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 the leading cause 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 it most often occurs between the ages of 50 and 60 in the UK. In younger individuals, hyperparathyroidism is often caused by a familial hyperparathyroidism syndrome.

About 80% of 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 hyperparathyroidism are the same as for hypercalcaemia and include gastro-intestinal symptoms such as constipation and effects on the central nervous system such as fatigue. 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. This delays treatment and increases the likelihood of long-term complications. Currently there are no standardised investigations or referral criteria 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.

57 This guideline is for:

58 • Healthcare professionals.
59 • People with suspected or confirmed primary hyperparathyroidism.

60 NICE guidelines cover health and care in England. Decisions on how they
61 apply in other UK countries are made by ministers in the Welsh Government,
62 Scottish Government, and Northern Ireland Executive.

63 *Equality considerations*

64 NICE has carried out an equality impact assessment during scoping. The
65 assessment:

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

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

70 3 What the guideline will cover

71 *3.1 Who is the focus?*

72 Groups that will be covered

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

75 Specific consideration will be given to women who are pregnant.

76 *3.2 Settings*

77 Settings that will be covered

78 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. Natural history of primary hyperparathyroidism.
2. Identifying and diagnosing symptomatic and asymptomatic primary hyperparathyroidism.
3. Indications for surgery (parathyroidectomy).
4. Investigations before and during parathyroid surgery.
5. Surgical management.
6. Pharmacological management.
7. Monitoring.
8. Providing information to people with primary hyperparathyroidism.

Areas that will not be covered

1. Diagnosing and treating multiple endocrine neoplasia.
2. Diagnosing and treating familial hyperparathyroidism.
3. Treating parathyroid carcinoma.
4. Treating secondary hyperparathyroidism.
5. Treating tertiary hyperparathyroidism.

Related NICE guidance

- Menopause: diagnosis and management (2015) NICE guideline NG23
- Minimally invasive video-assisted parathyroidectomy (2014) NICE interventional procedure guidance IPG501
- 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

109 • Cinacalcet for the treatment of secondary hyperparathyroidism in patients
110 with end-stage renal disease (2007) NICE technology appraisal guidance
111 TA117
112 • Renal stones. NICE guideline. Publication expected February 2019.

113 **NICE guidance about the experience of people using NHS services**

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

117 • Medicines optimisation. (2015) NICE guideline NG5
118 • Patient experience in adult NHS services (2012) NICE guideline CG138
119 • Medicines adherence (2009) NICE guideline CG76

120 *3.4 Economic aspects*

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

128 *3.5 Key issues and questions*

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

131 1 Natural history of primary hyperparathyroidism:
132 1.1 What is the natural history of symptomatic and asymptomatic primary
133 hyperparathyroidism?
134 2 Identifying and diagnosing symptomatic and asymptomatic primary
135 hyperparathyroidism:
136 2.1 What is the best strategy for identifying and diagnosing symptomatic
137 and asymptomatic primary hyperparathyroidism?

138 2.2 What is the diagnostic accuracy of the biochemical tests used (levels
139 of parathyroid hormone, blood calcium and phosphate, alone or in
140 combination) to detect primary hyperparathyroidism?
141 2.3 What is the diagnostic accuracy of non-invasive imaging techniques,
142 for example parathyroid ultrasound, sestamibi scanning, CT and MRI
143 scanning?
144 2.4 What is the diagnostic accuracy of invasive imaging techniques, for
145 example parathyroid venous sampling?
146 3 Indications for surgery (parathyroidectomy):
147 3.1 What are the indications for surgery (parathyroidectomy) in people
148 with symptomatic and asymptomatic primary hyperparathyroidism?
149 4 Investigations during surgery:
150 4.1 What is the diagnostic accuracy of intraoperative second- and third-
151 generation parathyroid hormone assays?
152 5 Surgical management:
153 5.1 What is the clinical and cost effectiveness of different types of
154 surgical intervention, for example the four-gland exploration, versus
155 minimally invasive techniques?
156 6 Pharmacological management
157 6.1 What is the clinical and cost effectiveness of calcimimetics?
158 7 Monitoring:
159 7.1 What is the optimum type and frequency of monitoring for people
160 with primary hyperparathyroidism?
161 8 Providing information to people with primary hyperparathyroidism:
162 8.1 What information do people with primary hyperparathyroidism need?

163 ### *3.6 Main outcomes*

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

166 1 Health-related quality of life.
167 2 Control of symptoms including fatigue, and gastrointestinal and cognitive
168 symptoms.
169 3 Bone loss associated with primary hyperparathyroidism.

