National Institute for Health and Care Excellence

Draft for consultation

Hyperparathyroidism (primary): diagnosis, assessment and initial management

[K] Evidence review for Patient information

NICE guideline

Qualitative evidence review

November 2018

Draft for consultation

This evidence review was developed by the National Guideline Centre

Disclaimer

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

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

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Contents

1 Patient information

1.1 Review question: What information is useful for people with primary hyperparathyroidism?

1.2 Introduction

The NICE guideline on patient experience in adult NHS services (CG138) outlines the key principles of general care. It is also important to identify and address the unique needs of people who are being considered for a diagnosis of primary hyperparathyroidism (PHPT), and those who have a diagnosis of PHPT and are receiving care and monitoring. Information and support is required to enable people to understand their condition and make the best choices for their care. A qualitative review is being undertaken to try to find out what specific information people with PHPT should be given.

1.3 Characteristics table

For full details see the review protocol in appendix A.

Table 1: Characteristics of review question

Objective	To determine what information should be provided to people with PHPT.
Population and setting	Adults (18 years or over) with confirmed primary hyperparathyroidism Strata: post-diagnosis, pre-surgery, post-surgery, people on pharmacological treatment
Context	Any type of information described by studies, such as: • Content of information and how this information is delivered • Information to include pre- and post-surgery Timing of information and support
Review strategy	Synthesis of qualitative research. Results will be presented in narrative format. Quality of the evidence will be assessed by a GRADE CerQual approach for each review finding.

1.4 Qualitative evidence

1.4.1 Included studies

A search was conducted for identifying what information is useful for people with primary hyperparathyroidism. No relevant qualitative studies exploring this topic were identified. See the study selection flow chart in appendix C.

1.4.2 Excluded studies

See the excluded studies list in appendix E.

1.4.3 Summary of qualitative studies included in the evidence review

No qualitative evidence was identified for this review question.

1.4.4 Qualitative evidence synthesis

No qualitative evidence was identified for this review question.

1.4.4.1 Narrative summary of review findings

No qualitative evidence was identified for this review question.

1.4.5 Qualitative evidence summary

No qualitative evidence identified for this review question.

1.5 Economic evidence

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

1.6 Resource impact

The recommendations made by the committee based on this review are not expected to have a substantial impact on resources.

1.7 Evidence statements

1.7.1 Qualitative evidence statements

No qualitative evidence was identified for this review question.

1.8 Recommendations

Pregnancy

Information and support before and during pregnancy

K1. For women with primary hyperparathyroidism who are pregnant or planning a pregnancy:

- follow the recommendations in information and support
- tell them that there is no evidence that primary hyperparathyroidism affects the baby either before or after birth.

Information and support

K2. Follow the recommendations on enabling people to actively participate in their care in the NICE guideline on patient experience in adult NHS services.

K3. Give people with primary hyperparathyroidism information about the condition, including:

- what primary hyperparathyroidism is
- what the parathyroid glands do
- causes of primary hyperparathyroidism
- symptoms
- diagnosis, including diagnosis if calcium or parathyroid hormone levels are normal
- prognosis

- possible effects on daily life
- possible long-term effects.

K4. Give people information about treatments for primary hyperparathyroidism that includes:

- the surgical and non-surgical treatments that are available
- how well the treatments are likely to work
- the advantages and disadvantages of each treatment, including possible complications and side effects
- why these particular treatments are being offered
- why other treatments are not advised.

K5. Give advice on how to reduce the symptoms of primary hyperparathyroidism and prepare for surgery or other treatment, including:

- exercise
- diet
- hydration
- pain relief
- what to expect after treatment, recovery time and return to daily activities, including return to work.

K6. Discuss ongoing care and monitoring for primary hyperparathyroidism, explaining the type and frequency of monitoring that will be offered and the purpose of each. See the recommendations for monitoring in this guideline.

1.9 The committee's discussion of the evidence

1.9.1 Interpreting the evidence

1.9.1.1 The quality of the evidence

No qualitative evidence was identified for this review question.

1.9.1.2 Findings identified in the evidence synthesis

No qualitative evidence was identified for this review question.

1.9.2 Cost effectiveness and resource use

Health economic studies were not sought for this question as it is a qualitative review.

