

This vision does not represent government policy but provides useful insight into how head, neck & thyroid cancer services might develop over the next 5 years

Annex F

Head & neck and thyroid cancers 2015

Epidemiology

1. *Head & neck* cancers have tremendous biological diversity – many are more common in older people but they are becoming an increasing issue for younger people. There are over 30 specific sites covered by the term *head & neck* cancer with the major ones being oral cavity (mouth), laryngeal and pharyngeal cancers. In addition there are a multitude of extremely rare pathological entities which constitute malignancy in this area as well. Taken together there are around 7,000 *head & neck* cancers a year in England.¹ This group of cancers is the 8th most common in England and makes up 3% of all cancers.^{1,2} The incidence of most head and neck cancers has increased since 1990. Cancer of the oral cavity has increased by more than 30% while the incidence of oropharyngeal cancer has more than doubled. However, the incidence of laryngeal cancer has dropped by 20% in the same time period.³
2. However, survival for most *head & neck* cancers has improved since 1990. For example, oral cancer has seen significant improvements in both 1- and 5-year survival rates with 5-year survival now at 56%. Oropharyngeal cancer has seen a 12% increase in 1- and 5-year survival rates with 5-year survival rates at 52%,³ a change in which HPV-related disease is an important factor.
3. *Thyroid* cancer is rarer with around 1,800 cases in the UK a year. The incidence has doubled between 1990 and 2006, which may be due in part to the increased detection of small papillary carcinomas through the increased use of cross-sectional imaging. It is often grouped with *head & neck* cancers because it is anatomically related. However, the cancers are very different, for example many *head & neck* cancer patients have a poor prognosis whilst the majority of *thyroid* cancer patients will be cancer survivors. There has been a 10% increase in 1- and 5-year survival rates in *thyroid* cancer patients since 1990, with the 5-year relative survival rate for the most recently diagnosed cases at 87%.³ There is some overlap of clinicians treating *thyroid* and *head & neck* cancers.
4. We predict that:
 - a. *head and neck* cancers will increase by around 500-1,000 cases a year and an increase in smoking and alcohol consumption in younger age groups will be a contributory factor. The incidence of HPV-related oral and oropharyngeal cancer will continue to increase;
 - b. *thyroid* cancer will increase, particularly in women of reproductive age.

¹ Office for National Statistics. *Cancer statistics registrations: registration of cancer diagnosed in 2007, England*. Series MB1 No. 38. National Statistics: London. [ICD 10: C00-C14 + C30-C32 (head and neck); C73 (thyroid)]

² all cancers excluding non-melanoma skin cancer

³ National Cancer Intelligence Unit. (January 2010) *Profiles of head and neck cancers in England: incidence, mortality and survival*.

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Prevention

5. Smoking and alcohol consumption are risk factors in the development of *head & neck* cancers. The smoking ban should have an impact on incidence in the longer term but will not be a factor by 2015. General lifestyle factors, particularly in the young where smoking and alcohol consumption rates remain high, are working against a long term reduction in incidence. In addition, in some ethnic minority communities the chewing of tobacco (with or without betel nut) is a risk factor.
6. As HPV infection is a significant risk factor for oropharyngeal cancer HPV vaccination will have an impact on incidence in the longer term although it is unlikely to have made a significant difference by 2015.
7. By 2015 we need to:
 - a. have expanded work on smoking cessation to focus on younger age groups (potentially aiming to stop them starting to smoke in the first place);
 - b. have taken more concerted action to reduce alcohol consumption especially binge drinking in younger age groups;
 - c. have run a successful campaign to discourage the chewing of tobacco (with or without betel nut);
 - d. have placed greater emphasis on the promotion of sexual health and distribution of HPV prevention advice;
 - e. have undertaken research on the feasibility and effectiveness of the HPV vaccination in males in reducing the incidence of oral and oropharyngeal cancers.
8. For *thyroid* cancer there is a small subset of people with or at risk of familial *thyroid* cancer where genetic testing is needed. Prophylactic thyroidectomy is required in gene carriers. The genetic testing facilities are largely in place but it can be difficult to get timely referrals. By 2015 these services need to have sufficient resource to see patients in a timely manner. In addition, because these patients may be at risk of other endocrine tumours it is essential they are managed by a specialist MDT including a suitably trained endocrine surgeon and endocrinologist.
9. By 2015 we need to ensure that more research is underway into the causes of *thyroid* cancer in view of the fact that incidence is increasing (particularly in women of reproductive age).