170 4 Kidney disease associated with primary hyperparathyroidism.
171 5 Surgical failure (for example, conversion from minimally invasive to open
172 surgery).
173 6 Postoperative hypocalcaemia.
174 7 Length of hospital stay.
175 8 Adverse events, including infection and re-operation.

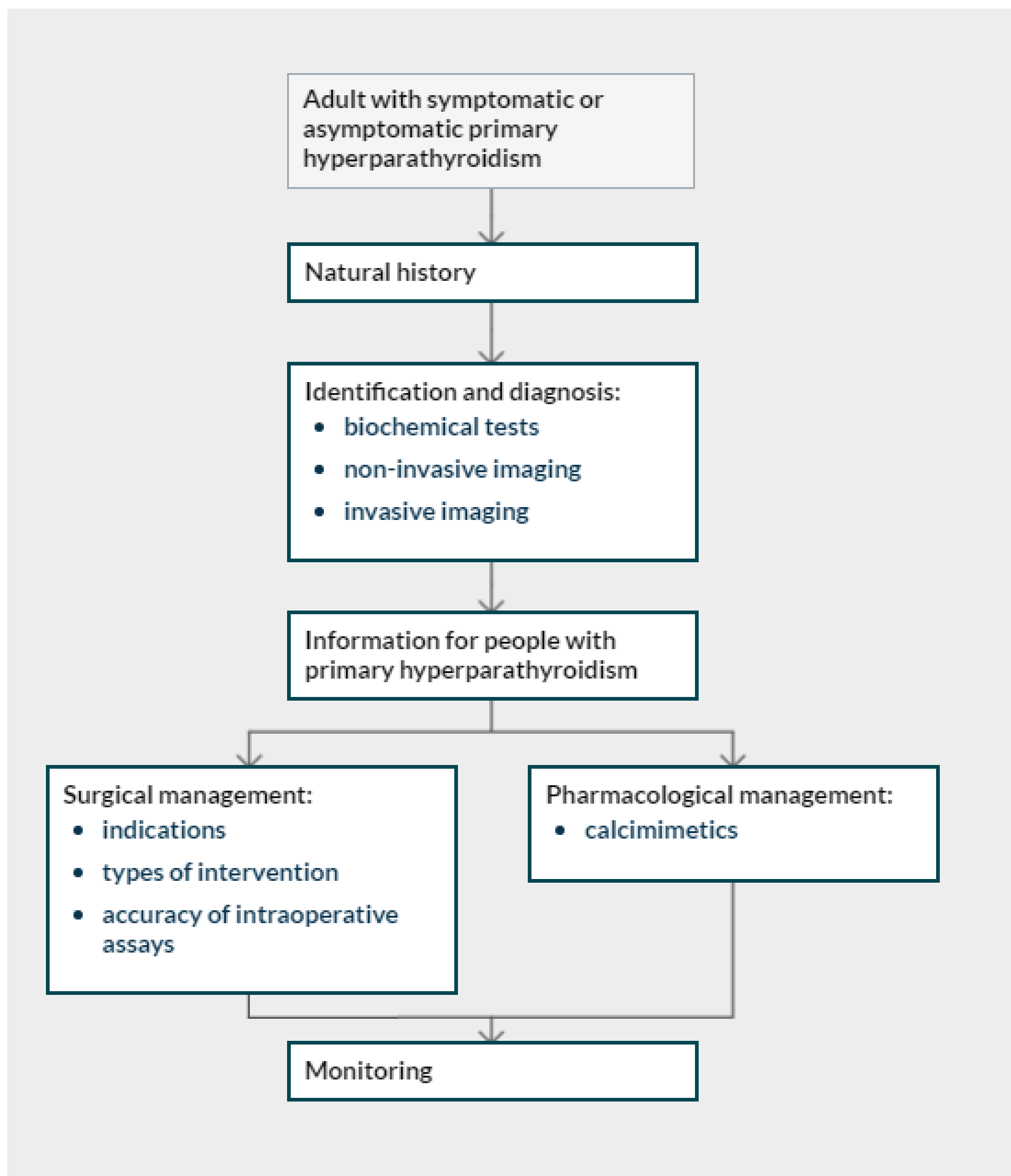
176 4 NICE Pathways

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

182 • Minimally invasive video-assisted parathyroidectomy (2014) NICE
183 interventional procedures guidance 501
184 • Thoracoscopic excision of mediastinal parathyroid tumours (2007) NICE
185 interventional procedures guidance 247

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

189



190

191

192

5 Further information

This is the draft scope for consultation with registered stakeholders. The consultation dates are 15 February to 15 March 2017.

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.

193