Thyroid Disease : scope workshop discussions – Group 1 Date: 19/09/17		
Scope details	**Questions for discussion**	**Stakeholder responses**
Groups that will be covered • Children and adults with thyroid disease • Specific consideration will be given to pregnant woman Groups that will not be covered • Neonates		• Agreed that the guideline should cover children and adults. • Agreed that special consideration should be given to pregnant women as pregnancy is a common trigger for hypoparathyroidism and hyperparathyroidism. • Agreed that neonates should not be covered in the guideline as there is currently a good screening programme for newborns and it would be very difficult to look at thyroid disease specifically in the neonate group.

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Settings that will be covered • All settings in which NHS-funded healthcare is received. Settings that will not be covered • None		• Agreed that all of these settings should be covered as the healthcare professionals involved in the care of patients with thyroid disease will range across primary, secondary and tertiary services. • Most thyroid disease patients are managed at GP level. There is a question about which groups of patients should be referred to an endocrinologist.

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Key areas that will be covered: 1 Investigation of thyroid dysfunction/thyroid enlargement • Indications for thyroid function tests • Indications for other tests or imaging		1. - Noted that clinicians should not rely on blood tests alone and consideration should be given to symptoms as well. - Thyroid reference ranges (target levels for TSH) were raised as some feel they are currently not fit for purpose. - As well as when thyroid antibodies should be tested, consideration should also be given to who conducts this test (GP or secondary care). - There is good existing guidance on investigating thyroid nodules (BTA, 2016), therefore this area is lower priority than other areas listed. The follow-up of thyroid nodules is however an area that could benefit from further guidance. - Autoimmunity is a significant cause of thyroid disease. - Candida and leaky gut syndrome are common co-existing conditions for people with thyroid problems.

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2 Management of non-malignant thyroid enlargement • Referral for surgery • Non-surgical treatment • Monitoring of non-malignant thyroid enlargement		2. - Noted that non-malignant thyroid enlargement needs to be clearly defined in the guidance. - The NICE Interventional procedures guideline (IPG562) on Ultrasound-guided percutaneous radiofrequency ablation for benign thyroid nodules was noted as related guidance. - U3 nodules (those of indeterminate appearance on ultrasound) would be covered by the BTA guidance. - Should specify in the management of non-malignant thyroid enlargement that these are EU thyroid patients (they have not been diagnosed with thyroid disease).

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3 Management of hypothyroidism • Treatment options: T4; T3; combination of both • Monitoring of hypothyroidism		3. - Noted the need to clearly define hypothyroidism, as it can vary slightly (for example different definition in European guidelines). - Noted the different types of hypothyroidism (primary, secondary, tertiary and central) which are all managed differently. Some members of the group felt the guideline could just cover primary, others felt all types should be covered. - In addition to how often patients with hypothyroidism should be monitored, the guidance should also cover how patients should be monitored. This will vary according to the type as noted above. - Felt that treatments outside of conventional treatment options (for example thyroid extracts) should be covered. - Consideration should also be given to patients who are already on non-conventional treatments and how clinicians should manage these patients. In particular it was noted that there is a potential harm from overtreatment in this group of patients. - Those working with patients note a high level of dissatisfaction with current treatments. - Treatment of hypothyroidism with T4, T3 and a combination is a priority area for economic analysis. Dose levels could also be an important consideration in this area. - Noted the ETA guidelines (2012) on L-T4 and L-T3 in the treatment of hypothyroidism.

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4 Management of thyrotoxicosis • Treatment options: antithyroid drugs; radioiodine; surgery • Monitoring of thyrotoxicosis		4. - The use of radioactive iodine vs anti-thyroid drugs vs surgery is a potential area for economic modelling. Quality of life and patient choice in the discussions about treatment options will be very important for this question. - When considering different medication regimens for thyrotoxicosis it is important to consider duration of treatment. It would also be useful for the guideline to give guidance on ranking of treatments (first-line, second-line etc.) - Monitoring of patients with thyrotoxicosis should consider the complications of the disease and the treatments. Certain drugs can affect liver function and bone marrow for example. - Noted the importance of testing thyroid antibodies before deciding on a treatment option, for example for Graves' disease. Thyroid antibodies also need to be monitored. - The management of children was noted as very different in this area; children are more difficult to treat and don't respond in the same way as adults to drugs. - Hypoadrenalism was noted as a rare complication.

