An audit of clinical resources available for the care of head and neck cancer patients in England

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Abstract

Objective: To undertake a postal survey of cancer networks to define the services available for the diagnosis, treatment and support of patients with head and neck cancer in England.

Findings: Thirty-four cancer networks are now responsible for the delivery of head and neck cancer services in England and 52 cancer units responded to our questionnaire. Multidisciplinary team working was evident in all centres. However such team working was not always fully staffed, especially in areas of national staff shortages such as pathology, radiology, dietetics and speech therapy. Rapid referral pathways were present for initial assessment of patients but clinically significant delays were identified in the provision of complex investigations, in access to intensive care beds and for oncological care – especially radiotherapy.

Conclusions: Major changes in service configuration are likely to be required if the current national targets of time to diagnosis and treatment are to be met.

Key words: Delivery of Health Care; Health Resources; Head and Neck Neoplasms; Radiology; Pathology; Radiotherapy; Interdisciplinary Communication

Introduction

Head and neck cancer is uncommon, with laryngeal cancer being the 14th most common cancer in males and even less common in females. However, all sites are showing a rising incidence not always in association with alcohol and smoking. The National Statistics Office and The National Cancer Register (England and Wales) documented 6863 cases of malignancy in the head and neck region in 1998 with the commonest single sites being the larynx and oral cavity, which is an incidence of just over 100 new cases per million per year. People living in deprived areas are more likely to get head and neck cancer, and are more likely to die from their disease than people living in affluent areas.

In 1995, the Calman-Hine Report set out the key principles governing the provision of high quality care and highlighted the importance of specialist multidisciplinary care teams.⁴ This report also heralded the development of cancer networks which brought together all of the services and organizations needed to provide high quality care. In 1999, cancer was declared to be a priority by the Prime Minister, and this led to the publication of the NHS Cancer Plan in 2000.⁵ This was the first ever comprehensive strategy to tackle cancer in England and it encompassed prevention, screening, diagnosis,

treatment and care.⁶ Importantly, the Cancer Plan committed substantial financial resources and recognized the need to invest in the cancer workforce and in equipment and modern treatment. The subtitle of the NHS Cancer Plan was 'A Plan for Reform' and the reforms required the establishment of:

- (1) 34 cancer networks across England;
- (2) around 1600 specialist multidisciplinary cancer teams;
- (3) improvement support by the Cancer Services Collaborative:
- (4) clear standards and a peer review quality assurance programme.

Following the Calman-Hine Report, the Department of Health commissioned a series of evidence-based 'Improving Outcomes Guidance' (IOG) reports related to the major cancers, which include breast, colorectal, lung and gynaecological malignancy. These guidance reports have been used to set measures for cancer care, and individual services are currently being assessed against these measures through a programme of peer review appraisal visits.

Head and neck cancer has always been practised

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in the environment of a multidisciplinary treatment team (MDT) in the UK and in most countries worldwide.⁷ The British Association of Head and Oncologists made recommendations, previously, about service provision improvements in 2000.8 Recent evidence has supported the concept that assessment by an MDT correlates strongly with improved patient survival. A previous audit, conducted in 2000, identified 108 teams but also identified 11 sole practitioners treating head and neck cancer in the UK.¹⁰ 2004 saw the publication of the long awaited Guidance on Cancer Service: Improving Outcomes in Head and Neck Cancer. 11 This document recognised that head and neck cancer is a heterogeneous group of diseases - patients present with many underlying health problems that require a large team of experts, both medical and non-medical, to provide treatment and dedicated patient rehabilitation over the long term - and admitted that the NHS provision for these patients is inconsistent across the country. Also treatment delivery has changed over recent years along with the reorganization of services for other cancer services.

It was against this background that a questionnaire/survey was performed, in 2004, of all Network Lead Clinicians in Head and Neck Cancer in the 34 Cancer Networks in England. Questions were then forwarded to the known local Lead Clinicians of the Multi-Disciplinary Head and Neck Teams in their network.

Material and Methods

The names and contacts of all Network Leads in Head and Neck Cancer in England were identified through the Cancer Services Collaborative 'Improvement Partnership'. However, the exact number of functioning Head and Neck Cancer Teams in England remains unknown.