Screening

10. There is now worldwide evidence from an RCT that visual screening for oral cancer in high risk groups can reduce mortality. There is therefore scope to introduce opportunist screening of the oral cavity. However, high risk groups are those less likely to have access to an NHS dentist and therefore less likely to have regular dental appointments. Although financial incentives to carry out dental checks for suspected cancer on those that do attend dental appointments could be considered it is unlikely that this will target the high risk population.
11. Due to the problems of dental capacity, which are outside the scope of the CRS to resolve, it may not be feasible to focus opportunistic screening with dentists. An

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alternative which could be considered is the role of the GP and practice nurses (who often see high risk groups for other issues such as high blood pressure) and pharmacists (who are often consulted about mouth ulcers). Training issues and financial incentives would need to be considered and research undertaken into the effectiveness of screening carried out by non-medical personnel.

12. By 2015:

- a. a pilot should have been held to assess the effectiveness of opportunistic visual oral screening. This might include:
 - i. an oral cavity check as part of a more general health check;
 - ii. setting up of a dedicated *head & neck* clinic every 3-4 months to which over 50s in high risk groups are invited;
 - iii. posters in pharmacies offering mouth checks for ulcers, although this will require training of pharmacists in conducting these.
- b. Action should have been taken with the manufacturers of products designed for self-medication of oral ulcers and related conditions for the carton to carry a clear health warning about oral cancer. This will need to be managed carefully to avoid large numbers of the “worried well” overwhelming services.

13. Screening of the larynx or pharynx would only be possible by endoscopy and there will be no evidence to support screening in high risk communities by 2015.

14. There is no evidence that the indiscriminate introduction of ultrasonic scanning of *thyroids* would improve the early identification of high risk cancers. It would over-diagnose clinically insignificant swellings and biologically insignificant thyroid cancer. Patients and their families who may have a familial form of *thyroid* cancer should have timely access to a clinical genetics service, thyroid screening and, where appropriate, screening for other associated endocrine disorders.

15. In the next 5 years there will have been a move to develop the genetic profile of *head & neck* and *thyroid* cancers but the clinical impact by 2015 is uncertain.

Raising Awareness / Improving referral

16. Raising awareness needs to be done in a responsible way to avoid flooding secondary care with people at very low risk of *head & neck* or *thyroid* cancer. For example, before promoting awareness of *thyroid* lumps there needs to be agreement on how to manage the worried well without swamping clinics and/or radiology. Awareness messages should encourage people to get neck lumps checked by a doctor but should also reassure them that most lumps will turn out to be benign due to the rarity of *thyroid* cancer.

17. By 2015 the Oral Cancer Awareness Week should have been extended to cover all *head & neck* cancers. Specific consideration needs to be given to targeting non English speaking communities, those in lower socio-economic groups and younger people at risk of HPV-driven malignancies.

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18. The NICE GP referral guidelines are not particularly helpful to GPs and need updating (particularly for *thyroid* cancer where information on neck lumps is disputable and where primary care clinicians do not necessarily realise that they should not request ultrasound prior to referral). NICE should convene a group to address this. The revision should focus on the perspective of primary rather than secondary care and consider mechanisms to enforce its implementation, e.g. should radiology staff refuse or triage requests for ultrasound of neck lumps?
19. There is some doubt as to whether GPs make sufficient use of such guidelines for them to be useful and whether or not they can be expected to have sufficient knowledge to pick up potential cases of *head & neck* or *thyroid* cancer early enough. An alternative to updating the guidelines would be to include some key messages in a document that GPs are known to use a lot e.g. the British National Formulary (BNF).
20. By 2015:
 - a. work should have been undertaken, potentially through the National Awareness and Early Diagnosis Initiative (NAEDI) to identify the best way to alert GPs and patients to signs and symptoms of cancer (including *head & neck* and *thyroid* cancers). One possible strategy which is in line with the move towards empowerment of patients is to design, with active patient input, a web resource to alert people to the signs and simple referral criteria for *head & neck* and *thyroid* cancers.
 - b. GP referral guidelines should be updated if it is agreed that they continue to have a role to play. Either way the GP role in supporting cancer diagnosis will continue and needs to be supported.