The recommendations generally provide guidance regarding the content of information and support specific to people with primary hyperparathyroidism in line with the general principles of provision of information already established in the existing NICE Patient Experience Guideline and so were not considered likely to have a substantial resource impact over and above this.

1.9.3 Other factors the committee took into account

The committee recognised the importance of having recommendations on what information should be given to patients, and drew on the experiences of the committee members and their interaction with their patient networks to inform their recommendations. They noted that there are two related areas that this information should address: information to inform the patient's understanding of the condition, and information to help the patient make informed decisions about their care. Currently the information provided to patients is not always felt to be adequate to inform understanding of the condition and decision-making, and from the experience of the lay members of the committee patients often resort to using the internet to find information. They highlighted in particular that it is important for GPs to be aware of the condition and to give full information to patients, although the need to give enough accurate, balanced and current information could still be improved in secondary care, particularly in the area of informed decision making for surgery.

The committee noted that the decision about whether to undergo surgery is a key one in the patient's experience of the condition. They emphasised the importance of clinicians being able to offer a balanced view based on the individual patient they are treating, with the acknowledgement upfront that in the majority of cases the treatment is surgery, and that pharmacological therapy is not curative. The lay members of the committee highlighted that where patients have chosen to have surgery, they often want to know how many procedures the surgeon has undertaken, their success rates and surgical experience. Clinicians should acknowledge this and provide information to patients where requested.

The committee highlighted people who are waiting for surgery or who have not met the criteria for surgery. Clinicians should be aware that this can be frustrating for patients, and should continue to provide timely information for those patients.

The lay members of the committee noted that it is important for clinicians to explain what the person can expect during the course of the management of their condition, including who will be involved in their care and at what stages. The committee highlighted that there is a concern about support being given too late, for example after the patient has recovered from surgery. They highlighted the need for timely support in their recommendations.

There is currently large variation in practice in terms of what monitoring and follow up is offered, and the committee considered it important for the clinician to fully explain what is being offered, when it will happen and why it is needed (see the recommendations on monitoring). Ongoing care may include advice on follow-up tests, supplementation (including calcium, vitamin D, magnesium and boron), exercises for the neck, and programmes of exercise and diet to help recover bone density.

There was no evidence for information and support for pregnant women with primary hyperparathyroidism. The committee discussed the need for clinicians to give advice to patients about the possible impact of primary hyperparathyroidism on the fetus, including survival and child development, and any potential long-term impact on intelligence or future disease. The committee discussed the importance of information on the risks and benefits of treatments including medicines and parathyroid surgery during pregnancy. The committee also felt that post-partum advice about breastfeeding would be appropriate.

References

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2. McGill JF, Moo TA, Kato M, Hoda R, Allendorf JD, Inabnet WB et al. World wide what? The quality of information on parathyroid disease available on the Internet. Surgery. 2009; 146(6):1123-9

3. Neary PM, Sung R, Corrigan M, O'Donovan M, Cahill RA, Redmond HP. The benefits of an interactive, individualized online patient pathway for patients undergoing minimally invasive radioguided parathyroidectomy: a prospective, double-blinded, randomized clinical trial. Surgical Innovation. 2010; 17(3):236-41

4. Perez-Ruiz L, Lasheras-Alonso M, Gomez-Arbones X, Ros-Lopez S, Pelayo-Salas A, Salcedo-Mata MD. The effects of successful parathyroidectomy on clinical and biological manifestations of primary hyperparathyroidism. Acta Chirurgica Belgica. 2006; 106(5):532-6

