Primary hyperparathyroidism

Consultation on draft scope
Stakeholder comments table

15 February 2017 to 15 March 2017

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Department of Health	General		I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.	Thank you for your comment.
Hyperparathyroid UK Action4Change		28-29	Here it states that the calcium level can be "only mildly elevated or is elevated intermittently". This very fact (of the intermittency of higher calcium levels) is underappreciated by the endocrinologists/endo surgeon who told me on the few occasions when my calcium was intermittently 'normal' that there was no way I could have primary HPT (I subsequently had 3 enlarged glands removed).	Thank you for your comment. Diagnosis, including biochemistry, is one of the key areas that will be covered by the guideline
Hyperparathyroid UK Action4Change		32-34	Long term effects include depression the cause of which gets misdiagnosed with much time and large costs to the NHS being wasted.	Thank you for your comment.
Hyperparathyroid UK Action4Change		41	Follow-up care is virtually non-existent and this is a problem. Many people still feel ill after surgery, this especially seems to be true when they went undiagnosed for a long time. There needs to be more information about the long-term damage this disease causes	Thank you for your comment. Monitoring, including post-operative care, is a key area of inclusion for the scope.
Hyperparathyroid UK Action4Change		46/47	There needs to be some revision of the level of calcium causing us all symptoms and poor life quality. If I lived in xxxx I'd have never had my adenoma removed! Looks	Thank you for your comment. Diagnosis, including biochemistry, is one of the key areas that will be covered by the guideline.

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			like complaining is the only way to bring about change. Looking at all the different reference points of calcium for referral. Endocrinologists need to get their act together and realise that adenomas cause problems whether calcium is normal or slightly raised and not just above 2.8	
Hyperparathyroid UK Action4Change		167	symptoms should also include here joint, bone and muscle pain, heart rhythm disorders, mental health problems such as depression and anxiety	Thank you for your comment. The symptoms listed are examples and not intended to be exhaustive. The outcomes for each review will be discussed with the guideline committee.
Hyperparathyroid UK Action4Change			Reoperation should only take place in the hands of the most skilled and experienced of surgical hands. This point cannot be stressed enough.	Thank you for your comment.
Hyperparathyroid UK Action4Change	General	General	Urologists need to know about this disease and how to spot it. If mine were aware of this disease, I could have been diagnosed a lot sooner. Since kidney stones are one of the symptoms this should be obvious.	Thank you for your comment. NICE are currently developing a guideline on Renal and ureteric stones: assessment and management Implementation plans for both guidelines will be formulated during guideline development. We hope the published guidelines will raise awareness of primary hyperparathyroidism.
Hyperparathyroid UK Action4Change	General	General	Lithium induced hyperparathyroidism (LIH). LIH does not seem to be known about by GPs and probably most endocrinologists. Patients who have been taking lithium for 10 years or more should have their calcium, PTH and Vit D levels checked at least annually. The document	Thank you for your comment. The NICE guideline on bipolar disorder (CG185) makes recommendations for monitoring people who are taking lithium. This guideline will cross refer to CG185 where appropriate.

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			does not mention multi gland hyperplasia which is often the outcome of LIH.	
Hyperparathyroid UK Action4Change	General	General	Thoughts that come to mind on equality are: "Women over 50? Patients with mild symptoms - this is a pernicious disease that if left undiagnosed and/or untreated can have significant effects on many parts of the body, including the brain. The longer the disease is left untreated the greater the damage no matter how small the raised calcium is."	Thank you for your comment. The guideline committee will be considering the evidence for both pharmacological and surgical treatment, including who should be offered these interventions. The committee may consider the evidence for specific subgroups separately for example post-menopausal women.
Hyperparathyroid UK Action4Change	General	General	There should be some consideration that this is a chronic condition and we may need to be on medication for life (for either vit D/calcium or painkillers etc due to lifelong damage). So the issue of free prescriptions should be included in the scope of the guidelines. At present it's only people with hypoparathyroidism that can get free prescriptions	Thank you for your comment. The issue of free prescriptions is outside of the remit of a NICE guideline.
Hyperparathyroid UK Action4Change	General	General	Where is vit D mentioned? Should we shouldn't we? So many arguments. Some people feel worse, some better. Not enough understand its importance. Can't be ignored in relation to PHPT.	Thank you for your comment. Diagnosis, including biochemistry, is one of the key areas that will be covered by the guideline. Vitamin D will be considered under this key area. We are unaware of any issues specific to people with primary hyperparathyroidism regarding the treatment of vitamin D deficiency. We have added the public health guidance PH56 Vitamin D: increasing supplement use in at-risk groups to the section on related guidance.

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Hyperparathyroid UK Action4Change	General	General	I haven't seen anything about normocalcemic hyperparathyroidism and the importance of having a blood test to check ionised calcium. Also the correct way to administer the blood tests	Thank you for your comment. The purpose of this section is to provide a general introduction to the condition and is not meant to be comprehensive. Diagnosis, including biochemistry, is one of the key areas that will be covered by the guideline.
Hyperparathyroid UK Action4Change	General	General	Initial Medical training seems outdated and needs advancing so that GPS/endos are aware of potential problems and cost savings to be made by early diagnosis and swift treatment.	Thank you for your comment. Implementation plans will be formulated during development.
Hyperparathyroid UK Action4Change	1	13	The draft scope reads: The parathyroid gland becomes overactive and secretes excess amounts of parathyroid hormone, causing hypercalcaemia. Doctors and endocrinologists need to be aware of the relationship between calcium and PTH as excessive pth does not mean always above range but excessive for the calcium level	Thank you for your comment. Diagnosis, including biochemistry, is one of the key areas that will be covered by the guideline. Implementation plans will be formulated during development.
Hyperparathyroid UK Action4Change	1	14-15	The accepted levels for raised calcium, hypophosphatemia and hypercalciuria need stating here for ease of reference for both clinicians and lay readers.	Thank you for your comment. The purpose of this section is to provide a general context to the condition and is not intended to be comprehensive. These terms will be defined in the full guideline.
Hyperparathyroid UK Action4Change	1	16-17	(an adenoma) in one of the parathyroid glands, *or enlargement of one or more glands."* Bold type phrase should be added to account for possibility of multiple adenoma or hyperplasia.	Thank you for your comment. Line 12 states that it is a disorder of one or more parathyroid glands. Lines 15-17 describe the most typical presentation.

