

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Guideline scope

Hyperparathyroidism (primary): diagnosis, assessment and initial management

NHS England has asked NICE to develop a guideline on the diagnosis, assessment and initial management of primary hyperparathyroidism.

The guideline will be developed using the methods and processes outlined in [Developing NICE guidelines: the manual](#).

1 Why the guideline is needed

Key facts and figures

Primary hyperparathyroidism is a disorder of one or more of the parathyroid glands. The parathyroid gland becomes overactive and secretes excess amounts of parathyroid hormone, causing hypercalcaemia, hypophosphataemia and hypercalciuria. The most common cause of primary hyperparathyroidism is a non-cancerous tumour (an adenoma) in one of the parathyroid glands.

Primary hyperparathyroidism is one of the leading causes of hypercalcaemia and one of the most common endocrine disorders. Current data suggest a prevalence of 1 to 4 per 1,000 in the general population. Women are twice as likely to develop primary hyperparathyroidism as men. It can develop at any age, but in women in the UK it is most often diagnosed between the ages of 50 and 60. In younger people, primary hyperparathyroidism can also be caused by a familial hyperparathyroidism syndrome.

Many people with primary hyperparathyroidism have few or no symptoms. In these people, primary hyperparathyroidism is typically detected as an incidental finding when a blood test is done for another reason. Most often, the person's calcium level is only mildly elevated or is elevated intermittently.

The signs and symptoms of primary hyperparathyroidism are predominantly brought about by hypercalcaemia and include gastro-intestinal symptoms such as constipation and effects on the central nervous system such as fatigue and memory impairment. Long-term effects include kidney stones, bone-related complications such as osteoporosis and cardiovascular disease.

Current practice

Although primary hyperparathyroidism is a common endocrine disorder, it is under-recognised in the general population and by health professionals. This delays treatment and increases the likelihood of long-term complications. Currently there are no standardised investigations or referral criteria in the UK to guide decision-making in primary care. In secondary care there is variation in the types of diagnostic tests and imaging used. Indications for surgical management, and follow-up after surgical or non-surgical treatment, also vary. This guideline aims to provide recommendations that will improve the recognition, diagnosis and initial management of primary hyperparathyroidism.

Guidelines are needed in primary care to standardise the investigation of patients with suspected PHPT and the criteria for referral on to secondary care in order to avoid delaying treatment. Guidelines are also needed in secondary care to standardise what diagnostic tests and imaging techniques to perform and indications for referral on for surgical management, as well as appropriate follow up for non-surgically treated patients and post-operative individuals.

2 Who the guideline is for

People with suspected or confirmed primary hyperparathyroidism, their families and carers, and the public will be able to use the guideline to find out what NICE recommends, and help them make decisions.

This guideline is for:

- Healthcare professionals.
- People with suspected or confirmed primary hyperparathyroidism.

NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the [Welsh Government](#), [Scottish Government](#), and [Northern Ireland Executive](#).

Equality considerations

NICE has carried out [an equality impact assessment](#) during scoping. The assessment:

- lists equality issues identified, and how they have been addressed
- explains why any groups are excluded from the scope.

The guideline will look at inequalities related to limited imaging options for women who are pregnant, because of the need to avoid radiation exposure.

3 What the guideline will cover

3.1 Who is the focus?

Groups that will be covered

The guideline will cover adults (18 years and over) with suspected or confirmed primary hyperparathyroidism.

Specific consideration will be given to women who are pregnant.

3.2 Settings

Settings that will be covered

All settings in which NHS-funded healthcare is provided or commissioned.

3.3 Activities, services or aspects of care

Key areas that will be covered

We will look at evidence in the areas below when developing the guideline, but it may not be possible to make recommendations in all the areas.

- 1 Identifying and diagnosing symptomatic and asymptomatic primary hyperparathyroidism.

- 2 Indications for surgery (parathyroidectomy).
- 3 Investigations before and during parathyroid surgery.
- 4 Surgical management.
- 5 Pharmacological management.
- 6 Monitoring.
- 7 Managing primary hyperparathyroidism during pregnancy.
- 8 Providing information to people with primary hyperparathyroidism.