1 Appendices

2 Appendix A: Review protocols

3 **Table 2: Review protocol: Patient information**

Field	Content
Review question	What information is useful for people with primary hyperparathyroidism?
Type of review question	Views and experiences (qualitative) A review of health economic evidence related to the same review question was conducted in parallel with this review. For details see the health economic review protocol for this NICE guideline.
Objective of the review	To determine what information should be provided to people with PHPT.
Eligibility criteria – population	Adults (18 years or over) with primary hyperparathyroidism Strata: • Post-diagnosis, pre-surgery, post-surgery, people on pharmacological treatment Exclude people: • with secondary and tertiary HPT • with multiple endocrine neoplasia • with familial hyperparathyroidism • with parathyroid carcinoma
Eligibility criteria – context	Any type of information described by studies. • Content of information and how this information is delivered • Information to include pre- and post-surgery • Timing of information and support
Eligibility criteria – comparator(s)	N/A
Outcomes and prioritisation	Synthesis of qualitative research: thematic analysis – information synthesised into main review findings. Results presented in a detailed narrative and in table format with summary statements of main review findings.
Eligibility criteria – study design	Qualitative studies (for example, interviews, focus groups, observations)
Other inclusion exclusion criteria	• Non-English language studies • Conference abstracts
Proposed sensitivity / subgroup analysis, or meta-regression	N/A
Selection process – duplicate screening / selection / analysis	Studies are sifted by title and abstract. Potentially significant publications obtained in full text are then assessed against the inclusion criteria specified in this protocol.
Data	CERQual will be used to synthesise data from qualitative studies.

management (software)	• Endnote for bibliography, citations, sifting and reference management • Data extractions performed using EviBase, a platform designed and maintained by the National Guideline Centre (NGC)
Information sources – databases and dates	Clinical search databases to be used: Medline, Embase, CINAHL and PsycINFO Date: all years Language: Restrict to English only Supplementary search techniques: backward citation searching Key papers: Not known
Identify if an update	N/A
Author contacts	https://www.nice.org.uk/guidance/indevelopment/gid-ng10051
Highlight if amendment to previous protocol	For details please see section 4.5 of Developing NICE guidelines: the manual.
Search strategy – for one database	[For details please see appendix B
Data collection process – forms / duplicate	A standardised evidence table format will be used, and published as appendix D of the evidence report.
Data items – define all variables to be collected	For details please see evidence tables in appendix D (clinical evidence tables) or H (health economic evidence tables).
Methods for assessing bias at outcome / study level	Standard study checklists will be used to critically appraise individual studies. For details please see section 6.2 of Developing NICE guidelines: the manual The risk of bias across all available evidence will be evaluated for each outcome using an adaptation of the 'Grading of Recommendations Assessment, Development and Evaluation (GRADE) toolbox' developed by the international GRADE working group http://www.gradeworkinggroup.org/
Criteria for quantitative synthesis	For details please see section 6.4 of Developing NICE guidelines: the manual.
Methods for quantitative analysis – combining studies and exploring (in)consistency	For details please see the separate Methods report for this guideline.
Meta-bias assessment – publication bias, selective reporting bias	For details please see section 6.2 of Developing NICE guidelines: the manual.
Confidence in cumulative evidence	For details please see sections 6.4 and 9.1 of Developing NICE guidelines: the manual.
Rationale / context – what is known	For details please see the introduction to the evidence review.

Describe contributions of authors and guarantor	A multidisciplinary committee developed the evidence review. The committee was convened by the National Guideline Centre (NGC) and chaired by Jonathan Mant in line with section 3 of Developing NICE guidelines: the manual. Staff from NGC undertook systematic literature searches, appraised the evidence, conducted meta-analysis and cost-effectiveness analysis where appropriate, and drafted the evidence review in collaboration with the committee. For details please see Developing NICE guidelines: the manual.
Sources of funding / support	NGC is funded by NICE and hosted by the Royal College of Physicians.
Name of sponsor	NGC is funded by NICE and hosted by the Royal College of Physicians.
Roles of sponsor	NICE funds NGC to develop guidelines for those working in the NHS, public health and social care in England.
PROSPERO registration number	Not registered

Appendix B: Literature search strategies

The literature searches for this review are detailed below and complied with the methodology outlined in Developing NICE guidelines: the manual 2014, updated 2017 https://www.nice.org.uk/guidance/pmg20/resources/developing-nice-guidelines-the-manual-pdf-72286708700869

For more detailed information, please see the Methodology Review.