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Hyperparathyroid UK Action4Change	1	18	Suggest ***"*** *one of the principal causes of hypercalcaemia in non-hospitalised patients "* as cancer can also cause hypercalcaemia, as I understand it.	Thank you for your comment. We have amended the sentence and we now refer to primary hyperparathyroidism as one of the causes of hypercalcaemia.
Hyperparathyroid UK Action4Change	1	19-20	I suspect these figures are grossly under estimated considering evidence of poor knowledge of this disease and its symptoms by GPs and the medical profession as a whole.	Thank you for your comment. These are the most recent figures we have available but we accept they may be an underestimate.
Hyperparathyroid UK Action4Change	1	15-23	Same standards needed across U.K. Despite having phpt, I have never been checked for hypercalciuria. Never been mentioned by GP/endo.	Thank you for your comment. One of the main purposes of the guideline is to reduce variation in practice. Diagnosis, including biochemistry, is one of the key areas that will be covered by the guideline.
Hyperparathyroid UK Action4Change	1	19-20	These numbers are too low. When I met Prof xxxx he said that he believed that there were many more sufferers than reported. There are probably a significant number of sufferers whose symptoms are not even considered as being related to hyperparathyroidism.	Thank you for your comment. These are the most recent figures we have available but we accept they may be an underestimate.
Hyperparathyroid UK Action4Change	1	19-20	In a study conducted within our group the most prevalent age range was between 30 and 50. I believe this figure of 50-60 to be inaccurate and that many people by the time they are diagnosed will have had PHPH decades.	Thank you for your comment. We have edited the sentence to refer to when people are diagnosed.
Hyperparathyroid UK Action4Change	1	23	"Younger individuals ....can also be caused by familial HPT syndromes would be more accurate" as I believe that younger people can also have primary HPT as seen within our *group.*	Thank you for your comment. We have edited the sentence as you have suggested.

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Hyperparathyroid UK Action4Change	1	22-24	I developed Hyperparathyroidism in my late teens to early 20's. No family history. When I asked to be tested for this disease my doctor's first response was that I was too young to have this.	Thank you for your comment.
Hyperparathyroid UK Action4Change	1	25	Few or no symptoms - these are often put down to other things, or you may not recognise them as such, it does not mean you don't have the symptom. Education of public and health professionals would address some of this. Some health professionals ignore the 'anecdotal' evidence and are dismissive.	Thank you for your comment. Implementation plans will be formulated during guideline development. We hope the published guideline will raise awareness of primary hyperparathyroidism.
Hyperparathyroid UK Action4Change	1	25	Suggest: "*Some people with PHPT have few or no symptoms".* It is another case of 'previously accepted wisdom' that a majority have no symptoms which is not necessarily true today. I was told that "symptoms only come from the high calcium, you don't have high calcium, so you can't be having any symptoms". I can attest to the fact that this was not correct, and I don't believe that most PHPT patients have no symptoms these days. Some maybe, but not 80%.	Thank you for your comment. We have edited this sentence and now refer to 'many' people, rather than using an approximate figure.
Hyperparathyroid UK Action4Change	1	25	Where does the 80% figure come from? Is it a historic figure being carried forward? Or have they researched all current patient files under treatment in the U.K. and compiled the data?	Thank you for your comment. The figure was based on the current literature but has been edited to say 'many' to reflect there is some uncertainty regarding the exact figure.

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Hyperparathyroid UK Action4Change	1	25	1.25 80% have few or no symptoms. A lot of people are disagreeing with this. Personally I think the comment is completely unnecessary. How on earth can anyone know either way. Or are 80% of cases found by accident. Early tiredness and aches will largely be dismissed as getting older or depression by both patients and doctors.	Thank you for your comment. We have edited this sentence and now refer to 'many' people, rather than using an approximate figure.
Hyperparathyroid UK Action4Change	1	25	Few or no symptoms - these are often put down to other things, or you may not recognise them as such, it does not mean you don't have the symptom. Education of public and health professionals would address some of this. Some health professionals ignore the 'anecdotal' evidence and are dismissive.	Thank you for your comment. Implementation plans will be formulated during guideline development. We hope the published guideline will raise awareness of primary hyperparathyroidism.
Hyperparathyroid UK Action4Change	1	25	I think many people are written off as being depressed or having other ailments so I think this number is not correct. I think parathyroid testing needs to be done in people who have suspected depression and/or anxiety and general aches and pains. I was told for years that I was just depressed and went through several anti-depressants that did not work and caused horrible side effects	Thank you for your comment. The key scope areas of identification and diagnosis will include who should undergo testing. However, screening the general population is outside of the scope of this guideline and we have made this clearer.
Hyperparathyroid UK Action4Change	1	27	It may well be diagnosed through a blood test for a different reason, however that reason turned out to be a symptom of phpt.	Thank you for your comment.

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Hyperparathyroid UK Action4Change	1	27	Define mildly elevated, so that same numbers are used across U.K.	Thank you for your comment. These terms will be defined in the full guideline.
Hyperparathyroid UK Action4Change	1	25-27	I didn't know I had hyperparathyroidism as I'd never heard of it but I knew I was ill. I kept getting headaches and was tired so "when a blood test was done for another reason" it didn't mean I didn't have the symptoms, just I didn't know the cause. This must be true for many people.	Thank you for your comment.
Hyperparathyroid UK Action4Change	1	25-27	I believe in reality this accounts for a very small percentage. Very few in our group found out incidentally. They just had never heard of hyperparathyroidism but were not asymptomatic to go to their doctors asking for help in the first place.	Thank you for your comment. The figures refer to those quoted in the current literature. We have amended the sentence to reflect to the uncertainty regarding these figures.
Hyperparathyroid UK Action4Change	1	25-27	Is this really true? Where are you getting this information from? Might it be that people don't actually know their symptoms are symptoms - they think they're just getting older or symptoms are explained away by other causes.	Thank you for your comment. The figures refer to those quoted in the current literature. We have amended the sentence to reflect to the uncertainty regarding these figures.
Hyperparathyroid UK Action4Change	1	34	Cardiovascular disease but iron deficiency and [prostate cancer should be considered as potential side effects (ref https://www.ncbi.nlm.nih.gov/pubmed/18349265)	Thank you for your comment.
Hyperparathyroid UK Action4Change	1	30-34	"The signs and symptoms of hyperparathyroidism are the same as for hypercalcaemia" I don't agree that all the symptoms are the same as hypercalcaemia, it is becoming clearer that some maybe caused by PTH itself. Also some of the symptoms of hypercalcaemia	Thank you for your comment. We have rephrased this sentence and now use the words 'predominately mediated'.

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			listed on the NHS website don't include some of our symptoms.	
Hyperparathyroid UK Action4Change	2	28	No mention of high normal calcium with raised PTH (Normocalcaemic PHPH) We have many people in our group with NCPHTH at various stages of diagnosis and also post op cured	Thank you for your comment. The purpose of this section is to provide a general introduction to the condition and is not meant to be comprehensive.
Hyperparathyroid UK Action4Change	2	28	Here we come to the very vexed question of whether serum calcium or adjusted should be the basis for diagnosis. As my albumin was always high, I was told my serum calcium might well be at the top of the range (paired from the same blood draw with inappropriately high/normal PTH levels, I would add here) but when adjusted for my high albumin level, Ta! Da!, my calcium level became "normal" again, and there was no way I could have PHPT. There needs to be standardisation on this matter. Some labs routinely adjust serum calcium downwards for high albumin, whereas some don't adjust it downwards when the albumin is above 45, as mine usually was.	Thank you for your comment. One of the scope's key areas is 'diagnosis' and this will include biochemical tests.
Hyperparathyroid UK Action4Change	2	28	no mention of high normal calcium with raised PTH	Thank you for your comment. The purpose of this section is to provide a general introduction to the condition and is not meant to be comprehensive.
Hyperparathyroid UK Action4Change	2	28	There is also the question here of use of a tourniquet when drawing blood. In 4 years of blood testing (2 years pre-surgery and 2 years post-op) I met only one	Thank you for your comment. We will consider the use of a tourniquet as part of the evidence on diagnostic assessment.