Areas that will not be covered

- 1 Multiple endocrine neoplasia.
- 2 Familial hyperparathyroidism.
- 3 Parathyroid carcinoma.
- 4 Secondary hyperparathyroidism.
- 5 Tertiary hyperparathyroidism.
- 6 Obstetric complications and neonatal care.
- 7 General population screening for primary hyperparathyroidism.
- 8 Management of long term complications of primary hyperparathyroidism
- 9 Management of vitamin D deficiency

Related NICE guidance

- [Multimorbidity: clinical assessment and management](#) (2016) NICE guideline NG56
- [Menopause: diagnosis and management](#) (2015) NICE guideline NG23
- [Minimally invasive video-assisted parathyroidectomy](#) (2014) NICE interventional procedure guidance IPG501
- [Vitamin D: increasing supplement use in at-risk groups](#) (2014) NICE public health guideline PH56
- [Osteoporosis: assessing the risk of fragility fracture](#) (2012) NICE guideline CG146
- [Alendronate, etidronate, risedronate, raloxifene and strontium ranelate for the primary prevention of osteoporotic fragility fractures in postmenopausal women](#) (2008) NICE technology appraisal guidance TA160
- [Thoracoscopic excision of mediastinal parathyroid tumours](#) (2007) NICE interventional procedure guidance IPG247

- [Cinacalcet for the treatment of secondary hyperparathyroidism in patients with end-stage renal disease](#) (2007) NICE technology appraisal guidance TA117
- [Renal stones](#). NICE guideline. Publication expected February 2019.

NICE guidance about the experience of people using NHS services

NICE has produced the following guidance on the experience of people using the NHS. This guideline will not include additional recommendations on these topics unless there are specific issues related to primary hyperparathyroidism:

- [Medicines optimisation](#). (2015) NICE guideline NG5
- [Patient experience in adult NHS services](#) (2012) NICE guideline CG138
- [Medicines adherence](#) (2009) NICE guideline CG76

3.4 Economic aspects

We will take economic aspects into account when making recommendations. We will develop an economic plan that states for each review question (or key area in the scope) whether economic considerations are relevant, and if so whether this is an area that should be prioritised for economic modelling and analysis. We will review the economic evidence and carry out economic analyses, using an NHS and personal social services perspective, as appropriate.

3.5 Key issues and questions

While writing this scope, we have identified the following key issues and draft review questions related to them:

- 1 Identifying and diagnosing symptomatic and asymptomatic primary hyperparathyroidism:
 - 1.1 What are the indications for diagnostic testing for primary hyperparathyroidism?
 - 1.2 Which biochemical test or combination of tests should be used for diagnosing primary hyperparathyroidism (for example levels of parathyroid hormone, blood calcium and phosphate, alone or in combination)?

- 2 Indications for surgery (parathyroidectomy):
 - 2.1 What is the clinical and cost effectiveness of surgery (parathyroidectomy) in people with symptomatic and asymptomatic primary hyperparathyroidism?
 - 2.2 What are the indications for surgery (parathyroidectomy) in people with symptomatic and asymptomatic primary hyperparathyroidism?
- 3 Investigations before and during parathyroid surgery:
 - 3.1 What is the clinical and cost effectiveness of non-invasive imaging techniques (for example parathyroid ultrasound, sestamibi scanning, CT and MRI scanning) before surgery?
 - 3.2 What is the clinical and cost effectiveness of invasive imaging techniques (for example parathyroid venous sampling) before surgery?
 - 3.3 What is the clinical and cost effectiveness of intraoperative second- and third-generation parathyroid hormone assays?
- 4 Surgical management:
 - 4.1 What is the clinical and cost effectiveness of different types of surgical intervention, for example four-gland exploration, compared with minimally invasive techniques?
 - 4.2 What is the optimal timing of re-operation in people for whom primary surgery fails?
- 5 Pharmacological management:
 - 5.1 What is the clinical and cost effectiveness of calcimimetics in people with primary hyperparathyroidism?
 - 5.2 What is the clinical and cost effectiveness of bisphosphonates in people with primary hyperparathyroidism?
- 6 Monitoring:
 - 6.1 What is the optimum type and frequency of monitoring for people with primary hyperparathyroidism (for example, pre-operative, , post-operative, non-surgical)?
- 7 Managing primary hyperparathyroidism during pregnancy:
 - 7.1 How should the management of primary hyperparathyroidism differ in pregnant women?
- 8 Providing information to people with primary hyperparathyroidism:

8.1 What specific information do people with primary hyperparathyroidism need?

3.6 Main outcomes

The main outcomes that will be considered when searching for and assessing the evidence are:

