of experiencing thyroid cancer,[11] diagnosis and surgical treatment of local-surgical recurrence of thyroid cancer,[18] papillary microcarcinoma diagnosis and treatment decisions,[21] preoperative needs of people with papillary thyroid cancer,[24] the impact of thyroid cancer and post-surgical radioactive iodine treatment on the lives of people with thyroid cancer,[25] treatment decisions,[16] and young people experiences of diagnosis and treatment.[26] Interpretations and explanations from the original studies were synthesised to gain an insight into themes present across the body of evidence as a whole. The main concepts found in each individual study which were relevant to our review question were drawn together to inform understanding of overarching themes.

Five studies used one-to-one interviews as their data collection method.[11, 18, 21, 24, 26] Two studies used focus groups.[25,16] Two studies were on the views of young adults.[11, 26] A variety of qualitative methodologies were used to inform the research.

1.1.5.2 Summary of studies included in the qualitative evidence

Table 2: Summary of studies included in the evidence review

Study	Design / Recruitment	Population	Research aim	Comments
Easley 2013[11]	Telephone interviews with open-ended questions with constructivist, grounded theory approach Participants were recruited via social networking Web sites (e.g. Facebook), classified advertisement websites (e.g. Kijiji), newsletters, online message boards at cancer advocacy groups (e.g. Young Adult Cancer Canada), posters in various oncology clinics,	Individuals aged 18 to 39, 1 to 5 years post-treatment n=12 Mean age at diagnosis: 32 years (SD 3.94) Range: 24 to 37 years Mean (SD) age at interview: 34 (3.26) years Range: 28 to 38 years Four Canadian provinces	To describe the survivorship experience of young adults with thyroid cancer	All themes identified applicable: impact of having the ‘good cancer’ and isolation

Study	Design / Recruitment	Population	Research aim	Comments
	newspapers and media articles			
Koot 2021[16]	Semi-structured focus group interviews using eight-dimension Picker domains Participants were recruited from six academic hospitals throughout the Netherlands, as well as the Dutch patient association	Two focus groups One group included low risk DTC participants (n = 6) discussing thyroid lobectomy or total thyroidectomy, including the need for the subsequent ablation of thyroid remnants with RAI. The other group included participants with advanced disease (n = 7), discussing the watchful waiting approach or starting with TKIs Mean (range) age: 57 (31 to 84) years Netherlands	To identify in-depth needs, preferences, and values of low risk DTC participants in two different treatment decision groups (thyroid lobectomy and TKIs)	Four themes relevant: information support, psychosocial support, team-based thyroid cancer care and avoidance of conflicting recommendations among healthcare providers, treatment as an individual
Misra 2013[18]	One face-to-face semi-structured individual interview with thematic analysis coupled with techniques borrowed from grounded theory	Individuals aged 18 years or older with a history of non-medullary thyroid cancer who had one or more neck operation(s) for recurrent thyroid cancer ≥ 6 months following complete surgical removal of the thyroid n=15 Mean (range) age at recurrence: 46.5 (26 to 77) years Primary diagnosis of thyroid cancer was made between 1 and 21	To explore individual patient experiences relating to diagnosis and surgical treatment of local-surgical recurrence of thyroid cancer, topics of interest initial reaction, sources of medical information and psychosocial support	One theme was relevant: sources of medical information and psychosocial support

Study	Design / Recruitment	Population	Research aim	Comments
		years prior (median 5 years) The time from last neck surgery for recurrent disease until the study interview ranges from 11 to 79 months University Health Network and Mount Sinai Hospital Canada		
Nickel 2018[21]	Semi-structured telephone and face-to-face interviews with Framework thematic analysis	Individuals aged 18 years or older, less than 1 year since initial diagnosis, diagnosis pre-operatively (before any surgical intervention) with a single focus < 1 cm PTC with no evidence of extra-thyroidal extension or lymph node metastasis. n=25 Age ranges and numbers: ≤25 years: 1 26 to 50 years: 5 51 to 75 years: 18 >75 years: 1 Australia	To explore PMC patient's diagnostic and treatment experience including communication and decision making	One theme was relevant: understanding of information related to a PMC diagnosis
Pitt 2019[24]	One-to-one semi-structured individual interviews with thematic analysis Participants were enrolled in a single-blinded RCT, comparing receiving versus not receiving a prophylactic central neck dissection	Participants aged 18 years or older and had at least one thyroid nodule that measured ≥ 1cm with a cytologic or frozen section diagnosis of PTC n=32 Mean (SD) age at consent; 47 (12) years	To characterise the needs of people with thyroid cancer prior to undergoing surgery	All themes relevant: informational support, emotional support, treatment as an individual

Study	Design / Recruitment	Population	Research aim	Comments
	(https://clinicaltrials.gov/ct2/show/NCT02138214) Interviews occurred after participants consulted with the surgeon and consented for the RCT, but prior to surgical intervention and randomisation	USA		
Sawka 2009[25]	Four focus groups with grounded theory approach All participants were recruited from University Health Network and Mount Sinai hospital in Toronto Canada through poster advertisements in endocrinology, otolaryngology, head and neck surgery and endocrine oncology clinics	Participants with well-differentiated PTC or FTC (or variant) that was completely resected at surgery and if they were offered adjunct RAI therapy n=32 Mean (range) age of participants; 44 years (28 to 75 years). Mean (range) age since the diagnosis of thyroid carcinoma; 5 (2 to 8) years Canada	To explore the impact of a thyroid cancer diagnosis, counselling and decision making about RAI therapy	Three themes relevant: life changing experience with thyroid cancer diagnosis (the 'good cancer'), the experience of receiving counselling and decision-making on adjuvant RAI therapy, and Team-based thyroid cancer care and avoidance of conflicting recommendations among healthcare providers
Smith 2018[26]	One face-to-face semi-structured individual interview with interpretative phenomenological analysis Purposive sampling was used to recruit participants from an established cancer clinic that provides long-term follow-up, potential participants were identified by the endocrinologists and oncologist involved in the study by review of	Participants aged between 16 and 35 years, diagnosed and treated for PTC or FTC in the last five years, and being at least 6 months post-diagnosis n=8 Aged between 19 and 34 years	To provide a detailed understanding of the issues faced by young people with thyroid cancer and to examine how they ascribed meaning to their experiences	Two themes were relevant: isolation and the best cancer to have

Study	Design / Recruitment	Population	Research aim	Comments
	clinic lists and medical records			

Abbreviations: DTC; differentiated thyroid cancer, FTC; follicular thyroid carcinoma, PMC; papillary microcarcinoma, PTC; papillary thyroid carcinoma, RAI; radioactive iodine, RCT; randomised controlled trial

See Appendix E for full evidence tables.

1.1.6 Qualitative evidence summary

Table 3: Review findings

Main findings	Statement of finding
Emotional support Pitt 2019[24]	Expressions of compassion and empathy by the surgeon at the initial consultation was a crucial source of reassurance
Experience of receiving counselling and decision-making on adjuvant radioactive iodine treatment Sawka 2009[25]	Written plain language information on the risks, benefits and uncertainty about radioactive iodine treatment was wanted
Impact of having the 'good cancer' Easley 2013,[11] Nickel 2018,[21] Pitt 2019,[24] Smith 2018[26]	Being told that thyroid cancer was a 'good cancer' was generally not reassuring to survivors and was accompanied by feelings of the diagnosis being dismissed as unimportant and consequently participants felt unworthy of seeking support
Information sharing about current clinical practice guidelines Sawka 2009[25]	Clinical practice guidelines were highly valued and a discussion of the application of the clinical practice guidelines to the individual case was appreciated
Informational support Pitt 2019[24] Koot 2021[16]	Information was wanted about all aspects of care from the diagnosis, treatment options, surgery, to postoperative care at and participants wanted the opportunity to ask questions
Isolation Easley 2013[11] Smith 2018[26]	Sense of isolation due to lack of information about thyroid cancer and further isolation by not being offered access to support groups and / or counselling
Medical information on recurrence Misra 2013[18]	Requirement for information on reasons for recurrence of thyroid cancer and risk of further recurrence
Psychosocial support Misra 2013[18] Koot 2021[16]	Support obtained from personal relations (such as spouses, family, co-workers, or friends) was highly valued, however, information and support from other people with recurrent cancer with was not available
Team-based thyroid cancer care and avoidance of conflicting recommendations among healthcare providers Sawka 2009[25] Koot 2021[16]	A multidisciplinary team-based, individualised approach to treatment of thyroid cancer was wanted
Treatment as an individual Pitt 2019[16, 24]	Being treated as an individual was a source of reassurance
Understanding of information related to a papillary microcarcinoma diagnosis Nickel 2018[21]	The natural history and generally indolent nature of papillary microcarcinoma was not understood

1.1.6.1 Narrative summary of review findings

Review finding 1: emotional support

Participants sought direct emotional support from their surgeons at their initial consultation. Expression of compassion and empathy by the surgeon was a crucial source of reassurance. Participants felt reassured when they heard comments such as, ‘Almost certainly you’re not going to need any radiation or chemo...’, or, ‘You will be taking the thyroid hormone pill daily, and once we get that adjusted, you should be good to go’. Validation of the cancer experience was important, ‘Cancer is cancer. It’s hard to deal with. There’s such a glut of emotion. [The surgeon] was still very sensitive to the fact that, anytime you say cancer it freaks you out.’ Participants were distressed when they felt that the surgeon failed to offer an empathetic response, but when surgeons directly addressed participants’ fears and provided emotional support, participants felt reassured. Participants also sought reassurance about their cancer diagnosis surgery (experiencing pain, having a noticeable scar, bleeding, and voice changes) and the postoperative period. However, when a surgeon did not respond to emotional cues, participants felt, ‘shell-shocked’ and ‘I feel horrible, because I’m worried about it. It’s all I think about!’.

Explanation of quality assessment: very minor concerns over methodological limitations because there was no explicit mention of reflexivity in the study, with nothing to lower our confidence. Coherence could not be assessed as there was only one study. No concerns about relevance. No concerns about adequacy. Overall assessment of confidence was high

Review finding 2: the experience of receiving counselling and decision-making on adjuvant radioactive iodine treatment

Thyroid cancer specialty physicians were the primary information source related to thyroid cancer treatment, including radioactive iodine treatment, Health care providers and the internet gave contradictory messages and information from the internet was not considered reliable. In general, the groups favoured the development and dissemination of written in plain language information on risks benefits and uncertainty about radioactive iodine treatment. Some participants preferred quantitated data and others preferred general descriptive information specifically without numbers. It was felt that personal relations lacked sufficient knowledge.