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			phlebotomist who knew that a prolonged tight tourniquet could alter serum protein (and consequently albumin) levels, which are used to "correct" serum calcium. This was an American who had worked in Emergency. My local phlebotomist was kind enough to ask the local lab if a prolonged tourniquet could alter serum protein levels, and was told that it would have no effect. Bone Profiles conducted to rule in/out osteoporosis include serum calcium, so this tourniquet question ought to be clarified to all phlebotomy departments and labs.	
Hyperparathyroid UK Action4Change	2	28	If it is accepted that intermittently elevated calcium levels can be indicative of PHPT, then more than one test should be arranged before a diagnosis is given. A run of blood tests will give an indication of "the climate" rather than of the "the weather" on just one single day, and will be a better indication of a PTH problem, or not.	Thank you for your comment. One of the scope areas is 'diagnosis' and this will include biochemical tests.
Hyperparathyroid UK Action4Change	2	28	It appears to be underappreciated by numerous endocrinologists that it is not just the high-in-the-range calcium that is at issue in the diagnosis, but that a high-in-the-range serum calcium level paired with any significant level of parathyroid hormone is inappropriate and hints at a parathyroid problem. My 2.63 calcium level paired with a PTH level of 8, should have rung	Thank you for your comment. One of the scope's key areas is 'diagnosis' and this will include biochemical tests.

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			alarm bells with several endocrinologists, but for 2 years this and other similar Ca/PTH pairings did not.	
Hyperparathyroid UK Action4Change	2	28	What classes as mildly elevated. Most docs seem to think anything below 3 is only a bit high, it's fine. Won't be causing any symptoms. Even high normal over long periods is too much and needs taking into consideration. Intermittently, docs need to remember that. Just because bloods return to normal one time, doesn't mean everything's fine and still needs monitoring.	Thank you for your comment. Terms used, such as 'mildly elevated', will be defined in the full guideline.
Hyperparathyroid UK Action4Change	2	30-31	Same as low vit d too that causes a lot of the fatigue, bone pain and brain fog. Also not always constipation. I had chronic diarrhoea for 15 years. Eased greatly post op.	Thank you for your comment. Diagnosis, including biochemistry, is one of the key areas that will be covered by the guideline. Vitamin D will be considered under this key area. We are unaware of any issues specific to people with primary hyperparathyroidism regarding the treatment of vitamin D deficiency. We have added the public health guidance PH56 Vitamin D: increasing supplement use in at-risk groups to the section on related guidance.
Hyperparathyroid UK Action4Change	2	30-34	"The signs and symptoms of hyperparathyroidism are the same as for hypercalcaemia" I don't agree that all the symptoms are the same as hypercalcaemia, it is becoming clearer that some maybe caused by PTH itself. Also some of the symptoms of hypercalcaemia listed on the NHS website don't include some of our symptoms.	Thank you for your comment. We have rephrased this sentence and now use the words 'predominately mediated'.

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Hyperparathyroid UK Action4Change	2	32-34	Prolonged elevated PTH levels are regarded as an independent risk factor for cardiovascular disease.	Thank you for your comment.
Hyperparathyroid UK Action4Change	2	32	Described kidneys stones/osteoporosis as a long term complication. I'm 31, and have had no mention of this from GP/endo's and no discussion of any further tests to check for any possible damage this states can be caused by phpt.	Thank you for your comment. Monitoring, including optimum type and frequency, is a key area of inclusion for the scope.
Hyperparathyroid UK Action4Change	2	37	under-recognised in the general population INCLUDING GPs AND ENDOCRINOLOGISTS	Thank you for your comment. We have amended the sentence to make it clear that the condition is under recognised by healthcare professionals.
Hyperparathyroid UK Action4Change	2	37	*under-recognised in the general population"* What does this actually mean? It sounds as if it means that the general public are not alerted to it, but I would argue that it is the medical profession that underappreciates the problem!	Thank you for your comment. We have amended the sentence to make it clear that the condition is under recognised by healthcare professionals.
Hyperparathyroid UK Action4Change	2	37	Current practice. This also seems to be under-recognized in doctor's offices as well. I was not diagnosed until I asked for the test myself.	Thank you for your comment. We have amended the sentence to make it clear that the condition is under recognised by healthcare professionals.
Hyperparathyroid UK Action4Change	2	37	Delayed treatment can lead to long term complications - after refusal of an operation by my endo I developed very high blood pressure. GP referred me straight to surgeon and I had my operation about 15 months later. Since then all symptoms except for high blood pressure have gone and I feel great, but my GP has warned me I will probably be on medication for the rest of my life to	Thank you for your comment. We have amended the sentence to make it clear that the condition is under recognised by healthcare professionals.

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			control my blood pressure. This may have been avoided if I'd had my operation sooner.	
Hyperparathyroid UK Action4Change	2	37	A lot of my symptoms going back to 2001 (pre-eclampsia, liver and kidney dysfunction and abnormal results, bone and muscle pain, brain fog depression and anxiety, multiple calcium deposits in soft tissues, spinal osteophytes, dysphagia, gallstones and subsequent gallbladder removal) could potentially be as a result of PTH problems. PTH never tested during presentation of any of these issues, so can't confirm. First PTH test done last week after 16 years of problems starting age 32.	Thank you for your comment. We have amended the sentence to make it clear that the condition is under recognised by healthcare professionals.
Hyperparathyroid UK Action4Change	2	37	At 23 I saw my GP about upper and lower back pain. He literally laughed at me saying "what problems could a 23 year old have with their back" left crying and devastated. I requested calcium PTH and vitamin D tests due to all these symptoms. He tried to refuse until I said my mum had just been diagnosed. He relented. I then got my results of 2.85Ca, 25.5 PTH. Genetic tests negative. We both had PHPT	Thank you for your comment. We have amended the sentence to make it clear that the condition is under recognised by healthcare professionals.
Hyperparathyroid UK Action4Change	2	37	Under recognised by GPs, endos and urologists. My urologist missed 10yrs of stones and high blood calcium. 10years all the signs were there and never once crossed the urologists mind. All specialists should be aware as	Thank you for your comment. We have amended the sentence to make it clear that the condition is under recognised by healthcare professionals.