A questionnaire was compiled by the two appointed National Clinical Leads for Head and Neck Cancer using their clinical knowledge and the steps and points they believed to be key in the management pathways of a patient with head and neck cancer. One questionnaire was circulated to all 34 network leads to establish the services and resources in each network. A 'second' questionnaire was circulated to all known head and neck teams in the UK, and was divided into several sections seeking information about the perceived care pathway for each head and neck patient, the referral process, diagnostic imaging, MDT meetings, membership of the MDT, pre-treatment assessment, treatment and waiting times, specialist head and neck nurse availability, follow-up policy and the improvements anticipated. The questionnaires were sent out in November 2003 and repeated several times; the survey closed in June 2004. A copy of the second questionnaire and raw data can be seen in Appendix A.

Results

Network Lead Clinicians

Of the 34 Lead Clinicians for the Cancer Networks contacted only 21 responded (62 per cent). The median number of Head and Neck Cancer MDTs or 'Teams per Cancer Network' was two (range: one to five) and was unknown in two. Twenty MDTs were discussing thyroid cancer as part of the Head and Neck MDT meetings, with only five having a separate thyroid cancer MDT. Only one Network Lead was receiving any sessional payment for their role.

When asked about their priorities and strategy changes five did not list a priority but, of the remaining responses, more than 95 per cent were concerned with rationalizing the service – either the MDTs or the service in general. Eighty per cent expressed concern about audit and data collection, and the majority felt that the imminent publication of the Head and Neck Improving Outcomes Guidance would help to solve local difficulties. Other areas of current activity in the Cancer Networks were the production of clinical guidelines, participation in research trials, patient information, and quality of life and health promotion.

Trust clinical leads

Fifty-two clinical leads from within separate trusts returned questionnaires. It is not currently known how many Head and Neck Teams operate around the UK but the number is estimated at 55: if this is true then our response rate is over 90 per cent.

Forty nine of the 51 clinical leads reported that there was a 'fast track referral form for GPs' (96 per cent) and in 64 per cent this was a common form agreed across the network. With regard to diagnostic services all clinical leads responded to the question of availability of radiology and pathology in their hospitals.

Radiology

Urgent computed tomography (CT), magnetic resonance imaging (MRI) and ultrasound scans were available within a median of seven to 10 days (range: one to 42), but the waiting time for routine radiology investigations for non-urgent referrals was a median of four weeks (range: two to eight) for CT scanning and 10 weeks (range: four to 28) for MRI (Table I). Positron emission tomography (PET) or PET/CT scanning was not widely available locally for most centres, but a number of responses indicated that patients could be referred to a specialist unit for the test.

Pathology

Pathology reporting for urgent specimens was a median of four days for a biopsy (range: one to 10), and seven days for radical resection specimens (range: two to 20). Non-urgent pathology specimens took from seven to 28 days to be reported, median was 10 days (Table I). In 96 per cent of clinics the diagnostic service of ultrasound, CT-guided fine-

TABLE I
WAITING TIMES FOR INVESTIGATION

	Urge	nt	Routin	e
	Median time	Range	Median time	Range
CT	6 days	1–14 days	6 weeks	1–12 weeks
MRI	7 days	2–14 days	7 weeks	1–24 weeks
Ultrasound	7 days	1–21 days	5 weeks	2–10 weeks
PET	3 weeks	1–6 weeks	Not available	
Path Bx	4 days	1–10 days	7 days	2–14 days
Path Def	4 days	1–10 days	10 days	7–28 days
FNAC	3 days	1–14 days	N/R	•

CT = computed tomography; MRI = magnetic resonance imaging; PET = positron emission tomography; PAT = pathology biopsy; PAT = pathology resection; PAC = fine-needle aspiration cytology; PAT = no response recorded

needle aspiration or core biopsy was available. A 'rapid access lump clinic' was available in 48 per cent of the 52 clinics. Many remarked that they conducted a 'lumps clinic', and that patients were examined by clinicians and, where appropriate, were further investigated by needle biopsy at the same time.

The multidisciplinary team clinic/meeting

More than 82 per cent responded that the MDT clinic/meeting was held in their own hospital with only 10 (17 per cent) requiring to travel to attend such meetings. The majority (79 per cent) held their MDT meeting weekly, 19 per cent held a meeting fortnightly, and one held their meeting three out of four weeks per month.