Explanation of quality assessment: very minor concerns over methodological limitations because there was no explicit mention of reflexivity in the study, with nothing to lower our confidence. Coherence could not be assessed as there was only one study. Moderate concerns about adequacy based on an overall assessment of the richness of the data and the quantity of the data (no participant quotes were given). No concerns about relevance. Overall assessment of confidence was moderate due to adequacy

Review finding 3: impact of having the ‘good cancer’

Participants were not generally reassured when being told that thyroid cancer was a ‘good cancer’. Participants had feelings that their diagnosis was being dismissed as unimportant, ‘I don’t think it’s fair to say it’s the best cancer to have. Like, it’s frustrating for those people who have to deal with it. Yeah it might be the best one, but it’s downplaying it, and it’s not helping people deal with the fact they have been diagnosed with cancer’.

Some Participants described feelings that they were not perceived as needing support and often felt unworthy of accessing available support programmes, ‘I wasn’t going to be very ill...I didn’t deserve all the resources and the attention that other people deserved’. Relatedly, although participants expressed a wish to attend a support group if one had been available, it was thought as ‘self-indulgent’.

Explanation of quality assessment: very minor concerns over methodological limitations because there was no explicit mention of reflexivity in three out of four studies, with nothing to lower our confidence No concerns about coherence as findings were concordant both within and between studies. Partial concerns about relevance because two out of four studies were conducted on young adults but on balance it was not considered to lower confidence. No concerns about adequacy. Overall assessment of confidence was high.

Review finding 4: information sharing about current clinical practice guidelines

The expertise of the authors of clinical practice guidelines was greatly valued by participants. A discussion of the application of the clinical practice guidelines to the individual case was appreciated.

Explanation of quality assessment: very minor concerns over methodological limitations because there was no explicit mention of reflexivity in the study, with nothing to lower our confidence. Coherence could not be assessed as there was only one study. Serious concerns about adequacy based on an overall assessment of the richness of the data and the quantity of the data (no participant quotes were given). No concerns about relevance. Overall assessment of confidence was low due to adequacy.

Review finding 5: informational support

Participants looked-for informational support from their surgeon at their initial consultation. Information was wanted in all aspects of their disease and treatment including their diagnosis, prognosis, treatment options, details of the surgery, possible complications, the surgeon's experience and complication rates, postoperative recovery, logistics related to their treatment and follow-up, and radioactive iodine. Participants felt empowered by knowledge gained. The option to ask questions was greatly appreciated by participants when questions were fully answered, participants felt 'comfortable', 'confident', 'calmer', 'less unsettled' and 'ready to go'. However, participants increased worry was experienced by participants when surgeons failed to adequately respond to questions. For example, if a surgeon said, 'Don't worry about it' without providing additional information, participants felt 'dismissed' and 'rushed'. Participants strongly wanted the surgeon to be the primary source of information. Information from other sources was sought from other healthcare professionals and the internet, but, when this information was perceived or false participants experienced increased anxiety, 'When you Google 'thyroid cancer', the stuff you might come up with is, 'You're gonna have leukaemia in 6 months!'

Explanation of quality assessment: very minor concerns over methodological limitations because there was no explicit mention of reflexivity in the study, with nothing to lower our confidence. No concerns about coherence. No concerns about relevance. No concerns about adequacy. Overall assessment of confidence was high.

Review finding 6: isolation

Isolation was strongly influenced by the theme of being told it was the 'good cancer'. Isolation was identified in three different areas: isolation from other cancer sufferers and support programmes, mandatory physical isolation periods following radioactive iodine treatment, and isolation from their peers without cancer.

Participants said they could not relate to people with other types of cancer because treatment for thyroid cancer was relatively well-tolerated compared to other types, as exemplified by, 'there are lots of group therapy at the Health Care Centre but again it's people who've got a serious cancer who are dying, they really don't want to hear about my little survival story when they are dying'.

Psychological isolation was reported by participants during their experience of radioactive therapy and a lack of information about the process was described, ‘It’s just the unknown. You just have no idea of what’s going to happen...or what kind of room it’s going to be’. Isolation from peers stemmed from an inability to identify with the carefree attitude of cancer-free peers.

Participants sought information from the internet and books because of their sense of isolation. However, the information found often caused more worry,’ I didn’t know if it was the most common one...or the most serious one’. This also tiggered difficulties when explaining the diagnosis to others which further isolated them. Many stated that they would have liked a detailed information guide that included material on the thyroid, the different types of thyroid cancer, the treatment process, the potential risks of radioactive iodine therapy, and side effects of the treatment. Other useful information would have been being made aware of the different treatment scenarios, time frames / map of progress, and having case studies of other patient’s experiences and outcomes. Further isolation was triggered by the participants not being given information about support groups and / or counselling.

Explanation of quality assessment: very minor concerns over methodological limitations because there was no explicit mention of reflexivity in one out of the two studies, with nothing to lower our confidence No concerns about coherence as findings were concordant both within and between the studies. No concerns about adequacy. Partial concerns about relevance as the studies were in young people and may not reflect the views of the general thyroid cancer population. Overall assessment of confidence was moderate due to relevance.

Review finding 7: medical information on recurrence

The thyroid cancer specialist was the primary source of medical information. Participants generally wanted more information on recurrence, ‘I would love to have more information about thyroid cancer and the recurrence of thyroid cancer….. the recurrence, the percentage, what's the future, why does it recur, you know, what's the next step after that’ and ‘what are the chances of it coming back again and how do they know if it is back’.

Explanation of quality assessment: very minor concerns over methodological limitations because there was no explicit mention of reflexivity in the study, with nothing to lower our confidence. Coherence could not be assessed as there was only one study. Moderate concerns about adequacy based on an overall assessment of the richness of the data and the quantity of the data. No concerns about relevance. Overall assessment of confidence was moderate due to adequacy.

Review finding 8: psychosocial support

Psychosocial support obtained from personal relations (such as spouses, family, co-workers, or friends) or formal support organisations was variable. Listening, empathy, and encouragement from relations were generally considered helpful, ‘it was really just [my family] being there and trying to point out the good things’ and ‘he/she will be able to the very least listen to you’. While many participants had contacted formal general oncology or thyroid cancer support organisations, information and support needs were incompletely met since participant's desired access to people who had experienced thyroid cancer disease recurrence, ‘there are no groups, I would like to seek help people who are ahead of me [experienced recurrence] for a change, so that I can get advice from. I ‘ve had to feel my way through this and that's frustrating, very frustrating’.

Explanation of quality assessment: very minor concerns over methodological limitations because there was no explicit mention of reflexivity in the study, with nothing to lower our confidence. No concerns about coherence Moderate concerns about adequacy based on an overall assessment of the richness of the data and the quantity of the data. No concerns about relevance. Overall assessment of confidence was moderate due to adequacy.

Review finding 9: team-based thyroid cancer care and avoidance of conflicting recommendations among healthcare providers

A multidisciplinary team-based, individualised approach to treatment of thyroid cancer was favoured by most participants. Open communication among specialty healthcare providers and individualised treatment recommendations were valued. Participants wanted clarity about the healthcare process.

Explanation of quality assessment: very minor concerns over methodological limitations because there was no explicit mention of reflexivity in the study, with nothing to lower our confidence. No concerns about coherence, Serious concerns about adequacy based on an overall assessment of the richness of the data and the quantity of the data. No concerns about relevance. Overall assessment of confidence was low due to adequacy.

Review finding 10: treatment as an individual

Participants were reassured when the surgeon treated them as an individual. The following advice was given, ‘Don’t forget that you’re treating a patient. You’re not treating statistics’. Treatment as an individual was particularly appreciated in people in voice-dependent professionals, ‘[The surgeon]...was very aware and sensitive to my situation, um, and how I use my voice... and changed the conversation or the focus of the explanation to fit. … that was reassuring’. The patient-surgeon relationship was undermined when participants did not feel as though they were being treated as individuals. Specific surgeon behaviour’s that engendered honesty and trust provided reassurance or calmed participants through actions like eye contact, direct speech, humour, and being comfortable in the participant’s space, ‘The [surgeon] looked directly at me, spoke directly to me, was comfortable in my body space. S/he wasn’t one of those doctors that push their chair back. S/he was comfortable’. Participants wanted treatment as an individual to encompass respect for their values and preferences.

Explanation of quality assessment: very minor concerns over methodological limitations because there was no explicit mention of reflexivity in the study, with nothing to lower our confidence. No concerns about relevance. No concerns about coherence. No concerns about adequacy. Overall assessment of confidence was high

Review finding 11: understanding of information related to a papillary microcarcinoma diagnosis

Participants did not appear to understand the natural history and generally indolent nature of papillary microcarcinoma. As such, they did not seem to be aware of the possibility of overdiagnosis and overtreatment. Some participants seemed to be conflicted by their cancer diagnosis, as they understood cancer to be something terrible, but they were told and felt that their cancer was a ‘good result’. One participant said, ‘I think it’s [cancer] its its reputation for a reason I suppose, that’s the way I look at it, I mean, it’s not to be taken lightly and, it’s, um, you know, it needs to be, needs to be addressed as quick as you can and, um, you know, there’s obviously all, all grades in all types and what have you but, um, it’s all cancer, isn’t it?’.

Explanation of quality assessment: very minor concerns over methodological limitations because there was no explicit mention of reflexivity in the study, with nothing to lower our confidence. Coherence could not be assessed as there was only one study. Serious concerns about adequacy based on an overall assessment of the richness of the data and the quantity of the data. No concerns about relevance. Overall assessment of confidence was low due to 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.

1.1.8 The committee's discussion and interpretation of the evidence

1.1.8.1 The quality of the evidence

Seven studies were included in the review. Only studies were found for people with confirmed thyroid cancer rather than suspected thyroid cancer. No studies were identified in family and carers. No studies were identified that explicitly set out to explore the specific desires of people with thyroid cancer in relation to information, education or support, however, the findings from people experiencing diagnosis and different treatment provided themes relevant to this review

Confidence in the review findings ranged from high to low. The CERQual (Confidence in the Evidence from Reviews of Qualitative Research approach was used. Quality assessment was examined over four domains. Methodological limitations were examined based on overall assessment of the primary studies contributing to the review finding. Coherence was determined by the identification of a clear pattern across the studies included in the review. Relevance considered the applicability to the context specified in the review protocol. Only very minor limitations were found for methodological interventions in that the studies did not discuss reflexivity between the researcher and the participant. The main reason for downgrading the evidence was adequacy. Relevancy was a reason for downgrading where information came from young adults. Coherence could not be assessed when there was only one study for a given theme.