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			PHPT effects all health aspects. Mental health practitioners, orthopaedics etc.	
Hyperparathyroid UK Action4Change	2	37/38	'Under-recognised in the general population'. This delays treatment and increases the likelihood of long-term complications. Essentially it is the fact it is under recognised in the medical profession which increases the likelihood of long term conditions.	Thank you for your comment. We have amended the sentence to make it clear that the condition is under recognised by healthcare professionals.
Hyperparathyroid UK Action4Change	2	37	I had a simple case that took 8 months from diagnosis to surgery. HOWEVER: from 15 years old I had bone pain, chronic fatigue, IBS, kidney stones. Brain fog started around 25. Depression continuously throughout life. Severe from age 25 resulting in nervous breakdown at 30. No real reason why. I had multiple kidney stone from 17 years old to present. Constantly being told I had high calcium levels. Every time I was in A&E or saw urologist I always told my level was fine.	Thank you for your comment. We have amended the sentence to make it clear that the condition is under recognised by healthcare professionals.
Hyperparathyroid UK Action4Change	2	37	under recognised by the general population – also some health professionals including endocrinologists	Thank you for your comment. We have amended the sentence to make it clear that the condition is under recognised by healthcare professionals.
Hyperparathyroid UK Action4Change	2	38	Delays treatment – yes it is lack of knowledge but it is also difficulties getting blood tests which cover calcium, vit d and PTH at the same time. This applies also to diagnosing and monitoring and post op follow ups.	Thank you for your comment. Diagnosis, including biochemistry, is one of the key areas that will be covered by the guideline.

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Hyperparathyroid UK Action4Change	2	40	We have seen massive inconsistencies within this group on scans. Sometimes adenomas show up but in others they don't. The adenomas are hard to see and need expertise to find, they need to be considered with blood tests results and the patients symptom list. This causes delays and distress is caused by these delays. People cannot work	Thank you for comment. Diagnosis, including imaging, is one of the key areas that will be covered by the guideline.
Hyperparathyroid UK Action4Change	2	42	Some GPs are barriers to referrals.	Thank you for your comment.
Hyperparathyroid UK Action4Change	2	41-42	Aftercare is appalling. The long term and permanent damage is dismissed. Explanations of what to expect is very poor. PTSD is very real and people who see a slight raise in levels post op go into meltdown because they don't know what's normal. I've seen it so many times. And I've done it myself.	Thank you for your comment. Post-operative care is included under monitoring, which is a key area of the guideline.
Hyperparathyroid UK Action4Change	2	44-46	Some GPs are able to order a simple ultrasound of the throat area, some are not. Some GPs are able to order a sestamibi scan, some are not and have to refer on to an endocrinologist. If you end up with an endocrinologist who does not understand the blood chemistry (high-in-the-range serum calcium paired at the same blood draw with inappropriately high or even a normal PTH level, with sufficient hydration and an adequate Vitamin D level) then as a patient you have a hard road ahead.	Thank you for your comment. Diagnosis is one of the key areas that will be covered by the guideline.

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Hyperparathyroid UK Action4Change	2	46/47	"patients with suspected PHPT", in most cases it is misdiagnosed, ie each symptom treated individually over a number of years and GPs not looking at the whole picture or symptoms as a whole so I don't feel people even get to the "suspected" stage so this condition generally isn't even considered whether it be lack of knowledge or otherwise	Thank you for your comment. Diagnosis is one of the key areas that will be covered by the guideline.
Hyperparathyroid UK Action4Change	2	46/47	The lack of education of the medical profession is astounding. A GP at my practice admitted that he knows nothing about it!	Thank you for your comment. Implementation plans will be discussed during guideline development. We hope the published guideline will raise awareness of primary hyperparathyroidism.
Hyperparathyroid UK Action4Change	2	46	'Guidelines are needed in primary care to standardise the investigation of patients with suspected PHPT' There is a lack of consistency across the UK with regards diagnosis and even within the endocrinology Dept. I attend endos range in quality from brilliant to very poor. It seems to me a lottery on what support you might get.	Thank you for your comment. One of the main purposes of the guideline is to reduce variation in practice.
Hyperparathyroid UK Action4Change	2	46	I have been diagnosed since Dec 2016 but not a single follow up letter/appointment/tests done since. No referral or appointment with a surgeon. Nothing explained about other possible damage or future tests. My GP thinks the endocrinologist is the person we wait for before they can do anything. GPs need the knowledge and confidence to act and make decisions regarding blood tests, scans and referral to parathyroid surgeons.	Thank you for your comment. Monitoring is one of the key areas that will be considered in this guideline. There is also a key area on indications for surgery.

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Hyperparathyroid UK Action4Change	2	46/47	7 years of symptoms (headaches, memory loss, confusion, bone pain, joint pain) were disregarded by my doctors as age related (33-40) despite calcium over 2.9. I was never once referred to secondary care	Thank you for your comment.
Hyperparathyroid UK Action4Change	2	46/47	My doctors did not take my health concerns seriously. I was once greeted with 'What now?	Thank you for your comment.
Hyperparathyroid UK Action4Change	2	47/48	'the criteria for referral on to secondary care in order to avoid delaying treatment' Primary and secondary care must be made aware of the far reaching implications of untreated PHPT beyond bones and kidney health	Thank you for your comment. Implementation plans will be discussed during guideline development.
Hyperparathyroid UK Action4Change	2	47/48	So often in our group we read about endocrinologists who obviously have no idea about the relationship between PTH and calcium. PTH well over range with high normal calcium is often misdiagnosed as vitamin D deficiency because calcium is 'normal'. Members consequently have to go through the process of getting a second opinion and eventually get a correct diagnosis and surgery (cure). We have seen in some cases this can take years.	Thank you for your comment. Implementation plans will be discussed during guideline development. We hope the published guideline will raise awareness of primary hyperparathyroidism.
Hyperparathyroid UK Action4Change	2	48/49	My endo only asked me about bone pain and kidney stones. No-one mentioned any of the other symptoms I had, and in fact I was told that some of them (joint and muscle pain and tenderness, palpitations) were definitely NOT related (the palpitations have gone post-op, the joint and muscle pain is improving). No-one ever asked if	Thank you for your comment.

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			I got confused, fatigued, found it hard to concentrate, muddled up words, had GERD, depression or memory loss.	
Hyperparathyroid UK Action4Change	2	49/50	I was recently prescribed increased vitamin d supplements after suggestion 'life issues' were to blame and the registrar stated he wasn't interested in my symptoms just in the numbers as he is a scientist!! My calcium was normal, my PTH slightly high and I have an adenoma as seen on two U/S scans!!	Thank you for your comment.
Hyperparathyroid UK Action4Change	2	50	There also needs to be **standardisation of procedures** to avoid the situation of one patient I am aware of who had an adenoma removed at 16, a subsequent sternotomy to find a hidden gland, and then a second sternotomy – and all before the age of 23. I would like to think that at a Centre of Excellence other procedures might have been followed (such as venous sampling, etc) that might have obviated the need for a second sternotomy.	Thank you for your comment. One of the main purposes of the guideline is to reduce variation in practice. Investigations prior to and during surgery are a key area of the scope.
Hyperparathyroid UK Action4Change	2	50	**Parathyroidectomy is delicate neck surgery** and there is some thinking (particularly from patients!) that if a surgeon does no more of these operations than one per week that is not a rate that would inspire confidence. In my view, PTH surgery should not be attempted by General Surgeons or ENT Surgeons who might not see a lot of cases. **Centres of Excellence** for this type of	Thank you for your comment. NICE guidelines do not have responsibility for establishing competencies of healthcare professionals but all healthcare professionals should be aware of and work within legal and professional codes.