B.1 Clinical search literature search strategy

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

Table 3: Database date parameters and filters used

Database	Dates searched	Search filter used
Medline (OVID)	1946 – 06 August 2018	Exclusions
Embase (OVID)	1974 – 06 August 2018	Exclusions
CINAHL, Current Nursing and Allied Health Literature (EBSCO)	Inception – 06 August 2018	Exclusions
PsycINFO (ProQuest)	Inception – 06 August 2018	Exclusions

Medline (Ovid) search terms

1.	hyperparathyroidism/ or hyperparathyroidism, primary/
2.	((primary or asymptomatic or symptomatic or mild or familial or maternal) adj6 (HPT or hyperparathyroidis*)).ti,ab.
3.	PHPT.ti,ab.
4.	Parathyroid Neoplasms/
5.	(parathyroid* adj3 (adenoma* or carcinoma* or hyperplasia* or neoplas* or tumo?r* or cancer* or metasta* or hypercalc?emi*)).ti,ab.
6.	or/1-5
7.	letter/
8.	editorial/

9.	news/
10.	exp historical article/
11.	Anecdotes as Topic/
12.	comment/
13.	case report/
14.	(letter or comment*).ti.
15.	or/7-14
16.	randomized controlled trial/ or random*.ti,ab.
17.	15 not 16
18.	animals/ not humans/
19.	exp Animals, Laboratory/
20.	exp Animal Experimentation/
21.	exp Models, Animal/
22.	exp Rodentia/
23.	(rat or rats or mouse or mice).ti.
24.	or/17-23
25.	6 not 24
26.	limit 25 to English language

1 **Embase (Ovid) search terms**

1.	hyperparathyroidism/ or primary hyperparathyroidism/
2.	((primary or asymptomatic or symptomatic or mild or familial or maternal) adj6 (HPT or hyperparathyroidis*)).ti,ab.
3.	PHPT.ti,ab.
4.	parathyroid tumor/ or parathyroid adenoma/ or parathyroid carcinoma/
5.	(parathyroid* adj3 (adenoma* or carcinoma* or hyperplasia* or neoplas* or tumo?r* or cancer* or metasta* or hypercalc?emi*)).ti,ab.
6.	or/1-5
7.	letter.pt. or letter/
8.	note.pt.
9.	editorial.pt.
10.	Case report/ or Case study/
11.	(letter or comment*).ti.
12.	or/7-11
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).ti.
22.	or/14-21
23.	6 not 22
24.	limit 23 to English language

1 **CINAHL (EBSCO) search terms**

S1.	(MH "Hyperparathyroidism")
S2.	((primary or asymptomatic or symptomatic or mild or familial or maternal) n6 HPT) OR ((primary or asymptomatic or symptomatic or mild or familial or maternal) n6 hyperparathyroidis*)
S3.	PHPT
S4.	(MH "Parathyroid Neoplasms")
S5.	(parathyroid* n3 (adenoma* or carcinoma* or hyperplasia* or neoplas* or tumor* or tumour* or cancer* or metasta* or hypercalcemi* or hypercalcaemi*))
S6.	S1 OR S2 OR S3 OR S4 OR S5
S7.	PT anecdote or PT audiovisual or PT bibliography or PT biography or PT book or PT book review or PT brief item or PT cartoon or PT commentary or PT computer program or PT editorial or PT games or PT glossary or PT historical material or PT interview or PT letter or PT listservs or PT masters thesis or PT obituary or PT pamphlet or PT pamphlet chapter or PT pictorial or PT poetry or PT proceedings or PT "questions and answers" or PT response or PT software or PT teaching materials or PT website
S8.	S6 NOT S7