Recommendations were made on moderate to high quality evidence.

1.1.8.2 The committee's discussion and interpretation of the evidence

The committee agreed with the findings in the review. They recognised from the evidence that thyroid cancer sufferers, family members and carers wanted more high-quality information on all aspects of their condition. Both the committee and the evidence found that it was often not the case.

The committee noted that some of the review findings are already covered by recommendations in NICE Guideline CG138 patient experience. They agreed that although these didn't need to be included in full in this guideline, the evidence demonstrated these were of particular importance in this context, and evidence from this review may suggest that these recommendations are not always being implemented. Therefore, the committee have cross referred to the patient experience guideline.

The committee also considered the review findings and the recommendations from the NICE Guideline NG145 thyroid disease. They agreed there was overlap for some for some of those recommendations and have included similar recommendations in this guideline. These are discussed below.

The committee considered it important to make recommendations for people with suspected thyroid cancer even though no evidence was found. People with suspected thyroid cancer should be made aware that the lump may not be cancerous, and that there should be explanation of the diagnostic pathway. The committee noted that those with suspected cancer required high-quality information and time to ask questions. The committee highlighted that people being considered for diagnostic hemithyroidectomy have specific information needs such as the potential risks, and implications of treatment. Information is needed on the thyroid and adjusting to living without a thyroid, particularly in relation to energy, fatigue, weight, and mood. The implications of removing the thyroid gland are not always fully understood. The evidence supports this view and recommendation was made to provide information on the function of the thyroid gland and the effect of its removal.

Evidence showed being told thyroid cancer was a ‘good cancer’ was generally not reassuring to people with thyroid cancer and was accompanied by feelings of the diagnosis being dismissed as unimportant and consequently participants felt unworthy of seeking support. This was confirmed by lay member experience who noted that dismissing the diagnosis as ‘a good cancer’ was damaging and had the effect of dissuading the patient from reaching out or asking for support when needed. The committee agreed and said the term was very damaging to patients. The committee also noted the use of the term ‘good cancer’ can lead to isolation and the evidence supported this. A recommendation was therefore made to avoid using the descriptor. They discussed that new diagnosed people with thyroid cancer need time to acknowledge that they have a cancer diagnosis. The committee agreed that in their experience, for few people this may involve further appointments, and even additional tests to help them accept their condition.

In addition to receiving information the committee thought that it was important for people with thyroid cancer to be signposted to where further information could be obtained. The review found that a lack of information on sources of help led to feelings of isolation. The committee considered it important to offer when needed follow-up appointments taking into account the person’s mental well-being.

The committee discussed the prognosis of differentiated thyroid cancer. The evidence showed there was a lack of understanding on the natural history and generally indolent nature of papillary microcarcinoma, a type of differentiated thyroid cancer. A recommendation was therefore made to emphasise that differentiated thyroid cancer has a high cure rate and the risk of recurrence should be explained.

Evidence found that people with thyroid cancer wanted information on the function of the thyroid and on all aspects of care. A recommendation was made to provide verbal and written information on specific areas of care. The committee discussed the importance of provision of a key worker and that people being treated for cancer in England and Wales are assigned a key worker. The committee noted that it can be confusing as to who is responsible for care, the surgeon, oncologist or general practitioner and agreed it is important to provide the key worker contact details. The key worker is usually a clinical nurse specialist but this is not always the case. Evidence found that people with thyroid cancer appreciated emotional support and a key worker would be very important in this respect.

The committee discussed the importance of follow-up care and information. They made specific recommendations on aspects of follow-up care including when it would be performed.

1.1.8.3 Cost effectiveness and resource use

Cost effectiveness evidence was not sought as this was a qualitative review. The recommendations provide guidance regarding the content of information and support required for people with differentiated cancer. This is in line with the general principles of provision of information already established in the existing NICE Patient experience guideline (CG138).

The recommendations were not considered likely to have a substantial resource impact over and above CG138. The committee agreed that giving people time to reflect on their diagnosis is current practice for newly diagnosed cancer patients. For a few people this also included additional appointments to help provide support.

1.1.8.4 Other factors the committee took into account

The committee discussed equality issues related to surgery and pregnancy, thyroid hormone withdrawal and its impact on people with mental health issues and those from a lower socioeconomic group, radioactive iodine and the implications for pregnant women and fertility. These areas are also discussed in evidence reports H, I, J and K. They are also addressed in the patient information recommendations where it is recommended that people are informed about: the implications of removal of part or all of their thyroid; how treatment may affect pregnancy and fertility; the risks, benefits and uncertainties of treatment and its potential effects on their quality of life, energy, weight and mood. The committee also advise considering further appointments, if this will be beneficial for a person's psychological wellbeing, even if they are not indicated for physical reasons.

The committee also agreed with and cross referred to the recommendations in the NICE guideline on patient information. The guideline covers a range of recommendations aimed at enabling all patients to actively participate in their care.

1.1.9 Recommendations supported by this evidence review

This evidence review supports recommendations 1.1.1 to 1.1.9.

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Appendices

Appendix A Review protocols

1.1.9.1 Review protocol for the information, education and support needed by people with suspected and confirmed thyroid cancer, and their families and carers

Field	Content
PROSPERO registration number	Not registered
Review title	The information, education and support needed by people with suspected and confirmed thyroid cancer, and their families and carers.
Review question	What information, education and support do people with suspected and confirmed thyroid cancer and their families and carers need?
Objective	To determine the information, education and support that people with suspected and confirmed thyroid cancer and their families and carers need
Searches	The following databases will be searched: • Cochrane Central Register of Controlled Trials (CENTRAL) • Cochrane Database of Systematic Reviews (CDSR) • Embase • MEDLINE

Field	Content
	- Cinahl Searches will be restricted by: - English language - Human studies - Letters and comments are excluded. Other searches: - Inclusion lists of relevant systematic reviews will be checked by the reviewer. The searches may be re-run 6 weeks before final submission of the review and further studies retrieved for inclusion if relevant. The full search strategies for MEDLINE database will be published in the final review.
Condition or domain being studied	Thyroid cancer

Field	Content
Population	Inclusion: People aged 16 or over with suspected and confirmed thyroid cancer, and their families and carers Exclusion: Children under 16
Intervention/Exposure/Test	Qualitative information on opinions/thoughts/feelings of people concerned
Comparator/Reference standard/Confounding factors	NA
Types of study to be included	Qualitative papers
Other exclusion criteria	Non-English language studies. Abstracts will be excluded as it is expected there will be sufficient full text published studies available.
Context	N/A
Primary outcomes (critical outcomes)	Thematic analysis will yield themes related to the types of information needed

Field	Content
Secondary outcomes (important outcomes)	N/A
Data extraction (selection and coding)	EndNote will be used for reference management, sifting, citations and bibliographies. Titles and/or abstracts of studies retrieved using the search strategy and those from additional sources will be screened for inclusion. The full text of potentially eligible studies will be retrieved and will be assessed for eligibility in line with the criteria outlined above. 10% of the abstracts will be reviewed by two reviewers, with any disagreements resolved by discussion or, if necessary, a third independent reviewer. A second reviewer will quality assure the extracted data. Discrepancies will be identified and resolved through discussion (with a third reviewer where necessary).
Risk of bias (quality) assessment	Risk of bias will be assessed using the appropriate checklist as described in Developing NICE guidelines: the manual. CASP 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.
Strategy for data synthesis	Thematic analysis

Field	Content
Analysis of sub-groups	<u>Stratification</u> TBD
Type and method of review	☐ Intervention ☐ Diagnostic ☐ Prognostic ☒ Qualitative ☐ Epidemiologic ☐ Service Delivery ☐ Other (please specify)
Language	English
Country	England
Named contact	**Named contact** National Guideline Centre **Organisational affiliation of the review** National Institute for Health and Care Excellence (NICE) and the National Guideline Centre

Field	Content
Review team members	From the National Guideline Centre: Carlos Sharpin, Guideline lead Mark Perry, Senior systematic reviewer Alfredo Mariani, Health economist Lina Gulhane, Head of Information specialists
Funding sources/sponsor	This systematic review is being completed by the National Guideline Centre which receives funding from NICE.
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.
Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of Developing NICE guidelines: the manual. Members of the guideline committee are available on the NICE website: https://www.nice.org.uk/guidance/indevelopment/gid-ng10150/documents
Other registration details	N/A

Field	Content
Reference/URL for published protocol	N/A
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.
Keywords	Qualitative, thyroid cancer
Details of existing review of same topic by same authors	N/A
Additional information	N/A
Details of final publication	www.nice.org.uk

Appendix B Literature search strategies

The literature searches for these reviews are detailed below and complied with the methodology outlined in Developing NICE guidelines: the manual, 2014 (updated 2020) https://www.nice.org.uk/process/pmg20/chapter/identifying-the-evidence-literature-searching-and-evidence-submission.

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

Literature search strategy

This literature search strategy was used for the following review:

- What information, education and support do people with suspected and confirmed thyroid cancer and their families and carers need?

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

Table 3: Database parameters, filters and limits applied

Database	Dates searched	Search filters and limits applied
Medline (OVID)	1946 – 13 January 2022	Exclusions (animal studies, letters, comments, editorials, case studies/reports, children) English language
Embase (OVID)	1974 – 13 January 2022	Exclusions (animal studies, letters, comments, editorials, case studies/reports, conference abstracts, children) English language
Current Nursing and Allied Health Literature (CINAHL) (EBSCO)	Inception – 13 January 2022	Human Exclusions (Medline records) English Language
PsycINFO (OVID)	Inception – 13 January 2022	English language

Medline (Ovid) search terms

1.	exp Thyroid Neoplasms/
2.	(thyroid adj3 (cancer* or carcinom* or microcarcinoma* or tumo?r* or neoplasm* or metast* or adenoma* or adenocarcinom* or node* or nodul* or nodal or lump* or papillar* or swollen or swell* or anaplastic or sarcoma* or cyst* or malignan*)).ti,ab.
3.	DTC.ti,ab.
4.	((papillar* or anaplastic) adj2 (cancer* or carcinom* or tumo?r* or neoplasm* or metast* or adenoma* or adenocarcinom* or nodul* or node* or lump*)).ti,ab.