Diagnostics

21. By 2015:
 - a. Neck lumps should be first assessed by anatomical site-specific specialists to agreed radiology and pathology standards. This may then lead to a discussion as part of a *head & neck* cancer, *thyroid* or other MDT once diagnosis of malignancy has been established. In some Trusts staff may work together in a *head & neck* and *thyroid* clinic or there may be separate clinics. Either way the clinics should be run by surgeons with special interest in these areas and the *head & neck* clinic should have links to haematologists/oncologists with a special interest in lymphoma;
 - b. staff should only assess neck lumps as part of a MDT, this includes consultant ENT, plastic and maxillofacial surgeons, nuclear medicine physicians and endocrinologists;
 - c. there should be a single common pathway within each trust for assessing *thyroid* swellings but professional agreement will be needed to support this;
 - d. there should be referral guidelines in place for patients found to have *thyroid* abnormalities incidentally on PET performed for other reasons e.g. staging lung cancer; and incidental lesions found on neck ultrasound (usually carotid artery assessments);
 - e. all *head & neck* and *thyroid* cancer histology should be double reported by specialist pathologists to avoid cancers being reported as benign by non-specialists. This is particular important in the case of salivary gland

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malignancies as these are particularly prone to misdiagnosis. Standard application of agreed international criteria for the diagnosis of thyroid cancer would be beneficial;

- f. it would be useful to have agreement on which TNM revision is best for *thyroid* cancer to ensure accurate and consistent staging.
- g. there should be increased numbers of trained specialist *head & neck* pathologists (inc. cytopathologists) and radiologists and the latter need to be empowered to request all the tests needed to confirm a diagnosis without going back to the referring consultant.
- h. National standards for HPV testing of biopsy samples from oral and oropharyngeal malignancies should be developed and implemented.

Treatment

22. New therapeutic agents in development (a number of which are in clinical trials in the UK) are likely to impact on practice by requiring surgical and non-surgical oncologists to work in a highly co-ordinated fashion, building on the MDT working that already exists. Present therapeutic regimens require 'pauses' between, for example, surgery and PORT. However, it is possible that in the future many *head & neck* cancer patients could move swiftly from induction chemotherapy to surgery to post-operative chemotherapy before radiotherapy and finally maintenance therapy. This will first require robust clinical trials to provide evidence of the efficacy of this protocol. If the results of trials support implementation, provision of facilities which allow close co-ordination of multidisciplinary care will become an increasingly important part of cancer management.
23. By 2015:
 - a. MDT working should be strengthened – all decision-making, treatment and research should be MDT driven;
 - b. work should take place on different cancers to identify where packages of care are needed with multiple treatments - a time limit should then be identified for the whole treatment package to be completed (subject to exemptions etc);
 - c. there should be an improved IT interface, for example to enable access to up to date pathology reports which will impact on treatment choices, etc;
 - d. all MDTs should apply agreed standards of quality assurance to established therapies (radiotherapy and surgery) and imaging protocols.
24. By 2015 the group expect for *head & neck* cancers:
 - a. more targeted therapies to be available – this will need more sophisticated molecular and immunohistochemical profiling of cancer specimens (eg. EGF receptor status) – this will have resource implications for pathology departments;
 - b. more complex advanced radiation techniques, such as IMRT, will have been adopted into widespread clinical practice;
 - c. trials underway of dose-reduction in treatment of non-smoking patients with HPV-related oral and oropharyngeal cancers!;
 - d. evidence to support increased use of sentinel node biopsy is unlikely to be available – studies will still be on-going;

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- e. *head & neck* surgery performed only by those with an established track record in ablative and reconstructive *head & neck* surgery;
 - f. the involvement of neurosurgeons in the treatment of patients with base of skull or craniofacial malignancy.
25. By 2015 for *thyroid* cancer the group expects to see:
- a. more evidence (incl. a Cochrane review) should be sought to support (or otherwise) the use of recombinant human TSH in high risk groups - existing trials focus on low risk patients;
 - b. an increased number of patients offered node dissection as part of their surgery. This will need additional theatre time and should be performed only by specialist surgeons as the risk of complications after node dissection is greater than for thyroidectomy alone;
 - c. patients with, or at risk of, medullary *thyroid* cancer treated in a small number of centres (maximum of 1 per network) with these centres offering prophylactic thyroidectomy in appropriate cases after gene testing;
 - d. surgery for children with *thyroid* cancer provided by specialist (high volume) *thyroid* surgeons within the paediatric care setting as there are few if any paediatric surgeons performing high volume *thyroid* surgery – there is good evidence that children are at greater risk of complications from *thyroid* surgery than adults.
 - e. no increase in minimally invasive surgery for *thyroid* cancer – this approach is still considered experimental and must be subject to careful appraisal, audit and research.
 - f. a recognition of endocrine surgery (which includes *thyroid* surgery) as a subspecialty of general surgery – this will give formal recognition of the specialty, better accreditation and appointment of certified competent surgeons resulting in a better provision of services and may reduce the complication rate including long term voice and parathyroid damage and the need for further surgery
 - g. *head & neck* MDTs being involved in treatment planning and treatment (particularly site-specific surgery) for *thyroid* cancer patients if anatomically relevant.
 - h. the involvement of *thyroid* clinical nurse specialists in care who have specific training and experience in the area (rather than only experience in *head & neck* cancers).
26. There are some potential cost savings in *head & neck* and *thyroid* cancer services:
- a. opportunistic visual oral screening could have potential cost savings in terms of earlier diagnosis and less need for complex treatment and/or palliative treatment although this could increase the referral of the worried well;
 - b. pre-operative diagnosis of *thyroid* cancer will save costs by reducing the number of clinic visits and therapeutic interventions for *thyroid* cancers. Appropriate first surgery (which may in some cases be guided by frozen section) will reduce the need for further operations (completion thyroidectomy, additional surgery for nodal metastases). Appropriate use of radioiodine will reduce the number of patients who need to be treated for recurrence;