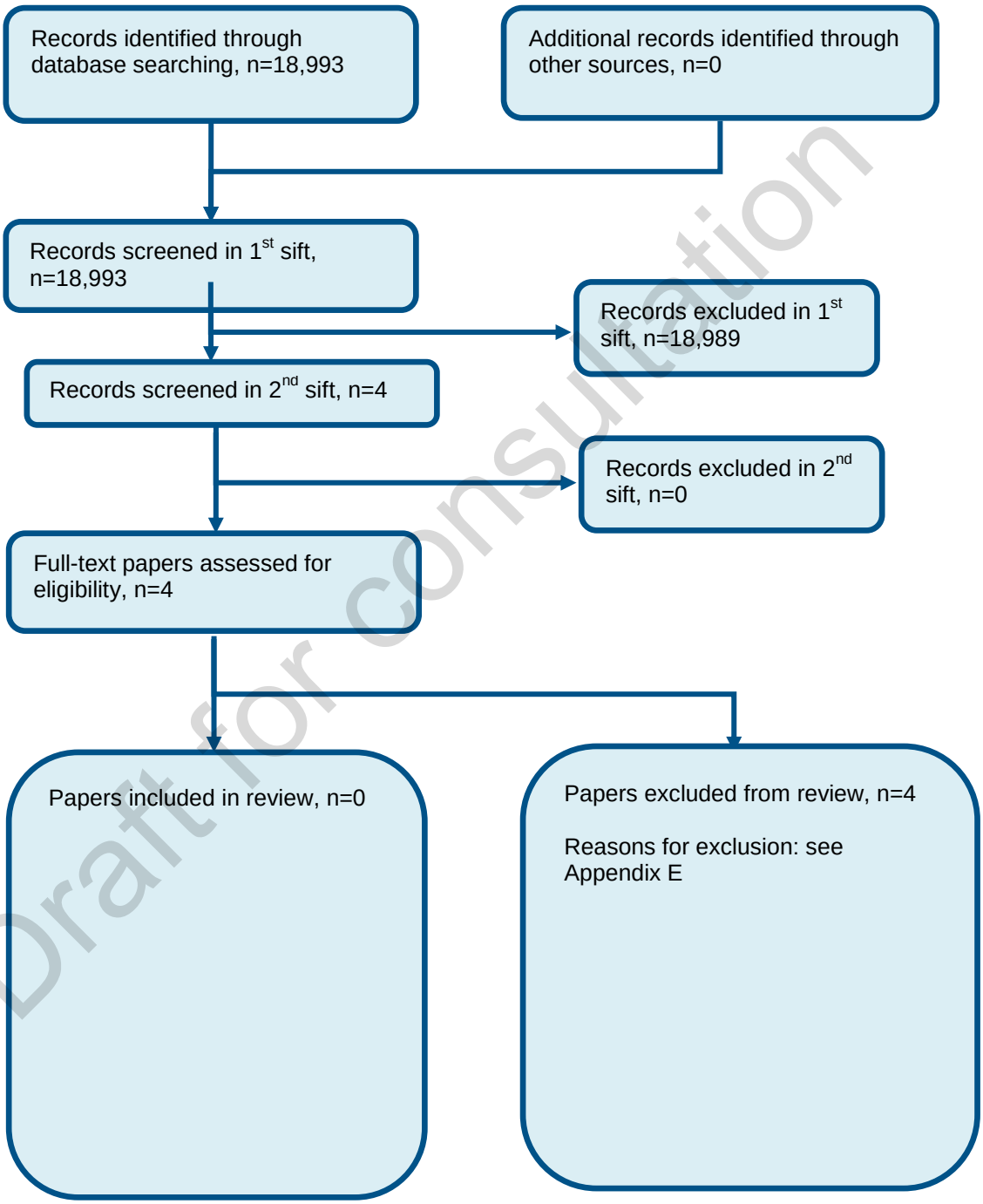
2 **PsycINFO (ProQuest) search terms**

1.	su.Exact("parathyroid neoplasms" OR "hyperparathyroidism" OR "hyperparathyroidism, primary")
2.	PHPT
3.	((primary or asymptomatic or symptomatic or mild or familial or maternal) Near/6 (HPT or hyperparathyroidis*))
4.	(parathyroid* near/3 (adenoma* or carcinoma* or hyperplasia* or neoplas* or tumor* or tumour* or cancer* or metasta* or hypercalcaemi* or hypercalcemi*))
5.	1 or 2 or 3 or 4
6.	(su.exact.explode("rodents") or su.exact.explode("mice") or (su.exact("animals") not (su.exact("human males") or su.exact("human females"))) or ti(rat or rats or mouse or mice))
7.	(s1 or s2 or s3 or s4) NOT (su.exact.explode("rodents") or su.exact.explode("mice") or (su.exact("animals") not (su.exact("human males") or su.exact("human females"))) or ti(rat or rats or mouse or mice))

3

Appendix C: Qualitative evidence selection

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



Appendix D: Qualitative evidence tables

No qualitative evidence identified for this review question.

Appendix E: Excluded studies

E.1 Excluded qualitative studies

Table 4: Studies excluded from the qualitative review

Reference	Reason for exclusion
Jones 2000[1]	No relevant themes
McGill 2009[2]	No relevant themes
Neary 2010[3]	Incorrect study design (RCT)
Perez-Ruiz 2006[4]	No relevant themes