5.	or/1-4
6.	letter/
7.	editorial/
8.	news/
9.	exp historical article/
10.	Anecdotes as Topic/
11.	comment/
12.	case report/
13.	(letter or comment*).ti.
14.	or/6-13
15.	randomized controlled trial/ or random*.ti,ab.
16.	14 not 15
17.	animals/ not humans/
18.	exp Animals, Laboratory/
19.	exp Animal Experimentation/
20.	exp Models, Animal/
21.	exp Rodentia/
22.	(rat or rats or mouse or mice or rodent*).ti.
23.	or/16-22
24.	5 not 23
25.	limit 24 to english language
26.	(exp child/ or exp pediatrics/ or exp infant/) not (exp adolescent/ or exp adult/ or exp middle age/ or exp aged/)
27.	25 not 26
28.	"patient acceptance of health care"/ or exp patient satisfaction/ or consumer health information/ or needs assessment/
29.	Patient Education as Topic/ or exp patients/ or exp family/ or caregivers/ or patient preference/ or communication barrier/
30.	((educat* or learn* or support* or teach* or train*) adj3 (service* or information* or material* or virtual* or app or apps or blog* or booklet* or brochure* or dvd* or elearn* or e-learn* or email* or e-mail* or e mail* or facebook or facetime or face time or forum* or handout* or hand-out* or hand out* or helpline* or hotline* or internet* or ipad* or iphone* or leaflet* or online or magazine* or mobile phone* or newsletter* or pamphlet* or palm pilot* or personal digital assistant* or pocket pc* or podcast* or poster? or skype* or smartphone* or smart phone* or social media or social network* or sms or text messag* or twitter or tweet* or video* or web* or wiki* or youtube* or manual* or publication* or literature or computer* or interactive or telephone* or phone*)).ti,ab.
31.	((patient* or carer* or client* or user* 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 inpatient* or outpatient* or in patient* or out patient* 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 inform* or experience or experiences or opinion* or preference* or focus group* or service* or information* or material* or virtual* or app or apps or blog* or booklet* or brochure* or dvd* or elearn* or e-learn* or email* or e-mail* or e mail* or facebook or facetime or face time or forum* or handout* or hand-out* or hand out* or helpline* or hotline* or internet* or ipad* or iphone* or leaflet* or online or magazine* or mobile phone* or newsletter* or pamphlet* or palm pilot* or personal digital assistant* or pocket pc* or podcast* or poster? or skype* or smartphone* or smart phone* or social media or social network* or sms or text messag* or twitter or tweet* or video* or web* or wiki* or youtube* or manual* or publication* or literature or computer* or interactive or telephone* or phone*)).ti,ab.

32.	(information* adj3 (need* or requirement* or support* or seek* or access* or disseminat* or barrier* or service*)).ti,ab.
33.	or/28-32
34.	27 and 33

Embase (Ovid) search terms

1.	exp Thyroid Cancer/
2.	(thyroid adj3 (cancer* or carcinom* or microcarcinoma* or tumo?r* or neoplasm* or metast* or adenoma* or adenocarcinom* or node* or nodul* or nodal or lump* or papillar* or swollen or swell* or anaplastic or sarcoma* or cyst* or malignan*)).ti,ab.
3.	DTC.ti,ab.
4.	((papillar* or anaplastic) adj2 (cancer* or carcinom* or tumo?r* or neoplasm* or metast* or adenoma* or adenocarcinom* or nodul* or node* or lump*)).ti,ab.
5.	or/1-4
6.	letter.pt. or letter/
7.	note.pt.
8.	editorial.pt.
9.	case report/ or case study/
10.	(letter or comment*).ti.
11.	(conference abstract or conference paper).pt.
12.	or/6-11
13.	randomized controlled trial/ or random*.ti,ab.
14.	12 not 13
15.	animal/ not human/
16.	nonhuman/
17.	exp Animal Experiment/
18.	exp Experimental Animal/
19.	animal model/
20.	exp Rodent/
21.	(rat or rats or mouse or mice or rodent*).ti.
22.	or/14-21
23.	5 not 22
24.	limit 23 to english language
25.	(exp child/ or exp pediatrics/) not (exp adult/ or exp adolescent/)
26.	24 not 25
27.	patient attitude/ or patient preference/ or patient satisfaction/ or consumer attitude/ or needs assessment/
28.	*patient information/ or *consumer health information/ or *family/ or *caregivers/
29.	communication barrier/ or *patient education/
30.	((educat* or learn* or support* or teach* or train*) adj3 (service* or information* or material* or virtual* or app or apps or blog* or booklet* or brochure* or dvd* or elearn* or e-learn* or email* or e-mail* or e mail* or facebook or facetime or face time or forum* or handout* or hand-out* or hand out* or helpline* or hotline* or internet* or ipad* or iphone* or leaflet* or online or magazine* or mobile phone* or newsletter* or pamphlet* or palm pilot* or personal digital assistant* or pocket pc* or podcast* or poster? or skype* or smartphone* or smart phone* or social media or social network* or sms or text messag* or twitter or tweet* or video* or web* or wiki* or youtube* or manual* or publication* or literature or computer* or interactive or telephone* or phone*)).ti,ab.
31.	((patient* or carer* or client* or user* 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 inpatient* or outpatient* 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 inform* or experience or experiences or opinion* or preference* or focus group* or service* or information* or material* or virtual* or app or apps or blog* or booklet* or brochure* or dvd* or elearn* or e-learn* or email* or e-mail* or e mail* or facebook or facetime or face time or forum* or handout* or hand-out* or hand out* or helpline* or hotline* or internet* or ipad* or iphone* or leaflet* or online or magazine* or mobile phone* or newsletter* or pamphlet* or palm pilot* or personal digital assistant* or pocket pc* or podcast* or poster? or skype* or smartphone* or smart phone* or social media or social network* or sms or text messag* or twitter or tweet* or video* or web* or wiki* or youtube* or manual* or publication* or literature or computer* or interactive or telephone* or phone*)).ti,ab.
32.	(information* adj3 (need* or requirement* or support* or seek* or access* or disseminat* or barrier* or service*)).ti,ab.
33.	or/27-32
34.	26 and 33

CINAHL (EBSCO) search terms

S1.	MH Thyroid Neoplasms
S2.	thyroid AND (cancer* or carcinom* or microcarcinoma* or tumo?r* or neoplasm* or metast* or adenoma* or adenocarcinom* or node* or nodul* or nodal or lump* or papillar* or swollen or swell* or anaplastic or sarcoma* or cyst* or malignan*)
S3.	DTC
S4.	(papillar* or anaplastic) AND (cancer* or carcinom* or tumo?r* or neoplasm* or metast* or adenoma* or adenocarcinom* or nodul* or node* or lump*)
S5.	S1 OR S2 OR S3 OR S4
S6.	(client* or patient* or user* or carer* or consumer* or customer* or parent* or famil* or spouse*) AND (attitud* or priorit* or perception* or preferen* or expectation* or choice* or perspective* or view* or satisfact* or inform* or experience or experiences or opinion* or preference* or focus group*)
S7.	(educat* or learn* or support*) AND (service* or information* or material* or virtual* or app or apps or blog* or booklet* or brochure* or dvd* or elearn* or e-learn* or email* or e-mail* or e mail* or facebook or facetime or face time or forum* or handout* or hand-out* or hand out* or helpline* or hotline* or internet* or ipad* or iphone* or leaflet* or online or magazine* or mobile phone* or newsletter* or pamphlet* or palm pilot* or personal digital assistant* or pocket pc* or podcast* or poster* or skype* or smartphone* or smart phone* or social media or social network* or sms or text messag* or twitter or tweet* or video* or web* or wiki* or youtube* or manual* or publication* or literature or computer* or interactive or telephone* or phone*)
S8.	(patient* or carer* or caregiver* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or next of kin or significant other* or partner* or guardian* or inpatient* or outpatient*) AND (service* or information* or material* or virtual* or app or apps or blog* or booklet* or brochure* or dvd* or elearn* or e-learn* or email* or e-mail* or e mail* or facebook or facetime or face time or forum* or handout* or hand-out* or hand out* or helpline* or hotline* or internet* or ipad* or iphone* or leaflet* or online or magazine* or mobile phone* or newsletter* or pamphlet* or palm pilot* or personal digital assistant* or pocket pc* or podcast* or poster* or skype* or smartphone* or smart phone* or social media or social network* or sms or text messag* or twitter or tweet* or video* or web* or wiki* or youtube* or manual* or publication* or literature or computer* or interactive or telephone* or phone*)
S9.	S6 OR S7 or S8
S10.	S5 AND S9