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- c. there is a tendency to over-treat some low risk *thyroid* patients – this may increase morbidity when there is no potential to demonstrate improved survival;
- d. re-organising follow up into groups with stratified risk of recurrence has the potential to release savings e.g. giving patients more information and the ability to book reviews might lessen the burden of follow up.

Supportive & Palliative Care

27. Pre-treatment and post-treatment support is vital for patients with *head & neck* and *thyroid* cancers. This should include access to appropriate counselling, patient support groups, speech & language therapists (SLTs), dietitians and dental assessments. There is now robust evidence of the need for psychological support for both *head & neck* patients and their carers. A psychologist should be considered a core member of the MDT. For *thyroid* patients, where prognosis is likely to be good, it is important that counselling reflects the risk and that anxiety levels are not inappropriately escalated. For patients with oral cancer (and some other *head & neck* cancers) it is highly likely that there will be a need for restorative dental work including dental implants. Facial rehabilitation is highly complex and also requires the highly specialised skills of maxillofacial prosthetics and technologists (MPTs) to achieve good results. More trained restorative dentists with skills in maxillofacial prosthodontics and support from hygienists will be needed by 2015 along with more MPTs – input from these groups are integral to returning patients to an acceptable quality of life and social integration.
28. Macmillan nurses are key links for *head & neck* cancer patients co-ordinating care from the GP, allied health professionals and the MDT as required. They play less of a role in the management of *thyroid* cancer patients unless the cancer is locally aggressive.
29. The shift to specialisation in bigger centres could mean that the capacity for specialist local longer term support (especially from allied health professionals) would be stretched as there are workforce shortages in this area.
30. There should be clear evidence-based national and local guidelines for the appropriate selection of methods of tube feeding via percutaneous gastrostomy (PEG) or nasogastric tube (NGT) for patients undergoing chemoradiation treatment for *head & neck* cancer.

Follow up

31. By 2015 action needs to have been taken to:
- a. stratify the risk of recurrence of *head & neck* and *thyroid* cancer as this will help to determine the appropriate level of support required and avoid an exponential increase in unnecessary follow-up attendances;
 - b. develop shared local protocols for follow-up between MDT, primary care and patients including easy access to support as and when needed – the long term follow up of *thyroid* cancer patients classed as low risk should be carried out by appropriately trained and experienced *thyroid* clinical nurse specialists or by the GP if deemed appropriate by the MDT and if the GP and patient are

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- given the relevant knowledge and education to be aware of the signs and symptoms of possible recurrence and late effects of treatment;
- c. educate patients moving to follow up for *head & neck* or *thyroid* cancer (and their GPs) about what to look out for in terms of a possible recurrence or late effects of treatment;
- d. ensure all patients have access to an appropriately trained CNS – they have a key role to play in ensuring back up care within the community and liaising between secondary and primary care;
- e. ensure all patients are informed of support organisations available nationally and locally;
- f. improve the quality of letters to GPs, ensuring that they are provided with the right information to support patients in the community;
- g. additional packages of support should have been developed to support patients at the point of discharge and provided long term.

32. Patient support groups should be fully involved in developing follow-up protocols.

Service Configuration

33. Concentration of expertise and progression towards integrated management throughout the pathway is integral to best patient care. Issues of workforce and resource must be addressed.