Fifty-seven per cent of MDT meetings were held within normal clinical working hours (9 am–5 pm) with the remaining being held in the early morning (8–9 am). Twenty-two per cent were held at 'lunch time'. The majority held their meeting just before their normal clinic. The duration of the meeting was less than one hour in 60 per cent of cases with no record being registered by four. However, 18 per cent of MDT meetings were reported to last more than two hours.

The numbers of patients discussed on average per clinic also varied greatly with the majority (70 per cent) discussing 10 or fewer patients. Three clinics reported that they discussed more than 20 patients. Two clinics did not report the average number of patients discussed. The majority, 36 of 51 clinics (71 per cent), had a suitable room available for discussions, with only three clinics having no room or unhappy with the facilities that were provided.

Core membership

Fifty-one of fifty-two (98 per cent) reported on the composition of membership of their MDT. The membership could be summarized as comprising medical members (clinical oncologists, otolaryngologists and oral and maxillofacial surgeons, pathologists and radiologists) and non-medical members (dieticians, speech and language therapists, clinical nurse specialists, ward-based nurses, and MDT coordinators). The actual membership data are summarised in Appendix A.

It would appear that while there is a need for other non-core specialists to attend the MDT their attendance was patchy. For example plastic surgeons were available only 58 per cent of the time, palliative care specialists only 25 per cent of the time, and restorative dentists (8 per cent), prosthetics (6 per cent) and data managers (22 per cent) even less frequently. The complete complement of desirable non-core team members is currently some way off owing to lack of availability of such staff in many centres.

The type of clinical problems discussed at MDT meetings varied from 'all newly diagnosed' to 'all patients attending clinic on that day' (Appendix A). However, it would appear prudent that patients who had a significant change in their clinical status should be discussed as well as patients who had completed any stage of their treatment such as surgery and/or radiotherapy. The discussion of patients receiving palliation would clearly be improved if there was a greater presence and availability of 'palliative experts' to attend each meeting.

An identifiable person coordinated the process of the MDT in 71 per cent of clinics leaving a significant minority having no coordinator support. In these clinics, booking of patients and organization of the MDT were performed either by the consultant or the consultant's secretary (the majority of cases), or by nurse specialists or pathologists. Fifty-four per cent stated that they had organizational problems with their MDT process, and cited either lack of a coordinator or, more commonly, lack of money or time, or of the presence of a pathologist, a radiologist or an oncologist.

Pre-treatment assessment

It is recommended that all patients with head and neck cancer should be evaluated and offered counselling in the pre-treatment stage, regardless of whether the treatment intended is surgery or radiotherapy. On current findings it would appear that the majority of patients are seen by a clinical nurse specialist (80 per cent), followed by a dietician (69 per cent), a speech and language therapist (46 per cent) and least of all by a specialist dentist (26 per cent) (Appendix A). Many responses indicated that the possibility of being consulted by such specialists depended on the tumour site; thus a patient who was to have a laryngectomy would see a speech and language therapist whereas a patient with an oral cavity tumour was more likely to see a specialist dentist. However, the numbers of such specialists available within the head and neck clinical practice appear sparse in comparison to the clinical

Treatment

Ninety-four per cent of respondents declared that they in general did not have any difficulty with obtaining beds for their patients' admission to hospital. However, there appeared to be problems with securing theatre sessions for surgery in 46 per cent of cases as well as difficulties in obtaining a bed in the intensive care unit (70 per cent).

Surgical services

Operating facilities to undertake head and neck surgery were available for the 'simple' and 'complex' procedures in the majority of centres, whereas facilities for undertaking skull-base surgery, no doubt reliant on neurosurgical expertise and ability to secure an intensive care bed, were limited nationally. Of interest was that two clinical practices were not equipped to undertake voice restoration after laryngectomy!

Oncology services

Only 60 per cent of clinics reported that their patients were likely to be able to commence radiotherapy as primary treatment within six weeks of diagnosis or surgery. Forty per cent of centres had radiotherapy waiting times of greater than four weeks and 10 per cent of greater than 12 weeks (Figure 1). Five clinicians did not record their anticipated time to commence radiotherapy locally for a diagnosis of head and neck cancer. The majority (90 per cent) reported that there existed a joint clinic with an oncologist, and that all patients were seen jointly before radical surgery to discuss treatment.