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			surgery are required and I myself would not have put myself (and my neck) in the hands of anyone other than an experienced endocrine surgeon.	
Hyperparathyroid UK Action4Change	2	51	My own post-operative care was left in the hands of endocrinologist who refused to see me post-surgery because they had been unable to diagnose PHPT from the biochemistry. I had to find an endocrinologist at another hospital to take me on to monitor my Hashimoto's thyroid and post-PTH surgery bone issues. So post-operative care guidelines need to be in place, especially for patients with thyroid issues as there can be changes to these after PTH surgery.	Thank you for your comment. The key area on monitoring which is in the final scope for this guideline includes post-operative care.
Hyperparathyroid UK Action4Change	2	51/52	Lack of primary care knowledge for post-operative care is detrimental to recovery and contributing to prolonged poor health for many	Thank you for your comment. The key area on monitoring which is in the final scope for this guideline includes post-operative care.
Hyperparathyroid UK Action4Change	3	71	Where will children's guidelines be covered?	Thank you for your comment. We considered we could not adequately address the needs of younger people with primary hyperparathyroidism within this guideline. Making recommendations for people under 18 years requires a different guideline committee constitution, reviews of different evidence and consideration of licensing issues in under 18s.
Hyperparathyroid UK Action4Change	3	73	I have seen cases involving children on several parathyroid groups. This should not be ignored.	Thank you for your comment. We considered we could not adequately address the needs of younger people with primary hyperparathyroidism within this guideline. Making

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			Paediatric doctors need to be aware of this disease and the guidelines also.	recommendations for people under 18 years requires a different guideline committee constitution, reviews of different evidence and consideration of licensing issues in under 18s.
Hyperparathyroid UK Action4Change	3	73	What guidelines are being put together for under 18s? This can't be ignored even if it's rare. I was under 18 when I started with symptoms, left until early 30s when I diagnosed myself. You're too young for all these problems was all I was ever told.	Thank you for your comment. We considered we could not adequately address the needs of younger people with primary hyperparathyroidism within this guideline. Making recommendations for people under 18 years requires a different guideline committee constitution, reviews of different evidence and consideration of licensing issues in under 18s.
Hyperparathyroid UK Action4Change	3	73/74	'The guideline will cover adults (18 years of age and over) with suspected or confirmed primary hyperparathyroidism'. Our group has at least 3 members aged 16 who have been diagnosed and surgically cured of PHPT. We believe that calcium level ranges for younger patients should be mentioned in the guidelines	Thank you for your comment. We considered we could not adequately address the needs of younger people with primary hyperparathyroidism within this guideline. Making recommendations for people under 18 years requires a different guideline committee constitution, reviews of different evidence and consideration of licensing issues in under 18s.
Hyperparathyroid UK Action4Change	3	73	This group is becoming aware of several under 18s being diagnosed with PHPT discovered after MEN investigations that have been negative. Is it possible to include young adults or include a consideration for them?	Thank you for your comment. We considered we could not adequately address the needs of younger people with primary hyperparathyroidism within this guideline. Making recommendations for people under 18 years requires a different guideline committee constitution, reviews of different evidence and consideration of licensing issues in under 18s.

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Hyperparathyroid UK Action4Change	3	75	Specific consideration will be given to women who are pregnant. Within our group we have several members who suffered miscarriage (some several) and at least 2 stillbirths. We would like to see blood screening become standard in maternity departments.	Thank you for your comment. We have edited the scope by adding a specific key area on pregnant women. Screening of the general population is outside of the scope of the guideline. This has been added to the section on areas that will not be covered.
Hyperparathyroid UK Action4Change	3	75	My son; born whilst I had PHPT is under a consultant as he was poorly with severe reflux and a dairy allergy. They think he's a bit asthmatic too. His calcium was high still at around 4 weeks but then it settled down. I think they all seem to have a wait and see approach as just not enough info is out there	Thank you for your comment.
Hyperparathyroid UK Action4Change	3	75	I had undiagnosed phpt all throughout my pregnancy. I ended up with pre-eclampsia, pneumonia and had to have my baby prematurely by emergency c section after a failed induction because he had stopped growing for two weeks. If my calcium had been checked then I may not have ended up in intensive care for the first week of my baby's life. I have since learned that pre-eclampsia can be caused by phpt. I'm certain that some of the dramatic events that unfolded could have been avoided. I developed sepsis from the pneumonia and that's what pit me in ICU. I know I'm very lucky both me and my little boy are here	Thank you for your comment. We have edited the scope by adding a specific key area on pregnant women. Screening of the general population is outside of the scope of the guideline. This has been added to the section on areas that will not be covered. Diagnosis, is one of the key areas that will be covered by the guideline.
Hyperparathyroid UK Action4Change	3	75	Pregnant women should have their calcium checked and gynaecologists should also know about the disease. I had this disease while pregnant. I was seeing a Primary	We have edited the scope by adding a specific key area on pregnant women. Screening of the general population is outside of the scope of the guideline. This has been

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			care, Gynaecologist, High-risk specialist (for another issue) and an urologist. None of them recognized that I had this disease. With the risk of miscarriage that comes with this disease, this is unacceptable	added to the section on areas that will not be covered. Diagnosis is one of the key areas that will be covered by the guideline.
Hyperparathyroid UK Action4Change	3	75	Not only pregnant women but gynaecologists need to be aware of PHPT. So many women in our group have needed hysterectomy due to tumours in the womb. When I had a hysterectomy last year I had a large fibroid, a non-cancerous mass in the womb.	Thank you for your comment. Implementation plans will be discussed during guideline development. We hope the published guideline will raise awareness of primary hyperparathyroidism.
Hyperparathyroid UK Action4Change	3	75	I had Adenomyosis and 1 fibroid resulting in a hysterectomy 2 years before my parathyroidectomy. I was not diagnosed with PHPT at that point despite records showing I had calcium of 2.91, was taking Bendroflumethiazide and also had undiagnosed type 2 diabetes which nobody noticed, not the anaesthetist or surgeon. I was dehydrated, and collapsed 2 days after my hysterectomy after being given intravenous dextrose due to poor appetite (another symptom of PHPT).	Thank you for your comment.
Hyperparathyroid UK Action4Change	3	75	I had pre-eclampsia with my last born. I was 24. Most of this pregnancy was spent hospitalized. No problems with the first 2 pregnancies. Also was in the hospital with double pneumonia when I was diagnosed at 6wks pregnant.	Thank you for your comment.