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5 Management of subclinical thyroid dysfunction • Treatment of subclinical hypothyroidism • Treatment of subclinical thyrotoxicosis • Monitoring of subclinical thyroid dysfunction		5. - Noted the need to define subclinical thyroid dysfunction (difficult to define). This would be through symptoms as well as blood tests. - Having good reference ranges is very important. - Noted that older people's TSH levels may be elevated through age and not due to clinically detectable thyroid disease.

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Scope details	**Questions for discussion**	**Stakeholder responses**
6 Thyroid dysfunction in pregnancy		6. - Feel that pre-conception screening, screening during pregnancy and information for thyroid disease is an important area for this group. - This area could however be lower priority if it is covered by the RCOG guidance in development. - Felt that the management of thyroid disease in pregnant women should cover all pregnant women (with both pre-existing and new onset disease). - The management of iodine levels is important. Iodine insufficiency is a problem in the general population at large but is particularly important here. Iron and vitamin D deficiency is also important to consider in pregnant women. Need to check whether this will be covered in the RCOG guidance.

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7 Information for patients and families and carers		7. - Information post-surgery - Information about available drugs - Information about thyroid extract - Information needs to be much more detailed and readily available for all patients as there is currently not enough so patients are having to get information from other sources such as the internet.
Areas that will not be covered 1. Thyroid eye disease 2. Thyroid cancer (except preliminary investigation) 3. Natural thyroid extracts (not licensed) 4. Screening for congenital hypothyroidism		- Felt that although thyroid eye disease cannot be covered by this guidance it does need to be covered by guidance. There are European Association guidelines. - Felt that natural thyroid extracts (not licensed) should be covered in this guidance. They are unusual among unlicensed products as they were routinely prescribed in the 60s/70s. There is a group of patients with hypothyroid disease who don't respond to conventional treatment. - Would need to add whether screening pregnant women is being covered or not (depending on scope of RCOG guidance).

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Is there anything not on the list that is a higher priority than the items listed?		- Diet and lifestyle was raised as an important area for patients with normal thyroid function but ongoing symptoms.
Health economics An economic plan will be developed that states for each review question/key area in the scope, the relevance of economic considerations, and if so, whether this area should be prioritised for economic modelling and	• Which practices will have the most marked/**biggest cost** implications for the NHS? • Are there any **new practices** that might **save the NHS money** compared to existing practice? • Do you have any further comments on economics?	- Hypothyroidism is a common disease (more prevalent in women) and so any change in practice is likely to have a cost impact. Affects roughly one in 20 people in the UK (3,250,000) - Pregnant women are more likely to get problems with ferritin, iron and oestrogen. - There would be potential cost savings for improved diagnostic testing.

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analysis.		
Main outcomes 1. Quality of life 2. Mortality 3. Resource use 4. Adverse effects of treatment		- Noted that it can be hard to define what is contributing to the quality of life outcome. A patient may continue to have symptoms even though their blood test results are within the normal range. It is important for the guidance to acknowledge this group of patients.

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GC membership Full committee members: • Chair • Lay member x2 • Endocrinologists x3 • Specialist nurse x1 • Paediatrician/paediatric endocrinologist x1 • GP x2 • Thyroid surgeon x1 • Radiologist x1 • Pharmacist x1 Co-opted members: • Clinical biochemist co-optee • Pathologist co-optee • Ultra sonographer co-optee • Obstetrician co-optee		• Suggested 2x paediatricians/paediatric endocrinologists as the guideline is covering children and some areas of management (as specified further above) will be very different. • Biochemist may be better as a full member as lots of the questions involve discussion of biochemical levels. • Could add a medical physicist co-optee for the discussions on radio-iodine. • Radiologist could be a co-optee if thyroid nodules are considered to be covered by other guidance. • Thyroid surgeon could be a co-opted member depending on how much is covered by the cancer guideline.