Specialist nurse for head and neck cancer

The majority (78 per cent) reported that they had a specialist head and neck nurse. The remainder did not, and one MDT reported that they had a shared nurse specialist. Twenty-eight specialist nurses were whole time equivalents (WTE) with six having less than a WTE contract. The availability of these nurse specialists to thyroid cancer patients varied, with 25 of 38 centres having access and 13 not having this facility. Three teams did not respond.

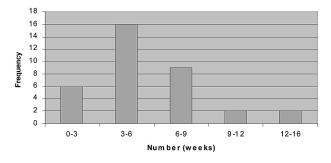


Fig. 1

Waiting times for radiotherapy for head and neck cancer in England (the recommended maximum wait is six weeks. https://doi.org/10.1258/0022215054516214 Published online by Cambridge University Press

Follow-up patient policy

The majority followed the recommendations of the British Association of Otolaryngologist–Head and Neck Surgeons (BAOHNS)' consensus document by arranging follow up at four to six weeks for the first year, eight weeks for the second and third years, three months for the fourth year, six months for the fifth year, and yearly follow up thereafter. The availability of staff (particularly dieticians and speech and language therapists) for long-term follow up was variable, but those who had seen the patients at diagnosis or during active treatment either remained available to each patient for the 'rest of their life time' or at least were willing to have such patients re-referred when required.

Improved outcomes guidance

When asked to comment on the improvements that would be expected from the publication of the Head and Neck IOG, the responses could be divided into improving structure (25), staffing resources and recruitment (13), capacity (eight) and miscellaneous (four). The comments on structure related to the possible threats and solutions that the IOG may bring to a current well structured local MDT which would be considered 'too small', or the fear that there may be 'possible forced amalgamations' of small MDTs to 'economise' the local resources. The majority of responses anticipated that there would be a requirement to help solve the centralization issues of the cancer services and, while some were enthusiastic that the IOG would close down small units and force a more focussed approach, others felt that 'small was good as long as it was efficient'. Comments concerning staffing were those that have been recognized for some time given that there is a country-wide shortage of radiologists, pathologists and radiotherapists. There were also comments concerning the lack of available restorative dentists, speech and language therapists, psychologists and clinical nurse specialists, as well as the need for dedicated data managers. The issue of improved capacity was mainly with regard to the surgical services and the availability of beds, operating theatres and post-surgery intensive care support. The miscellaneous group of responses were on genuinely wider issues, and included comments such as the impression that 'the Primary Care Trusts do not understand head and neck cancer issues' through to the fear that competing targets result in clinical chaos as well as the feeling that we should aim at 'improving public education'.

Discussion

This audit of NHS provision of services for head and neck cancer patients is only the second¹⁰ such national survey to be reported in Britain as far as we can ascertain. The purpose of the survey was to highlight the extent of head and neck cancer provision across England, where there are in the region of 55 centres currently treating such patients.

The audit has highlighted a number of areas of

excellent practice, such as the widespread practice of multidisciplinary care and the dedication of specialist teams for head and neck cancer patients. The MDT methodology is clearly well established nationally although the running of such a service is time and resource intensive. The delivery of the main components of treatment (surgery and radiotherapy) is in place although the provision of some of these services falls below acceptable standards in a minority of cases. The need for improvement in radiotherapy, radiology and histopathology services is well recognized across all of the cancer network, not just the head and neck cancer services. 12,13 In particular, the lack of availability of intensive care and surgical beds for complex cases and the unacceptable waiting times for radiotherapy in some regions of the country are known, and are mirrored in the findings for cancer treatment on a national basis.12

- This is a survey of cancer networks to define the services available for the diagnosis, treatment and support of patients with head and neck cancer in England
- Multidisciplinary team working was widespread but was not always fully staffed especially in areas of national staff shortages
- Rapid referral pathways were present but clinically significant delays were identified in the provision of complex investigations, the access to intensive care beds and for oncological care
- The paper concludes that major changes in service configuration are likely to be required if the current national targets of time to diagnosis and treatment are to be met

Another area of deficiency is the provision of supportive services for the management of head and neck cancer patients. At diagnosis there are delays due to limited availability of CT and MRI scanning, and delays in processing pathological material, both of which result in the time to treatment being delayed. Against this background, and given the complexity of the initial assessment of some head and neck cancer patients, the target of 62 days from referral to treatment is unlikely to be met.