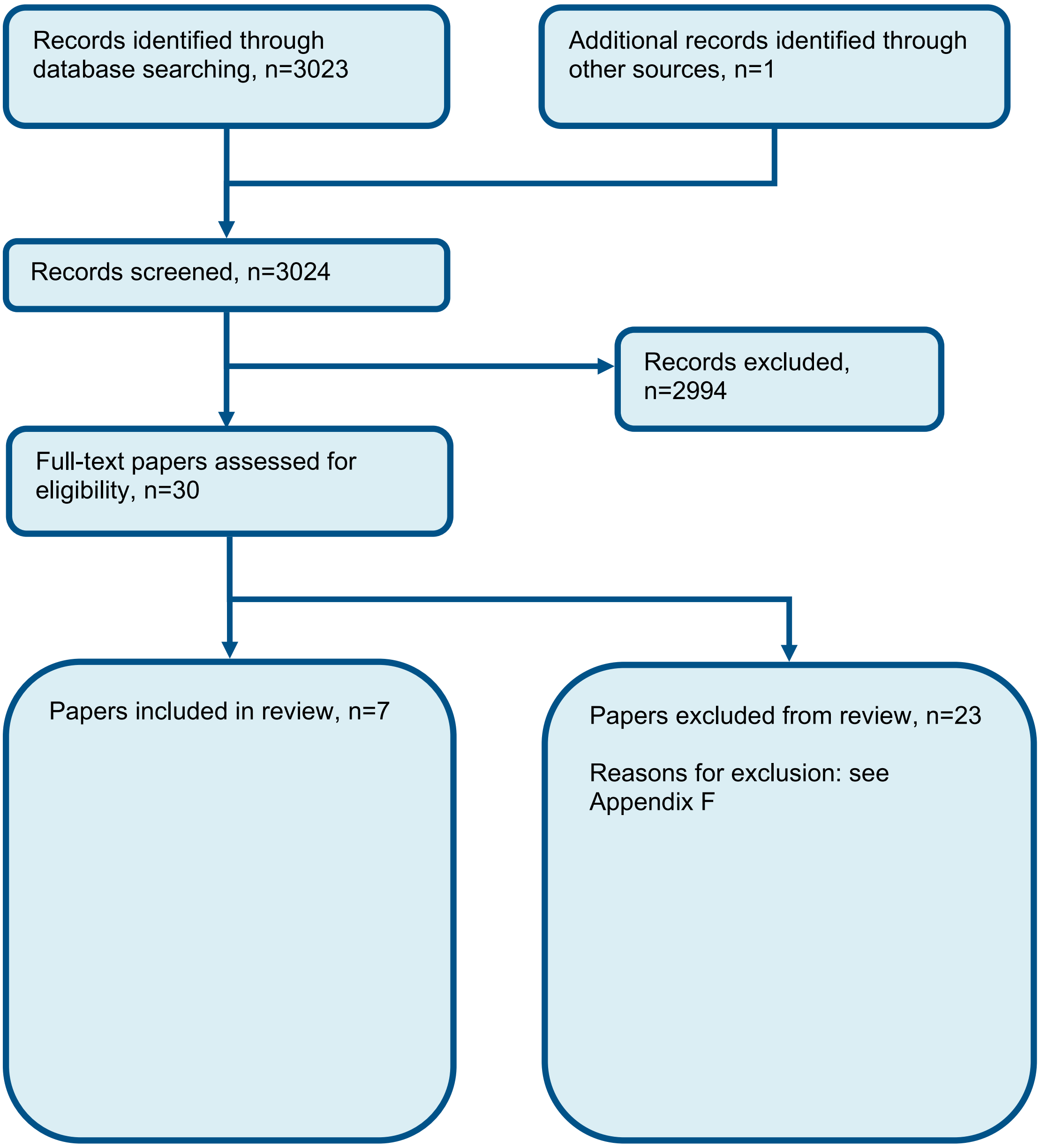
PsycINFO search terms

1.	neoplasms/ or endocrine neoplasms/
2.	exp thyroid disorders/ or exp thyroid gland/

3.	1 and 2
4.	(thyroid adj3 (cancer* or carcinom* or microcarcinoma* or tumo?r* or neoplasm* or metast* or adenoma* or adenocarcinom* or node* or nodul* or nodal or lump* or papillar* or swollen or swell* or anaplastic or sarcoma* or cyst* or malignan* or hormone*)).ti,ab.
5.	DTC.ti,ab.
6.	((papillar* or anaplastic) adj2 (cancer* or carcinom* or tumo?r* or neoplasm* or metast* or adenoma* or adenocarcinom* or nodul* or node* or lump*)).ti,ab.
7.	exp thyroid hormones/ or exp thyroidectomy/ or thyrotropin/ or thyroxine/
8.	(thyroidectomy or thyrotropin* or thyroxine).ti,ab.
9.	or/3-8
10.	Letter/
11.	Case report/
12.	exp Rodents/
13.	or/10-12
14.	9 not 13
15.	limit 14 to (human and english language)
16.	qualitative methods/ or exp interviews/ or exp questionnaires/
17.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
18.	(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.
19.	or/16-18
20.	exp Caregivers/ or Client Satisfaction/ or Health Information/ or exp Needs Assessment/ or Client Attitudes/ or Client Education/ or communication barriers/
21.	((educat* or learn* or support* or teach* or train*) adj3 (service* or information* or material* or virtual* or app or apps or blog* or booklet* or brochure* or dvd* or elearn* or e-learn* or email* or e-mail* or e mail* or facebook or facetime or face time or forum* or handout* or hand-out* or hand out* or helpline* or hotline* or internet* or ipad* or iphone* or leaflet* or online or magazine* or mobile phone* or newsletter* or pamphlet* or palm pilot* or personal digital assistant* or pocket pc* or podcast* or poster? or skype* or smartphone* or smart phone* or social media or social network* or sms or text messag* or twitter or tweet* or video* or web* or wiki* or youtube* or manual* or publication* or literature or computer* or interactive or telephone* or phone*)).ti,ab.
22.	((patient* or carer* or client* or user* 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 inpatient* or outpatient* or in patient* or out patient* 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 inform* or experience or experiences or opinion* or preference* or focus group* or service* or information* or material* or virtual* or app or apps or blog* or booklet* or brochure* or dvd* or elearn* or e-learn* or email* or e-mail* or e mail* or facebook or facetime or face time or forum* or handout* or hand-out* or hand out* or helpline* or hotline* or internet* or ipad* or iphone* or leaflet* or online or magazine* or mobile phone* or newsletter* or pamphlet* or palm pilot* or personal digital assistant* or pocket pc* or podcast* or poster? or skype* or smartphone* or smart phone* or social media or social network* or sms or text messag* or twitter or tweet* or video* or web* or wiki* or youtube* or manual* or publication* or literature or computer* or interactive or telephone* or phone*)).ti,ab.
23.	or/20-22
24.	15 and (19 or 23)

Appendix C Qualitative evidence study selection

Figure 1: Flow chart of qualitative study selection for the review of information, education and support needed by people with suspected and confirmed thyroid cancer, and their families and carers



Appendix D CASP risk of bias assessment

Study	Was there a clear statement of the aims of the research?	Is qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered ?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research ?	Overall
Eastley 2013	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	minor limitations
Koot 2021	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	minor limitations
Misra 2013	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	minor limitations
Nickel 2018	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	minor limitations
Pitt 2019	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	minor limitations
Sawka 2009	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	minor limitations
Smith 2018	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	minor limitations

Appendix E Quality of evidence

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Findings**	**Criteria**	**Rating**	**Overall assessment of confidence**
Emotional support					
1 Pitt 2019[24]	Individual interviews	Information was wanted about all aspects of care from the diagnosis, treatment options, surgery, to postoperative care at the initial consultation and participants wanted the opportunity to ask questions	Limitations	Very minor limitations[a]	HIGH
			Coherence	No concerns about coherence	
			Relevance	Directly applicable	
			Adequacy	No concerns about adequacy	

[a] *There was no explicit mention of reflexivity, researchers did not detail insight into how medical background may have influenced the interview and analysis process*

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Findings**	**Criteria**	**Rating**	**Overall assessment of confidence**
The experience of receiving counselling and decision-making on adjuvant radioactive iodine treatment					
Sawka 2009[25]	Focus groups	Written plain language information on the risks, benefits and uncertainty about	Limitations	Very minor limitations[a]	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Directly applicable	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Findings	Criteria	Rating	Overall assessment of confidence
		radioactive iodine treatment was preferred	Adequacy	Moderate concerns about adequacy[b]	

[a]There was no explicit mention of reflexivity, researchers did not detail insight into how medical background may have influenced the interview and analysis process

[b]Based on an overall assessment of the richness of the data and the quantity of the data

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Findings	Criteria	Rating	Overall assessment of confidence
Impact of having the ‘good cancer’					
4 Easley 2013[11] Nickel 2018[21] Sawka 2009[25] Smith 2018[26]	A combination of individual interviews (3 studies) and focus-groups (1 study)	Being told that thyroid cancer was a ‘good cancer’ was generally not reassuring to survivors and was accompanied by feelings of the diagnosis being dismissed as unimportant and consequently participants felt unworthy of seeking support	Limitations	Very minor limitations[a]	HIGH
			Coherence	No concerns about coherence	
			Relevance	Partially applicable [b]	
			Adequacy	No concerns about adequacy	

[a]in 3/4 studies there was no explicit mention of reflexivity, researchers did not detail insight into how medical background may have influenced the interview and analysis process

[b]2/4 studies were conducted in young adults (16 to 39 years)

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Findings**	**Criteria**	**Rating**	**Overall assessment of confidence**
Information sharing about current clinical practice guidelines					
1 Sawka 2009[25]	Focus groups	Clinical practice guidelines were highly valued and a discussion of the application of the clinical practice guidelines to the individual case was appreciated.	Limitations	Very minor limitations[a]	LOW
			Coherence	No concerns about coherence	
			Relevance	Directly applicable	
			Adequacy	Serious concerns about adequacy[b]	

[a] There was no explicit mention of reflexivity, researchers did not detail insight into how medical background may have influenced the interview and analysis process

[b] Based on an overall assessment of the richness of the data and the quantity of the data

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Findings**	**Criteria**	**Rating**	**Overall assessment of confidence**
Information support					
2 Pitt 2019[24] Koot 2021[16]	Individual interviews Focus groups	Information was wanted about all aspects of care from the diagnosis, treatment options, surgery, to postoperative care and participants wanted the opportunity to ask questions	Limitations	Very minor limitations[a]	HIGH
			Coherence	No concerns about coherence	
			Relevance	Directly applicable	
			Adequacy	No concerns about adequacy	

[a] There was no explicit mention of reflexivity, researchers did not detail insight into how medical background may have influenced the interview and analysis process

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Findings	Criteria	Rating	Overall assessment of confidence
Isolation					
2 Easley 2013[11] Smith 2018[26]	Individual interviews	Sense of isolation due to lack of information about thyroid cancer and further isolation by not being offered access to support groups and / or counselling	Limitations	Very minor limitations[a]	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Partially applicable[b]	
			Adequacy	No concerns about adequacy	

[a] In 1/2 studies there was no explicit mention of reflexivity, researchers did not detail insight into how medical background may have influenced the interview and analysis process

[b] Studies were in young people and may not reflect the views of the general thyroid cancer population

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Findings	Criteria	Rating	Overall assessment of confidence
Medical information on recurrence					
1 Misra 2013[18]	Individual interviews	Requirement for information on reasons for recurrence of thyroid cancer and risk of further recurrence	Limitations	Very minor limitations[a]	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Directly applicable	
			Adequacy	Moderate concerns about adequacy[b]	

[a] *There was no explicit mention of reflexivity, researchers did not detail insight into how medical background may have influenced the interview and analysis process*

[b] *Based on an overall assessment of the richness of the data and the quantity of the data*