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Hyperparathyroid UK Action4Change	3	84	**Diagnosis is primarily based on the biochemistry, not the symptoms.** It must be spelled out to clinicians that it is not just a case of measuring calcium and parathyroid hormone from the same blood draw, but understanding that a relatively high calcium paired at the same blood draw with even a mid-range normal parathyroid hormone level is inappropriate and indicates a parathyroid disorder.	Thank you for your comment. Diagnosis, including biochemistry, is one of the key areas that will be covered by the guideline.
Hyperparathyroid UK Action4Change	3	84	Indications for surgery must NOT be restricted by age. PHPT is a progressive disease and to refuse surgery for anybody over 50 only condemns them to years of treatment and suffering with related conditions. How can this possibly be cost effective for the NHS? A study produced by British surgeons concludes that parathyroidectomy is safe and improves symptoms in the elderly. https://www.ncbi.nlm.nih.gov/pubmed/19222492	Thank you for your comment. One of the key issues and questions for review is on indications for surgery. NICE would not normally make recommendations for specific age groups unless there is good evidence to support this. NICE guidelines consider equality issues at each stage of the guideline development process. The separate document entitled the Equality Impact Assessment' is designed to support NICE's compliance with the Equality Act 2010.
Hyperparathyroid UK Action4Change	3	86	Care must be taken when quoting age ranges within which surgery is acceptable or not, as these can often be too strictly adhered to. 70-yr olds these days might benefit hugely from the improved quality of life that a parathyroidectomy might confer, or otherwise spend their later years in much pain and discomfort from the late ongoing effects of primary HPT.	Thank you for your comment. One of the key issues and questions for review is on indications for surgery. NICE guidelines consider equality issues at each stage of the guideline development process. The separate document entitled the Equality Impact Assessment' is designed to support NICE's compliance with the Equality Act 2010.

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Hyperparathyroid UK Action4Change	3	159	Don't leave people just because they have little or no symptoms. Encourage surgery. Prevention is always better than cure.Don't let that person get so bad they can't think or walk. It can come on very quickly.	Thank you for your comment. One of the key issues and questions for review is on indications for surgery.
Hyperparathyroid UK Action4Change	4	84	Identifying and diagnosing symptomatic and asymptomatic primary.. We believe calcium, phosphate, vitamin D should be standard screening when presented with 'mild' symptoms such as fatigue, memory loss and depression before assuming age and lifestyle are the cause.	Thank you for your comment. The key area on identification and diagnosis includes biochemical tests. Screening of the general population is outside of the scope of the guideline. This has been added to the section on areas that will not be covered.
Hyperparathyroid UK Action4Change	4	88	Day surgery with good post-operative advice and a hospital contact number in case of issues in the first few days	Thank you for your comment.
Hyperparathyroid UK Action4Change	4	88	Patients currently have no post-operative advice regarding immediate treatment for tingly hands and face (hypocalcaemia) that could result in tetany. Post-operative advice regarding calcium, vitamin D and magnesium supplementation should be given.	Thank you for your comment. The scope of this guideline lists a key area on monitoring which includes post-operative care.
Hyperparathyroid UK Action4Change	4	89	I do not see pharmacological management as a good option. Delaying surgery will only allow the disease more time to slowly destroy the body from the inside out.	Thank you for your comment. The committee will discuss the circumstances when pharmacological management may be appropriate: both pharmacological management and indications for surgery are key areas that will be covered by the guideline.
Hyperparathyroid UK Action4Change	4	90	monitoring- have not been monitored for levels for past 3 months-so again standards needed especially for GP's	Thank you for your comment. Monitoring is one of the key areas that will be covered by the guideline.

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			who like to wait for instructions from consultant as they not used to dealing with phpt. Recommendations needed for how often levels should be tested whilst waiting for surgery etc.	
Hyperparathyroid UK Action4Change	4	91	All doctor's surgeries and Endocrine Units should offer comprehensive information to the public, as is done currently for Pituitary issues, etc.	Thank you for your comment. Provision of information is one of the key areas that will be covered by the guideline.
Hyperparathyroid UK Action4Change	4	96	Secondary Hyperparathyroidism will have to be mentioned at some point – if only because many primary HPT patients are currently misdiagnosed with it !!	Thank you for your comment. Differential diagnosis including secondary hyperparathyroidism will be considered under the key area of 'diagnosis'.
Hyperparathyroid UK Action4Change	4	102	I was refused a dexa several times because I was too young for any problems that wouldn't go away. Guess what...cervical and lumbar problems that won't fix themselves because of the long term degeneration. Don't refuse young patients with long term illness to save on money.	Thank you for your comment.
Hyperparathyroid UK Action4Change	5	120	Economic aspects. What appear to be expensive blood tests will work out cost effective as early diagnosis will result in fewer doctor and hospital appointments, less prescriptions issued, less days lost due to sickness. There should be no upper age limit as the benefits of surgery will save ££££s in fewer broken bones due to osteoporosis, hospitalisation for kidney stones etc. I have had numerous UTIs, 2 broken bones, both needing physio, and damage to my teeth	Thank you for your comment. The economic aspects will be considered when making the recommendations as outline in section 3.4. We agree that there are many relevant trade-offs that will be considered for the interventions the guideline will be investigating. Please note that NICE guidelines only consider costs relevant to the NHS, and not costs borne by the individual or related to productivity, as whilst there may be a wider

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				cost impact to individuals, days lost from work for example are not costs that would be paid for by the NHS.
Hyperparathyroid UK Action4Change	5	134	I was told a calcium level of 2.76 was not causing all my symptoms, the vast majority resolved post op. I don't think all the symptoms are properly recognised. For example eye problems are rarely mentioned.	Thank you for your comment. Diagnosis, including biochemistry, and identifying people to be tested for primary hyperparathyroidism are key areas that will be covered by the guideline.
Hyperparathyroid UK Action4Change	5	134	I was told a calcium level of 2.76 was not causing all my symptoms, the vast majority resolved post op. I don't think all the symptoms are properly recognised. For example eye problems are rarely mentioned.	Thank you for your comment. Diagnosis, including biochemistry, and identifying people to be tested for primary hyperparathyroidism are key areas that will be covered by the guideline.
Hyperparathyroid UK Action4Change	5	134	Consultants are getting it wrong. After pancreatitis, gall stones and gall bladder removal my surgeon ignored the fact that my calcium was up. I only found out after more hospital admissions and I still have not been referred for surgery. One consultant put me on calcichew (with hypercalcemia).	Thank you for your comment. Diagnosis, including biochemistry, is one of the key areas that will be covered by the guideline.
Hyperparathyroid UK Action4Change	6	66	I was very poorly monitored by the endocrinologist at one point I had a 7 month wait for my next appointment when I was told it would be 7 weeks, by which time my calcium levels had 'suddenly' increased.	Thank you for your comment. Monitoring is one of the key areas that will be covered by the guideline.