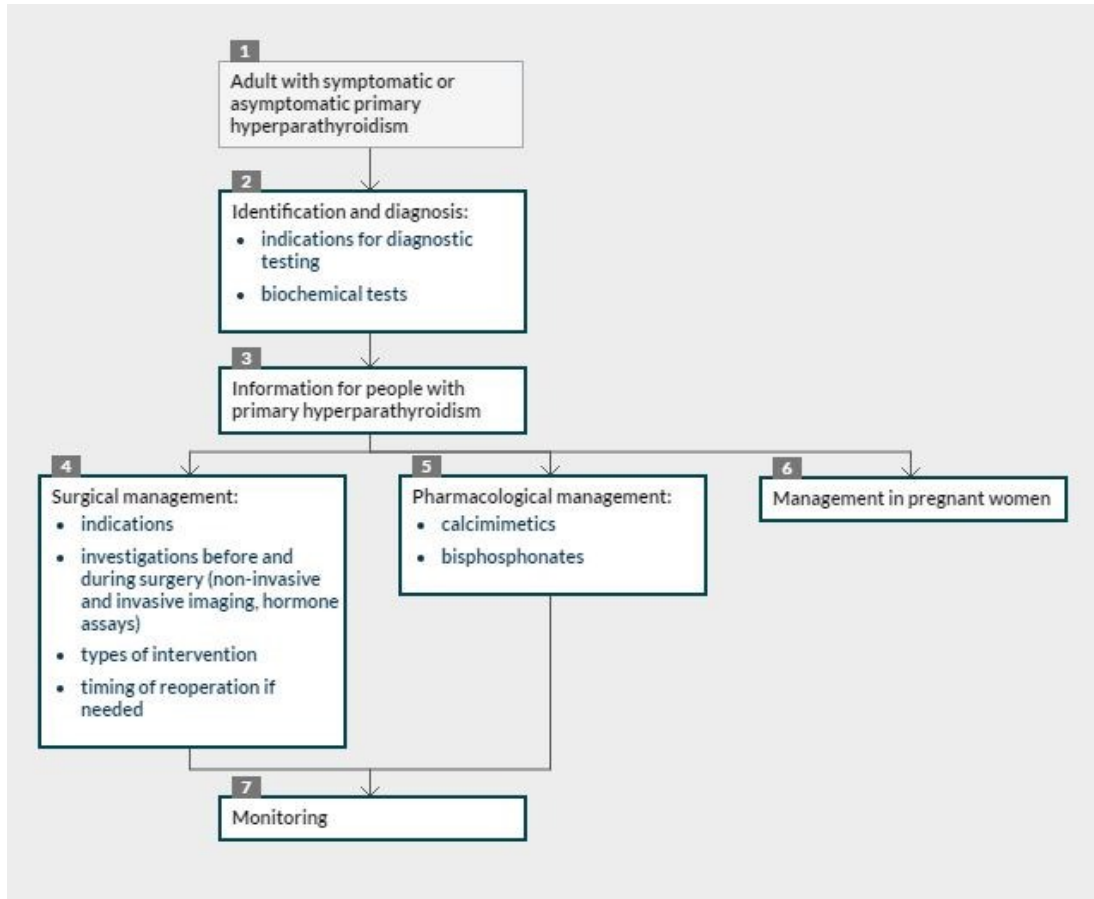
- 1 Health-related quality of life.
- 2 Control of symptoms including fatigue, and gastrointestinal and cognitive symptoms.
- 3 Bone loss associated with primary hyperparathyroidism.
- 4 Kidney disease associated with primary hyperparathyroidism.
- 5 Success of surgery.
- 6 Complications associated with surgery (for example postoperative hypocalcaemia and recurrent laryngeal nerve pathology).
- 7 Length of hospital stay.
- 8 Adverse events.

4 NICE Pathways

NICE Pathways bring together all related NICE guidance and associated products on a topic in an interactive topic-based flowchart. When this guideline is published, the recommendations will be added to NICE Pathways. Other relevant NICE guidance will also be added to the NICE Pathway, including:

- [Minimally invasive video-assisted parathyroidectomy](#) (2014) NICE interventional procedures guidance 501
- [Thoracoscopic excision of mediastinal parathyroid tumours](#) (2007) NICE interventional procedures guidance 247

A pathway outline on primary hyperparathyroidism, based on the scope, is included below. It will be adapted and more detail added as the recommendations are written during guideline development.



5 Further information

This is the final scope, incorporating comments from registered stakeholders during consultation.

The guideline is expected to be published in May 2019.

You can follow [progress of the guideline](#).

Our website has information about [how NICE guidelines are developed](#).