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Findings**	**Criteria**	**Rating**	**Overall assessment of confidence**
Psychosocial support					
2 Misra 2013[18] Koot 2021[16]	Individual interviews Focus groups	Support obtained from personal relations (such as spouses, family, co-workers, or friends) was highly valued, however, information and support from other people with recurrent cancer with was not available	Limitations	Very minor limitations[a]	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Directly applicable	
			Adequacy	Moderate concerns about adequacy[b]	

[a] *There was no explicit mention of reflexivity, researchers did not detail insight into how medical background may have influenced the interview and analysis process*

[b] *Based on an overall assessment of the richness of the data and the quantity of the data*

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Findings**	**Criteria**	**Rating**	**Overall assessment of confidence**
Team-based thyroid cancer care and avoidance of conflicting recommendations among healthcare providers					
1	Focus groups	A multidisciplinary team-based, individualised approach	Limitations	Very minor limitations[a]	LOW
			Coherence	No concerns about coherence	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Findings**	**Criteria**	**Rating**	**Overall assessment of confidence**
Sawka 2009[25]		to treatment of thyroid cancer was preferred	Relevance	Directly applicable	
			Adequacy	Serious concerns about adequacy[b]	

[a] There was no explicit mention of reflexivity, researchers did not detail insight into how medical background may have influenced the interview and analysis process

[b] Based on an overall assessment of the richness of the data and the quantity of the data

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Findings**	**Criteria**	**Rating**	**Overall assessment of confidence**
Treatment as an individual					
2 Pitt 2019[24] Koot 2021[16]	Individual interviews Focus groups	Being treated as an individual was a source of reassurance	Limitations	Very minor limitations[a]	HIGH
			Coherence	No concerns about coherence	
			Relevance	Directly applicable	
			Adequacy	No concerns about adequacy	

[a] There was no explicit mention of reflexivity, researchers did not detail insight into how medical background may have influenced the interview and analysis process

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Findings**	**Criteria**	**Rating**	**Overall assessment of confidence**
Understanding of information related to a papillary microcarcinoma diagnosis					
1 Nickel 2018[21]	Individual interviews	Support obtained from personal relations (such as spouses, family, co-workers, or friends) was highly valued, however, information and support from other people with recurrent cancer with was not available	Limitations	Very minor limitations[a]	LOW
			Coherence	No concerns about coherence	
			Relevance	Directly applicable	
			Adequacy	Serious concerns about adequacy[b]	

[a] *There was no explicit mention of reflexivity, researchers did not detail insight into how medical background may have influenced the interview and analysis process*

[b] *Based on an overall assessment of the richness of the data and the quantity of the data*

Appendix F Qualitative evidence

Study	**Easley 2013**[11]
Aim	To describe the survivorship experience of young adults with thyroid cancer.
Population	Young adults aged 18 to 39 years who were 1 to 5 years post-treatment. n=12; Male: 8%, Female: 92%; Mean age at diagnosis: 32 years (SD 3.94), Mean age at interview: 34 years (SD 3.26)
Setting	Four Canadian provinces, most from Ontario
Study design	Qualitative interview study
Methods and analysis	Recruitment: Participants were recruited via social networking Web sites (e.g. Facebook), classified advertisement websites (e.g. Kijiji), newsletters, online message boards at cancer advocacy groups (e.g. Young Adult Cancer Canada), posters in various oncology clinics, newspapers and media articles. Interviews: Interviews were conducted using 11 open-ended questions, the first 2 questions were to put the participants at ease. The interviews included questions about current cancer care follow-up, broad issues about cancer care follow-up (psychological, physical, social and relationships) and recommendations for improvement. Analysis: Constructivist grounded theory approach. Constructivist is a research paradigm that rejects the notion of an objective reality, but views reality as social constructs; data are narrative constructs that may have multiple meanings. Using the theory researchers must go beyond the surface of the data to find meaning and values. Two coinvestigators and 2 research assistants read the same three transcripts independently and developed a coding scheme. The rest of the transcripts were coded line by line by one researcher to ensure consistency using the constant comparison method, and coding was refined through discussion with the team members. The coding system was facilitated by use of the qualitative data analysis programme NVivo 9.
Findings	**Impact of having the ‘good cancer’** Having the ‘good cancer’ was a paradox; phrase was meant to reassure and give the impression that there was an excellent chance of survivorship, but participants felt it downplayed the diagnosis and experience. They described feelings that they were not perceived as needing support and often felt unworthy of accessing available support programmes. However, participants still acknowledged that their cancer was life-altering even if it was not thought of as life-threatening and the illness affected them physically and psychologically.

Study	**Easley 2013[11]**
	Isolation Isolation was strongly affected by the theme of being told it was the ‘good cancer’. Isolation was discussed in relation to three different areas: isolation from other cancer sufferers and support programmes, mandatory physical isolation periods following radioactive iodine treatment, and isolation from their peers without cancer. Many participants said that they could not relate to people with other types of cancer, and they felt that other people with other types of cancer did not want to hear about their experiences because thyroid cancer treatments were generally well tolerated. Younger participants found it difficult to relate to older people with thyroid cancer because of the differences in life stages. Participants discussed the psychological effect of being isolated from family, friends and healthcare workers during radioactive iodine therapy. One participant compared the experience to being a zoo animal or having the plague at a time when she needed support and contact when she most needed it. Participants could not relate to the care-free attitude to their peers and felt that their peers could not relate to the psychological effects impact of a cancer diagnosis.
Funding	None stated
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis. However, of note is that there was no explicit mention of reflexivity. The researchers did not detail their professional backgrounds or provide insight into how this may have influenced the interview and analysis process. The researchers provided an in-depth analysis of the themes that emerged in participants’ talk about their experiences of having thyroid cancer. There were no concerns about data adequacy based on an overall assessment of the richness of the data and the quantity of the data. Partial concerns over applicability due to the study being conducted in young adults.

Study	**Koot 2021[16]**
Aim	To identify in-depth needs, preferences, and values of people with low risk DTC in two different treatment decision groups (thyroid lobectomy and TKIs)
Population	Two treatment decision-making groups were involved, namely: (1) patients with low-risk DTC who had surgery, and (2) patients with advanced RAI refractory DTC who started or considered TKIs. The inclusion criteria for the low-risk group were being diagnosed with DTC, having been treated with surgery within one year, and being capable of understanding their treatment trajectory as judged by their physician. Inclusion criteria for the advanced disease group were people who started or considered TKIs within one year and were capable of understanding their treatment trajectory as judged by their physician. n=6: low-risk DTC; n=7 refractory DTC. 6/13 of the study population was a female; Mean (range) age: 57 (31 to 84) years.
Setting	Twelve hospitals (six academic and six non-academic) and the Dutch patient association “Schildklier Organisatie Nederland (SON)”
Study design	Qualitative interview study
Methods and analysis	Recruitment: Participants were recruited from clinics of MDTs and from a patient association

Study	Koot 2021[16]
	Interviews: Focus groups with open-ended questions, focused on needs, preferences, and values; communication with the health care provider; strong and weak points of the received health care; and points to improve the current health care. Analysis: All five focus group interviews were transcribed verbatim and qualitatively analysed using ATLAS.ti, 8.4.15 Two researchers independently analysed all of the transcripts. The perspectives of participants in the two different treatment decisions were analysed separately. The eight-dimension Picker domains were used as a basis for analyses. Expressed needs, preferences, and values were categorized into one of the eight Picker domains, particularly involvement in decisions and respect for preferences, coordination and integration of care, clear information, and communication and emotional support. All interviews were open coded independently by both researchers. Once codes were created using open coding, they were analyzed using the axial coding process], two concept coding trees were made, one for the surgery decision and one for the TKI decision. The codes were compared and discussed until a consensus was reached. The codes were categorized into similar themes and subthemes within one of the domains.
Findings	**Information support** Participants in both decision groups needed clear, honest, and detailed information. In both groups, participants were not at all or only slightly satisfied with the amount of information received.
	Psychosocial support Participants mentioned the importance of offering psychological care. In both decision groups, emotional support and the involvement of family was important, as well as reassurance by health care providers.
	Team-based thyroid cancer care and avoidance of conflicting recommendations among healthcare providers Participants wanted the involvement of an MDT. It was important to have a contact person for questions and problems.
	Treatment as an individual Participants indicated needing a doctor who takes care and is available most of the time. Integrity and mutual respect were necessary for a good doctor–patient relationship. For participants treated with surgery, it was important to be involved in their treatment process and to discuss the options with their physician.
Funding	Dutch Cancer Society
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis. However of note is that there was no explicit mention of reflexivity. The researchers did not detail insight into how medical background may have influenced the interview and analysis process. There were no concerns about data adequacy based on an overall assessment of the richness of the data and the quantity of the data. No concerns over applicability.

Study	**Misra 2013**[18]
Aim	To explore individual patient experiences relating to diagnosis and surgical treatment of local-surgical recurrence of thyroid cancer, topics of interest initial reaction, sources of medical information and psychosocial support.
Population	Individuals aged 18 years or older with a history of non-medullary thyroid cancer who had one or more neck operation(s) for recurrent thyroid cancer ≥ 6 months following complete surgical removal of the thyroid. n=15; 12/15 of the study population was a female; Mean (range) age at recurrence: 46.5 (26 to 77) years. The primary diagnosis of thyroid cancer was made between one and 21 years prior (median 5 years). The time from last neck surgery for recurrent disease until the study interview range from 11 to 79 months.
Setting	University Health Network and Mount Sinai Hospital, Canada
Study design	Qualitative interview study
Methods and analysis	Recruitment: Participants were recruited from clinics of thyroid surgeons and endocrinologists. Interviews: All participants participated in one, face-to-face semi-structured interview. All interviews were recorded and transcribed verbatim. Data collection occurred between February to August 2011. Analysis: The approach was thematic analysis coupled with techniques borrowed from grounded theory (phenomenological). Transcripts of interviews were transcribed by a research assistant trained in qualitative methods. A subset of 11 interviews were also independently coded by a student with consensus for the codes. Once detail coding in most complete, thematic analysis was conducted, coupled with techniques borrowed from grounded theory. Themes were discovered, developed, and provisionally verified. Techniques to ensure analytic rigor including checking questioning and theorising. Consensus was achieved on extracted themes and supporting quotations among the two coders, a clinical content expert, and an experienced qualitative researcher who reviewed the data.
Findings	**Medical information** The primary sources of medical information and advice utilised by participants throughout the experience of diagnosis and treatment of diseased recurrence was obtained from thyroid cancer specialist physicians and surgeons. Participants generally reported a need for more specific information about thyroid cancer recurrence.
	Psychosocial support. Psychosocial support received from personal relations (such as spouses, family, co-workers, or friends) or formal support organisations was variable. Listening, empathy, and encouragement from relations were generally considered helpful. Many individuals had contacted formal general oncology or thyroid cancer support organisations. However, information and support needs were incompletely met since patient's desired access to survivors who had experienced thyroid cancer disease recurrence. The opportunity to obtain peer advice and support from individuals who had survived thyroid cancer recurrence, was generally highly valued.
Funding	Dr Anna Sawka (senior author) was supported by the Cancer Care Ontario Research Chair Program in Health Services Research.