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Hyperparathyroid UK Action4Change	6	66	I lost a year of my life from diagnosis to op. I would sleep very badly get up late, nap and rest in the afternoon and go to bed early. The economic and social impact on patients and their families is massive, plus an extra load on the GP.	Thank you for your comment. Clinical and cost effectiveness will be considered throughout the guideline and this includes patient reported outcomes. Please note that NICE guidelines only consider costs relevant to the NHS, and not costs borne by the individual or related to productivity, as whilst there may be a wider cost impact to individuals, days lost from work for example are not costs that would be paid for by the NHS.
Hyperparathyroid UK Action4Change	6	138	My calcium was on the high end of the normal range. Although it had gone up over the years, my doctors did not notice. My calcium never left the normal range even though I did have a large adenoma.	Thank you for your comment. Diagnosis, including biochemistry, is one of the key areas that will be covered by the guideline.
Hyperparathyroid UK Action4Change	6	141	Don't refuse surgery for those who have negative scans. All mine were negative but they pulled a huge 3cm adenoma out. Maybe refer to a more experienced surgeon who finds missing glands instead of the surgeon giving it a go anyway. This is why people end up with failed surgeries.	Thank you for your comment. Investigations prior to surgery is a key area that will be covered by the guideline.
Hyperparathyroid UK Action4Change	6	141	My neck ultrasound and all 3 of my sestamibi scans were negative, yet I had an adenoma the size of a grape. These tests were all wrong for me. They caused me time, stress, money and unnecessary radiation exposure. We NEED better scans!	Thank you for your comment. Diagnosis, including imaging, is one of the key areas that will be covered by the guideline.

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Hyperparathyroid UK Action4Change	6	141/2	What is the diagnostic accuracy of non- invasive technology like ultrasound? My GP arranged for me to have an ultrasound scan on my neck at diagnosis. My endo cancelled that appointment saying it was a waste as the glands are only the size of a grain of rice so never show up. After GP referral direct to a surgeon the first thing she did was arrange an ultrasound scan on my neck and there it was. 1 large adenoma as clear as anything.	Thank you for your comment. Diagnosis, including imaging, is one of the key areas that will be covered by the guideline.
Hyperparathyroid UK Action4Change	6	147	Quality of Life has to be a major factor in deciding indications for surgery.	Thank you for your comment. Quality of life is an outcome that will be considered when assessing the evidence.
Hyperparathyroid UK Action4Change	6	153	I think you have to look at history. If a single adenoma is located then great, minimal invasive but at least check bloods and check again intra op. If bloods aren't satisfactory they check the rest. It's devastating having to go through it all again. Will only cost the NHS more money	Thank you for your comment. Investigations during surgery is one of the key areas that will be covered by the guideline.
Hyperparathyroid UK Action4Change	6	153	In skilled hands, a 4-gland investigation can be conducted with a minimal incision. In my own view, minimally invasive surgery has been used by less experienced non-endocrine surgeons to remove only those glands that have shown up on scans. It is not cost-effective to take out only those glands visible on scans leaving others that might be there to grow bigger in the future, necessitating repeat (and possibly more complex) re-operation. Four-gland investigation should be carried	Thank you for your comment. One of the proposed key issues and questions that will be covered by the guideline is the clinical and cost effectiveness of different types of surgical intervention.

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			out by an experienced endo-surgeon at the initial surgery, in my view – preferably with intra-operative PTH monitoring. This is another reason to support the establishment of Centres of Excellence for this type of surgery.	
Hyperparathyroid UK Action4Change	6	153	Long term cost effectiveness: The number of elderly patients with problems due to phpt- has any data been gathered on the amount of hip ops/heart problems/ dementia/depression etc., performed over the last 10/20 years whilst phpt has no NICE guidelines? How many would have been preventable?	Thank you for your comment.
Hyperparathyroid UK Action4Change	6	159	Monitoring should be done whilst waiting for the op and further diagnostic tests of Vit D, PTH and calcium are not being done till 6- 8 weeks surgery when some people are left not knowing what to do or who to consult as their levels change. If you are extremely ill, then more often. Calcium, PTH and Vit D should be done immediately post op, then 6 weeks later and then another 6 weeks. There is too much emphasis on calcium without the other elements being looked at.	Thank you for your comment. Your comment will be passed onto the guideline committee when they discuss the evidence review protocol for this scope topic.
Hyperparathyroid UK Action4Change	6	159	Labs should all work with the same ranges for blood work. A standardisation of the tests after diagnosis. I was never offered kidney or dexa scan. Regular monitoring of bloods whilst waiting for surgery. I felt after diagnosis that I shouldn't bother the GP with symptoms	Thank you for your comment. Your comment will be passed onto the guideline committee when they discuss the evidence review protocol for this scope topic.

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			as the cause had been found and the ball was in motion towards surgery.	
Hyperparathyroid UK Action4Change	6	159	I was very poorly monitored by the endocrinologist at one point I had a 7 month wait for my next appointment when I was told it would be 7 weeks, by which time my calcium levels had 'suddenly' increased.	Thank you for your comment. Monitoring is one of the key areas that will be covered by the guideline.
Hyperparathyroid UK Action4Change	6	162	What info is needed for patients? Step by step guidelines: process-tests-scan- then regular monitoring in order to avoid lengthy delays and cause long term damage and expense.	Thank you for your comment. Information provision is one of the key areas that will be covered by the guideline.
Hyperparathyroid UK Action4Change	6	162	People with this disease need to know about the damage it can cause to the body, they need to know to find an EXPERIENCED surgeon, they need to know what to expect during surgery and after. They need to know they are not alone and have access to support groups	Thank you for your comment.
Hyperparathyroid UK Action4Change	6	166	Health related quality of life. After parathyroidectomy I am now cured and leading a normal healthy life. I'm back to work with no sick days, no GP or hospital appointments and no longer a burden on the NHS.	Thank you for your comment.
Hyperparathyroid UK Action4Change	6	166	I lost a year of my life from diagnosis to op. I would sleep very badly get up late, nap and rest in the afternoon and go to bed early. The economic and social impact on patients and their families is massive, plus an extra load on the GP.	Thank you for your comment. Clinical and cost effectiveness will be considered throughout the guideline and this includes patient reported outcomes. Please note that NICE guidelines only consider costs relevant to the NHS, and not costs borne by the individual

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				or related to productivity, as whilst there may be a wider cost impact to individuals, days lost from work for example are not costs that would be paid for by the NHS.
Hyperparathyroid UK Action4Change	6	166	This disease has destroyed my quality of life. Even after being cured I still have issues. People with this disease are not being given the compassion that they need, the time to heal after surgery and the follow-up care they deserve.	Thank you for your comment. The key area that will be covered in the guideline is monitoring which includes post-operative care.
Hyperparathyroid UK Action4Change	6	166	Both physical health and very crucially mental health - not just for the patient but for their loved ones.	Thank you for your comment. The outcomes for each review will be discussed by the guideline committee.
Hyperparathyroid UK Action4Change	6	167	For fatigue and insomnia I have been offered antidepressants by GP who thinks it is nothing to do with having phpt.	Thank you for your comment.
Hyperparathyroid UK Action4Change	6	167	Once my calcium hit over 3 I could no longer drive. Advised to drink 3 litres a day which helped at the margin, no other symptom management was offered.	Thank you for your comment.
Hyperparathyroid UK Action4Change	6	169	There has been no monitoring of my bone-loss post op.	Thank you for your comment. The key area that will be covered in the guideline is on monitoring which includes post-operative care
Hyperparathyroid UK Action4Change	6	175	I believe many re-ops could be prevented if surgeons had better training and/or if more people were sent to parathyroid EXPERT surgeons and not just any general surgeon.	Thank you for your comment. NICE guidelines do not have responsibility for establishing competencies of healthcare professionals but all healthcare professionals should be aware of and work within legal and professional codes.