34. Some centralisation will also be needed by 2015 for specific patient groups such as those with base of skull cancers and some sarcomas. Patients with Multiple Endocrine Neoplasia and other familial *thyroid* cancers should be treated in a smaller number of specialist centres. Discussions about the funding and provision of these future services must take place as a priority with implementation by 2015.

Underpinning programmes

Workforce & Training

35. Increased numbers of physicists and therapy radiographers will be required in order to support timely delivery of standard and more advanced radiation therapies such as IMRT.

36. The role of the CNS is central to support *head & neck* cancer patients. AHPs also have a key role to play in rehabilitation. Such posts are perceived as soft targets when budgets are tight. By 2015:

- a. there should be a means to measure the impact of CNSs and AHPs on patient experience to demonstrate to budget holders the key role they have to play in the care of these patients;
- b. implementation of the NCAT rehabilitation pathways and investment in the AHP workforce will mean that all *head & neck* cancer patients will have support from specialist AHPs, particularly speech & language therapists and dietitians, throughout their pathway of care. At present some groups of patients (e.g. some maxillofacial cancer patients) do not receive this care and others do not receive this service at all stages in the pathway. An increase in specialist AHPs will be needed to accommodate this.

37. By 2015:

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- a. all *thyroid* cancer services should have support from a CNS – at the present time the CNS's time is prioritised on *head & neck* cancer patients who tend to be older with more co-morbidities. An increase in CNS numbers will be needed to accommodate the needs of high risk *thyroid* cancer patients in particular;
- b. new consultant appointments must take into account the need to provide a specialist service for patients with benign and malignant *thyroid* disease. It is possible that in the future patients with *thyroid* disease, and therefore *thyroid* cancer, will be treated in greater numbers by fewer surgeons in fewer centres. Medical directors should ensure that *thyroid* surgery is only undertaken by those designated to carry it out.

Information

38. By 2015:

- a. Acquisition, reporting and analysis of robust audit data is essential and needs to be prioritised. Data collected should include patient experiences and information on quality of life after treatment. It should be mandatory for all MDTs that manage *head & neck* cancer patients to submit complete data (including co-morbidity, staging and performance status) on all cases to an agreed national format audit. Trust identifiable risk-adjusted performance and outcome data based on this information should be published. Seamless record linkage to allow clinical and clinical trial databases to be linked to a common stem should be developed as a priority measure. Data collection and analysis needs support including workforce and resource;
- b. an equivalent audit for *thyroid* cancer needs to be up and running – the possibility of further developing the already well established BAETS database for this purpose should be explored;
- c. patient experience surveys need to be embedded into services and inform how services are commissioned;
- d. patients should have ready access to a range of information including about new treatments and participation in clinical trials. This should include signposting to support groups and charities.

Research

39. The biological and population diversity of *head and neck* cancer and lack of robust data on age, site and disease characteristics (biological) data carries a risk that treatments might be directed where they are futile. To underpin future therapies for both *head & neck* and *thyroid* cancers, robust cohort studies, powered to guide future therapeutic strategies, will constitute value for money and the recent award to enable such a study is welcome. The pathway for *head & neck* cancer is relatively short compared to other cancers. It must be remembered that *thyroid* has a longer disease course and trials in this area require long term funding.
40. In addition a range of trials need to be established to examine key issues and questions and these should be co-ordinated by and/or involve regional and national centres. For example research should be commissioned via the NCRI/NCRN:
 - a. into the long term effects of chemo-radiation treatments for upper aerodigestive tract cancers such as survival, morbidity and quality of life;

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- b. to determine the cost effectiveness of the use of Thyrogen in the treatment and follow up of patients with *thyroid* cancer.

41. More generally:

- a. Patients should be encouraged and empowered to allow their data to be used in research and to become involved in clinical trials. They should be involved in research priority setting and the design of research from the earliest stages to ensure studies and trials are acceptable to patients and that design is optimised for inclusivity and minimal burden on patients.
- b. quality of life and functional issues (in addition to usual measures such as disease free progression and survival) should be built into all trials;
- c. NICE should be involved in the design of trials to ensure that they deliver the information that NICE is likely to need if a treatment is assessed;
- d. there should be more collaborative RCTs across centres in England and better co-ordination between investigators and networks. For example:
 - i. if networks are not prepared to sign up to a trial they should feedback to investigators why that is;
 - ii. once signed up then networks should make a full contribution to the trial;
 - iii. the default should be that all networks commit to take part in good quality clinical trials.

Improving Outcomes: A Strategy for Cancer Stakeholders
December 2010