Study	Misra 2013[18]
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis. However of note is that there was no explicit mention of reflexivity. The researchers did not detail insight into how medical background may have influenced the interview and analysis process. There were moderate concerns about data adequacy based on an overall assessment of the richness of the data and the quantity of the data. No concerns over applicability.

Study	Nickel 2018[21]
Aim	To explore PMC patient's diagnostic and treatment experience including communication and decision making.
Population	Individuals aged 18 years or older, less than 1 year since initial diagnosis, diagnosis pre-operatively (before any surgical intervention) with a single focus < 1 cm PTC with no evidence of extra-thyroidal extension or lymph node metastasis. n=25; male/female; 8/17, age ranges and numbers; ≤25 years: 1, 26 to 50 years: 5, 51 to 75 years: 18, >75 years: 1
Setting	Australia
Study design	Qualitative interview study
Methods and analysis	Recruitment: 1) the Queensland Thyroid Cancer Study (QTCS) run by the QIMR Berghofer Medical Research Institute in Brisbane, Queensland; 2) patient clinics at the Chris O'Brien Lifehouse in Sydney, New South Wales; and 3) an Endocrine surgical database from the Royal North Shore Hospital in Sydney, New South Wales Interviews: Semi-structured telephone and face-to-face interviews with Framework thematic analysis. Interviews were conducted between October 2015 and July 2016 and took place at participants' homes or by telephone. Interviews lasted between 15 and 40 min and were audio-recorded and transcribed verbatim. The interviewer was a public health researcher with experience conducting qualitative interviews and using qualitative research methods. Analysis: In the analysis a step-by-step approach was taken by the research team. The first step was familiarisation of the data, where one researcher independently reviewed and made notes on all 25 interview transcripts. Next was the creation of a thematic framework where 3 researchers read a sub-set of transcripts covering a range of ages and genders and developed and revised with continuous discussions the framework based on emerging topics and themes arising from the transcripts. Following the development of the framework, an additional researcher read a further sub-set of interviews and approved the framework for coding. Coding was done by two researchers; one independently coded all 25 interviews into the framework and the second independently double coded a random

Study	**Nickel 2018[21]**
	set of 3 interviews. Similarities or differences in the coding between the two researchers was discussed and re-assessed. Once coding was complete, two researchers examined the framework within and across themes and participants to identify the overarching themes and relationships. These themes were summarised and checked by two additional members of the research team by each reading an additional transcript. The final results were further discussed with the entire research team.
Findings	**Understanding of information related to a PMC diagnosis** Participants did not appear to understand the natural history and generally indolent nature of PMC. As such, they did not seem to be aware of the possibility of overdiagnosis and overtreatment. Some participants seemed to be conflicted by their cancer diagnosis, as they understood cancer to be something terrible but they were told and felt that their cancer was a 'good result'.
Funding	BN is supported by the Sydney Catalyst Research Scholar Award. JPB is supported by the Karl-Erivan Haub Family Career Development Award in Cancer Research at Mayo Clinic in Rochester, honouring Richard F. Emslander, M.D. AB, RM and KM are investigators on a National Health and Medical Research Council of Australia (NHMRC) funded CRE grant No.1104136. SJ and KM are supported by fellowships from the NHMRC. The QTCS is supported by a project grant from the NHMRC.
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis. However, of note is that there was no explicit mention of reflexivity. The researchers did not detail insight into how medical background may have influenced the interview and analysis process. Identification of the theme and exploration on the theme was not fully detailed. Therefore, there are serious concerns about data adequacy based on an overall assessment of the richness of the data and the quantity of the data. No concerns over applicability.

Study	**Pitt 2019[24]**
Aim	To explore the impact of a thyroid cancer diagnosis, counselling and decision making about RAI therapy
Population	Participants aged 18 years or older diagnosed with papillary thyroid cancer who were enrolled in a single-blinded, RCT (RCT-Clinical Trial Registration Number NCT02138214; https://clinicaltrials.gov/ct2/show/NCT02138214). Participants had at least one thyroid nodule that measured ≥ 1cm with a cytologic or frozen section diagnosis of papillary thyroid cancer. Participants with lymph node metastases discovered pre- or intraoperatively were excluded. n=32; male/female; 24/8, mean (SD) age at consent; 47 (12) years
Setting	Part of a single-blind RCT, USA
Study design	Qualitative interview study
Methods and analysis	Recruitment: Participants enrolled in a single-blinded RCT, comparing receiving versus not receiving a prophylactic central neck dissection (https://clinicaltrials.gov/ct2/show/NCT02138214)

Study	Pitt 2019[24]
	Interviews: Semi-structured interviews. Interviews occurred between May 2014 and April 2016 after participants consulted with the surgeon and consented for the trial, but prior to surgical intervention and randomization. On average, 17 days elapsed between the time of consent and the interview (range 0 – 67 days). Interviews lasted on average 1 hour (range 45 −120 minutes) and followed a piloted, semi-structured interview guide developed by the principal investigators in conjunction with a qualitative methodologist. All interviews were transcribed verbatim and de-identified. Analysis: Four team members thematically analysed a subset of interview transcripts (n=8) to develop an initial coding framework.27. After the open coding process, trained study team members coded all transcripts using NVivo software (QSR International, Victoria, Australia). A constant comparative method was used to continuously integrate emerging themes into the codebook and recode previously coded transcripts. Themes and coding structures were compared, and discrepancies resolved by consensus. The overall inter-coder reliability of the trained coders was excellent (kappa >0.77). After the open coding period, two members of the research team analysed codes related to (1) communication, (2) barriers and facilitators of care, and (3) fear and anxiety to identify any patterns as part of the higher level analysis that aimed to characterise participants' preoperative experience, focusing on their needs and values. Analysis continued until saturation was reached. The entire study team met regularly during this process to discuss the descriptive summaries and collaboratively develop a model that represents the patient experience and needs. Throughout this manuscript, participants are referred to by number to demonstrate the range of responses.
Findings	**Informational Support** Thyroid cancer participants strongly desired informational support from their surgeon at their initial consultation. Participants wanted details about multiple aspects of their disease and treatment including: their diagnosis, prognosis, treatment options, details of the surgery, possible complications, the surgeon's experience and complication rates, postoperative recovery, logistics related to their treatment and follow-up, and radioactive iodine. Gaining knowledge from their surgeon about these aspects of the treatment continuum reassured and empowered participants, providing them with a greater sense of control. Participants also wanted their surgeon to provide information that was individualised and specific to their case. This finding was particularly pronounced in participants whose job involved using their voice professionally. Another vital avenue for obtaining information came from participants being able to ask the surgeon questions. However, when surgeons failed to adequately respond to questions, participants experienced increased worry and felt unsettled. While participants strongly desired the surgeon to be the primary source of information, they did seek information from the internet and other medical professionals, such as primary care physicians and endocrinologists. When participants perceived that these outside sources were unreliable or false, they experienced increased anxiety.
	Emotional support In addition to desiring informational support, participants sought direct emotional support from their surgeon. Expression of compassion and empathy by the surgeon was a critical source of reassurance. By contrast, participants were distressed when they felt that the surgeon failed to offer an empathetic response. Participants also desired emotional support from the surgeon through validation of their cancer experience. Despite the excellent prognosis of thyroid cancer and low likelihood of metastasis, the diagnosis elicited significant anxiety and fear from the 'C-word.' Many participants feared poor outcomes, such as metastasis or death, especially if they had a long

Study	**Pitt 2019[24]**
	wait to see the surgeon or had a prior negative cancer-related experience. When surgeons directly addressed participants' fears and provided emotional support, participants felt reassured. However, when a surgeon did not respond to emotional cues, participants felt, 'shell-shocked' In addition to needing support related to their cancer diagnosis, participants desired reassurance from the surgeon about surgery and the postoperative period. Participants wanted the surgeon to address their anxiety about being 'sliced and diced' (P-2), experiencing pain, having a noticeable scar, bleeding, and voice changes. However, not all participants experienced anxiety related to surgery and minimized the possibility of complications because they saw surgery as a necessary step to removing the cancer. Some participants had anxiety about the postoperative logistics of surgery, because their surgeon planned to send them home the same day. On the other hand, others were reassured that the procedure was performed on an outpatient basis. The desire for emotional support from the surgeon was an overarching need of the participants with thyroid cancer, but intersected at times with their similar need for emotional support from external sources, such as family, other professionals, or survivors.
	Treatment as an Individual Participants with papillary thyroid cancer also desired their surgeon to see and treat them as an individual with unique traits, personalities, sources of happiness, and satisfactions. Participants wanted surgeons to recognise the how the cancer diagnosis impacted their daily life, such as the need to miss school or work. This need for attention to individual characteristics was most pronounced in voice-dependent professionals, like singers and teachers, because of the risks of thyroidectomy related to the recurrent laryngeal nerve and resulting damage to their voice. Being treated as an individual by the surgeon was a significant source of reassurance. On the contrary, when participants did not feel as though they were being treated as individuals, this shortcoming undermined the patient-surgeon relationship. The participants also expressed an appreciation for a bedside manner that respected them as individuals. Participants cited specific surgeon behaviours that engendered honesty and trust. For instance, surgeons provided reassurance or calmed participants through actions like eye contact, direct speech, humour, and being comfortable in the patient's space.
Funding	University of Wisconsin Carbone Cancer Center Support Grant P30 CA014520 and the National Cancer Institute of the National Institutes of Health (NIH) award number R01 CA176911.
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis. However, of note is that there was no explicit mention of reflexivity. The researchers did not detail insight into how medical background may have influenced the interview and analysis process. The researchers provided an in-depth analysis of the themes that emerged in participants' talk about their experiences. There were no concerns about data adequacy based on an overall assessment of the richness of the data and the quantity of the data. No concerns over applicability.