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Hyperparathyroid UK Action4Change	7	174	Partly due to lack of monitoring by the time I saw the surgeon, and had my pre-op check, my calcium level was so high I had to be admitted to hospital 2 days prior to my op for an IV so I would be able to have the general anaesthetic at a time beds were very short. The first night the surgical triage unit I was in had no more beds, there were no beds on the surgical ward.	Thank you for your comment. Monitoring is one of the key areas that will be covered by the guideline.
Hypopara UK	1	21-22	We feel that hyperpara may be underdiagnosed (for example, it may only come to light after a woman has had a fracture due to osteoporosis) and that it may be better expressed as: It can develop at any age, but is **most usually** identified in women between the ages of 50 and 60	Thank you for your comment. We have edited the sentence to now refer to when the condition is most often diagnosed.
Hypopara UK	1	25-29	We feel the statement that 80% of people have few or no symptoms may be an overstatement based on the many questions we receive. This statistic may result in GPs treating hyperpara as a trivial disorder and that it may be an overestimate based on patients who have symptoms that have gone unrecognised. We propose this paragraph be replaced by: Primary hyperparathyroidism is often detected as an incidental finding when a blood test is done for another reason. In some of these cases symptoms may have gone unrecognised previously, which may be	Thank you for your comment. We have edited this sentence and now refer to 'many' people, rather than an approximate figure. In the previous paragraph we now refer to when the condition is diagnosed.

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			dangerous. In others there may be only mild symptoms or the calcium level may be only mildly elevated.	
Hypopara UK	2	30	We suggest to add: …effects on the central nervous system such as fatigue, anxiety, feelings of being unable to cope, which may be mistakenly attributed to pressures arising from daily living, care of family, work etc. or the approach of the menopause.	Thank you for your comment. The purpose of this sentence is to cite examples of how the condition may present and is not meant to be a comprehensive list.
Hypopara UK	2	32	Add: …fatigue, and cognitive symptoms such as mood changes, memory issues, confusion, and depression	Thank you for your comment. The purpose of this sentence is to cite examples of how the condition may present and is not meant to be a comprehensive list. However, we have added 'memory impairment' as an example of a cognitive symptom.
Hypopara UK	2	37	We propose extending this to: It is under-recognised in the general population and is also under-recognised in general practice and by health care professionals who are well placed to pick up signs and symptoms (such as, orthopaedic specialists, physiotherapists, urologists, dentists, psychologists and psychotherapists)	Thank you for your comment. We have edited the sentence to clarify that the condition is under-recognised by healthcare professionals.
Hypopara UK	3	75	Due to the fluctuations in pregnancy, childbirth and breastfeeding reported by some of our members we suggest adding:	Thank you for your comment. We have added a separate key area to the guideline scope on pregnant women with primary hyperparathyroidism.

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			… and in women who are lactating.	
Hypopara UK	4	88	We suggest adding: Surgical management including ectopic adenoma and reoperative surgery	Thank you for your comment. These are key issues and questions on the clinical and cost effectiveness of surgery. Your comment will be passed on to the guideline committee to consider when writing the review protocol. We have added a separate draft question/issue on re-operation.
Hypopara UK	4	83-91	We suggest including: - normocalcaemic hyperpara - post-surgical monitoring	Thank you for your comment. Normocalcaemic primary hyperparathyroidism will be considered under the key area 'identification and diagnosis'. The guideline also will cover a key area on monitoring which includes post-operative care.
Hypopara UK	6	152	We propose adding: 5.2 What is the best surgical management for 4-gland hyperplasia? 5.3 What is the best surgical management for ectopic adenoma? 5.4 What is the evidence for parathyroid autotransplantation, how widely is this performed, and what is the success rate?	Thank you for your comment. There is a key issue and question on the clinical and cost effectiveness of surgery. Your comments (5.2 and 5.3) will be passed on to the guideline committee to consider when writing the review protocols. Only a very small proportion of people undergo autotransplantation and it is therefore not included as a key area of the scope.
Hypopara UK	7	175	We propose extending this list to include: - socioeconomic impact and ability to work	Thank you for your comment We are unaware of any issues specific to people with primary hyperparathyroidism regarding the treatment of vitamin D deficiency. We have

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			- speed of return to work after surgery/treatment - Vitamin D3 deficiency – to treat or not to treat	added the public health guidance PH56 Vitamin D: increasing supplement use in at-risk groups to the section on related guidance. Please note that NICE guidelines only consider costs relevant to the NHS, and not costs borne by the individual or related to productivity, as whilst there may be a wider cost impact to individuals, days lost from work for example are not costs that would be paid for by the NHS. Ability to undertake normal activities (including work) as an outcome can be captured through quality of life and other symptom related outcomes.
NHS England	General		Thank you for the opportunity to comment on the above clinical guideline. We can confirm that there are no comments to be made on behalf of NHS England.	Thank you for your comment.
Royal College of General Practitioners	General	General	National NICE guidance will substantially help GPs and secondary care clinicians to offer a consistent approach to patients. Several of our members report that the abnormal level of serum albumin-adjusted calcium outside the normal range that require further investigation is inconsistent across pathology laboratories and endocrinology departments in hospital trusts. Secondary cares appears to seldom further investigate or intervene unless the albumin-adjusted calcium is above 3 mmol/L.	Thank you for your comment. Diagnosis, including biochemistry, is one of the key areas that will be covered by the guideline.

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Royal College of General Practitioners	General	General	The national guidance should clarify how GPs and their teams can optimally manage marginally raised serum albumin-corrected calcium levels without leading to over diagnosis or undue stress to patients.	Thank you for your comment. Diagnosis, including biochemistry, is one of the key areas that will be covered by the guideline.
Royal College of General Practitioners	General	General	It may be useful to consider how to develop primary care IT clinical systems to identify potentially undiagnosed patients with hyperparathyroidism.	Thank you for your comment. The guideline does cover the identification of people who may have primary hyperparathyroidism but it is up to local commissioners to determine how to best implement the guideline recommendations to meet the needs of their local population.
Royal College of Nursing	General		This is to inform you that the Royal College of Nursing have no comments to submit to inform on the above draft scope consultation. Thank you for the opportunity to participate.	Thank you for your comment.
Society of Endocrinology	General	General	There is no reference in scoping to three issues we think should be included : Role and modaility of urine calcium excretion measurement Role of measurement and replacement of Vitamin D deficiency in HPTH Role of bone density measurement (BMD) for osteoporosis and bisphosphonate therapy and BMD in selection for surgery and suggested frequency of monitoring	Thank you for your comment. Urine calcium excretion and the role of vitamin D will be considered under the key issue 'identification and diagnosis'. We have added a key question/issue on bisphosphate therapy and we now also refer to 'Alendronate, etidronate, risedronate, raloxifene and strontium ranelate for the primary prevention of osteoporotic fragility fractures in postmenopausal women' (TA160). The guideline will also cover the question/issue on indications for surgery.

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University hospitals of Morecambe Bay NHS Trust	General		No comments submitted as no issues with current quality standard	Thank you for your comment.