Study	**Sawka 2009[25]**
Aim	To explore the impact of a thyroid cancer diagnosis, counselling and decision making about radioactive iodine therapy

Study	**Sawka 2009**[25]
Population	Participants were eligible if they had well differentiated papillary or follicular thyroid carcinoma that was completely resected at primary surgery and is they were offered adjunctive radioactive iodine therapy. The definition of completely resected thyroid cancer was the lack of knowing visible residual cancer identified at the time of surgery n=32; male/female; 8/24 The mean age of participants was 44 years (range 28 to 75 years). The mean age since the diagnosis of thyroid carcinoma was 5 years (range 2 to 8 years)
Setting	University Health Network and Mount Sinai hospital in Toronto Canada
Study design	Qualitative focus group study
Methods and analysis	Recruitment: All participants were recruited from University Health Network and Mount Sinai hospital in Toronto Canada through poster advertisements in endocrinology, otolaryngology, head and neck surgery and endocrine oncology clinics. Focus groups: In-depth qualitative study using focus groups to allow participants to build upon ideas raised by other participants. Three in depth of focus group sessions work conducted in July 2007. Each group included participants with well differentiated thyroid carcinoma (WDTC) forward total of 16 participants. All sessions were moderated by medical facilitator and qualitative researcher. Analysis: The practice of coding transcribed data initially exploring for responses related to general research questions and then coding the data for respondents' meanings, feelings and actions. The content of the transcripts were systematically coded using N Vivo software. The data were examined for processes and relationships between specific events and general processes. Coding data lead to new categories and the data were collected on the developing categories upon reviewing all transcripts. Newly gathered data from each focus group was continually compared with previously collected data from prior sessions and their coding. The data analysis was based on grounded theory, which relies on the process of constant comparison of qualitative data retrieved from participants. One researcher performed the comparative analysis and the identification of themes. The identified themes were then reviewed with another observer who was present at all the sessions. Clinical context of themes was clarified by discussion. There was final consensus on the identify themes by both researchers. The identified themes were also verified by third researcher. Theoretical saturation of themes was achieved upon analysis of the data from three sessions.
Findings	**Life changing experience with thyroid cancer diagnosis (the 'good cancer')** Experience of being diagnosed with thyroid cancer changed the lives and the outlook on life of survivors. The diagnosis was followed by feelings of fear and uncertainty about the future. Being told that thyroid cancer was a good cancer was generally not reassuring to survivors and was accompanied by feelings at the diagnosis being dismissed as unimportant. Support from family, friends and healthcare providers was appreciated.

Study	**Sawka 2009**[25]
	The experience of receiving counselling and decision-making on adjuvant radioactive iodine treatment The primary information source related to thyroid cancer treatment, including radioactive iodine treatment, was thyroid cancer specialty physicians. Contradictory messages were given by health care providers and Internet sources. The Internet was considered easily accessible but the information available on it was generally not considered relevant to their own disease and life situation. Plain language information about the risks, benefits and uncertainty about radioactive iodine treatment was desired. The desire for numerical data on disease prognosis and treatment benefits was variable, with some participants preferring quantitated data and others preferring general descriptive information specifically without numbers. In general, the groups endorsed the development and dissemination of written in plain language information on risks benefits and uncertainty about radioactive iodine treatment. The availability of web-based individualised information was also endorsed by individuals that felt comfortable using computers, although additional printed information was still supported. Family and friends were identified as an important source of emotional support throughout the disease trajectory, although such individuals often lacked sufficient information about thyroid cancer or its treatment
	Team-based thyroid cancer care and avoidance of conflicting recommendations among healthcare providers A multidisciplinary team-based, individualised approach to treatment of thyroid cancer was favoured by most participants. Open communication among specialty healthcare providers and individualised treatment recommendations were valued.
	Information sharing about current clinical practice guidelines Participants greatly valued the expertise of the authors of clinical practice guidelines and indicated that it is important for healthcare providers to explain current guideline recommendations to future people being offered radioactive iodine treatment. A discussion of the application of the clinical practice guidelines to the individual case was valued.
Funding	None stated
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis. However, of note is that there was no explicit mention of reflexivity. The researchers did not detail insight into how medical background may have influenced the interview and analysis process. Identification of the theme and exploration on the theme was not fully detailed as no participant quotes given. Therefore, there were no serious concerns about data adequacy based on an overall assessment of the richness of the data and the quantity of the data. No concerns over applicability.

Study	**Smith 2018**[26]
Aim	To provide a detailed understanding of the issues faced by young people with thyroid cancer and to examine how they ascribed meaning to their experiences.
Population	Participants aged between 16 and 35 years, diagnosed and treated for papillary thyroid cancer or follicular thyroid cancer in the last five years, and being at least 6 months post-diagnosis. Papillary thyroid cancer and follicular thyroid cancer were chosen due to both being highly treatable and having a similar prognosis. The majority had undergone a total thyroidectomy at their local hospital and had been referred for radioactive iodine treatment. n=8; male/female; 2/6; Aged between 19 and 34 years.

Study	Smith 2018[26]
Setting	United Kingdom
Study design	Qualitative interview study
Methods and analysis	Recruitment: Purposive sampling was used to recruit participants from an established cancer clinic that provides long-term follow-up. Potential participants were identified by the endocrinologists and oncologist involved in the study by review of clinic lists and medical records. Interested participants were introduced to the first author to discuss the study further and provided with the patient information sheet. Interviews: Semi-structured interviews were face-to-face, audio-recorded, and conducted by the first author in private consultation rooms at the hospital, with two at a university. The interviews ranged from 1 to 1.5 hours. The audio-recorded interviews were transcribed verbatim. Analysis: The study employed interpretative phenomenological analysis because of its dual emphasis on the importance of describing and interpreting the personal meaning of a particular experience of major significance Each interview was read and listened to on multiple occasions to gain a holistic sense of the participant's account. Notes on anything that appeared significant or of interest were made and then transformed into more specific themes or phrases which called upon psychological concepts and abstractions. Thematic labels were assigned to capture what was most salient for the participant, and these were jotted down in a notebook alongside illustrative material with separate dividers for each participant. The thematic labels for each participant were added to a Microsoft Excel spread sheet and organized by cutting and pasting electronically, to review connections and establish interrelationships across the group. Following interpretative phenomenological analysis' cyclical nature, connections between main themes and constituent themes were maintained, modified, discarded, or reintroduced. A master list was produced to record each superordinate theme and the themes of which it was comprised.
Findings	**Isolation** The variability in the young peoples' emotional experiences is seen during the treatment process as well, in terms of their actions and responses to their dealings with those involved in their treatment. Most reacted by becoming self-reliant and sought information via the Internet or books. However, the information found often caused more worry. This also caused difficulties when explaining the diagnosis to others which further isolated them. Many stated that they wished they had been given a detailed information guide that included material on the thyroid, the different types of thyroid cancer, the treatment process, the potential risks of radioactive iodine therapy, and side effects of the treatment. Other suggestions included being made aware of the different treatment scenarios, time frames/ map of progress, and having case studies of other patient's experiences and outcomes. All the young people said that they had not been given information about support groups and/or counselling which consolidated their sense of being disregarded and discounted throughout the process. Most had not met anyone in the 'same boat' and needed to hear success stories and speak to others with thyroid cancer who could understand what they were going through. Similarly, some reported needing an outlet like counselling as they found it 'draining' to remain upbeat to supportive family and friends. Their general feeling was of an indifferent attitude on the part of the health care professionals because the cancer was treatable.

Study	**Smith 2018[26]**
	The best cancer to have Having a treatable cancer set them apart from people with other forms of cancer and disrupted perceptions of what it means to be ill. However, this sort of reassurance prevented some from feeling worthy of help.
Funding	None stated
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis. The first author kept a reflexive diary during the analysis. It was noted that reflecting on personal reactions to the narratives often involved revisiting the data and diary entries at several points during the process. Identification of the theme and exploration on the theme was fully detailed. Therefore, there were no serious concerns about data adequacy based on an overall assessment of the richness of the data and the quantity of the data. Partial concerns over applicability as the study was conducted in young adults.

Appendix G Excluded studies

Table 4: Studies excluded from the qualitative review

Reference	Reason for exclusion
Banach 2013[1]	Incorrect study design: included interviews but findings are based on questionnaire i.e., cross-sectional data with no qualitative analysis; no relevant themes
Barbus 2018[2]	Incorrect study design: included interviews but findings are based on questionnaire i.e., cross-sectional data with no qualitative analysis; no relevant themes
Bender 2016[3]	No relevant themes: thyroid cancers survivors' satisfaction with and perceptions of survivorship care follow-up options
Buttner 2021[4]	Incorrect study design: findings based on survey, quantitative analyses.
D'Agostino 2015[5]	Not available
D'Agostino 2018[6]	No relevant themes: treatment decision making in people with early-stage papillary thyroid cancer undergoing surgery vs active surveillance
Davies 2019[7]	No relevant themes: views of people with thyroid cancer under active surveillance
Dhillon 2020[8]	Incorrect study design: findings based on survey, quantitative analyses.
Diez 2021a[9]	Incorrect study design: findings based on questionnaire i.e., cross-sectional data with no qualitative analysis; no relevant themes
Diez 2021b[10]	Incorrect study design: findings based on questionnaire i.e., cross-sectional data with no qualitative analysis; no relevant themes
Gallop 2015[12]	No relevant themes: impact of differentiated thyroid cancer (DTC) on health-related quality of life
Hyun 2016[13]	Incorrect study design: systematic review of studies doing quantitative analysis
Jensen 2021[14]	Incorrect study design: non-systematic review
Karrer 2021[15]	Incorrect study design: quantitative analysis
Lovic 2018[17]	Wrong population: individuals with various cancers
Mobley 2018[19]	Wrong population: combination of central nervous system, leukaemia, lymphoma, neuroendocrine, sarcoma, and thyroid cancer
Morley 2015[20]	Incorrect study design: quantitative analysis
Nixon 2020[22]	Wrong study type: analysis of archival online data
Pitt 2021[23]	No relevant themes: experiences of participants at first diagnosis
Stahl 2018[27]	Wrong population: indeterminate thyroid nodules
Stajduhar 2000[28]	No relevant themes: experiences of participants treatment with iodine-131
Trimboli 2021[29]	Incorrect study design: quantitative analysis
Wiener 2019[30]	Wrong study type: quantitative analysis of registry data