Head and neck tumours typically cause problems with swallowing and speech, and so dieticians and speech and language therapists are key members of the team delivering care. However they are not usually part of the oncology, ENT or maxillofacial departments in the UK, and are funded as separate departments within trusts. This means that the provision of these services for cancer patients is patchy and is often dependent on local facilities, priorities and workload.

Current guidelines suggest that thyroid cancer patients should be managed as part of the head and neck MDT or as an 'associated multidisciplinary team to the head and neck service'. This appears to be current practice as thyroid cancer is frequently operated on by otolaryngologists, but it is clear that endocrine surgeons or general surgeons with thyroid practices often fall outside these MDTs. This area of practice needs addressing in order to ensure that the best service for these patients is provided.

The recent publication of the Improved Outcomes Guidance for head and neck cancer is to be followed by a call for each centre treating head and neck cancer to produce a plan for the development of their service such that they come into line with the guidance. There are issues of centralization and service re-organization, but it is our view that big is not always best, as some of the MDTs in large conurbations would be unable to cope with the workload if head and neck cancer therapy were to be concentrated into a few large centres. It does not appear that a large investment is likely, and this needs to be recognized early and taken into consideration when planning service re-organization.8 The realization of the IOG will likely involve the reorganization of services, provision of fully compliant MDTs and analysis of care pathways to attempt to meet the targets set nationally.

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Mr P J Bradley takes responsibility for the integrity of the content of the paper.

Competing interests: None declared

Appendix A

Survey of Facilities Available for Provision of Head and Neck Cancer Service

Questions presented and responses summarised

N/R = No response recorded

1 REFERRAL		
Do you have a fast track		
for GPs?	Yes (49/51)	96%
If yes is this a common form	, ,	
agreed across the network?	Yes (32/50)	64%

2 DIAGNOSTIC SERVICES: PATIENT ACCESS TIME (see Table I)

Do you have access to U/S or

CT-guided biopsy? Yes (50/52) 96%
Do you run a rapid access lump clinic? Yes (25/52) 48%

3 The multidisciplinary team (MDT) meeting

Do you hold MDT meeting

at your hospital? Yes (43/52) 82.7% If no do you travel to another hospital? 10/49 How often is the MDT meeting held? Weekly 41/52 79%

Fortnightly 10/52 19%
Three weeks every four weeks 1/52

Time of meeting:

08.00	2	11.00	1	15.30	1
08.15	4	13.00	1	Afternoon	1
08.30	10	13.15	2		
08.45	1	13.30	7		
09.00	10	13.45	1		
09.15	1	14.00	3		

Duration of meeting:

30 minutes	2	2 hours	6	
45 minutes	8	2–3 hours	2	
1 hour	21	3 hours	1	
1.5 hours	8	N/R	4	
MDT clinics	were for	1 hour or less:	31/48	60%

Do you have a suitable room?

Yes 36/52 No 2/52 Partially 1/52 N/R 14/52

Do you have a MDT coordinator?

Yes 33/52 No 16/52 Part time 1/52 N/R 2/52 If no who organizes the MDT?
Consultant 5
Con Secretary 5
Clin Nurse Spec 2
A secretary 2
Pathologists 2

4 CORE MEMBERSHIP

Clinical Oncologist	50/51	98%
Otolaryngologist	47/51	92%
Maxillofacial Surgeon	47/51	92%
Plastic Surgeon	29/50	58%
Pathologist/Cytologist	44/51	86%
Radiologist	47/51	92%
Medical Oncologist	4/51	8%
Restorative Dentist	4/51	8%
Dietician	38/51	74%
Speech & Language Therapist	42/51	82%
Clinical Nurse Specialist	42/51	82%
Nursing staff from Ward	36/51	71%
Palliative Care Physician/Nurse	13/51	25%
Clinical Psychologist	3/51	6%
Occupational Therapist	2/51	4%
Prosthetist	3/51	6%
Team Secretary	6/51	12%
Data Manager	11/51	22%
MDT Coordinator	40/51	78%
Others		

What categories of patients are discussed at MDT meeting?

"All new" 46 Current with problems 11 32 Change of status "Difficult cases" 20 17 Palliative All 1st follow up 2 13 All post-surgery All post-radiotherapy 5 3 "All patients attending"

On average how many patients are discussed at each MDT meeting?

>5 14 6-10 21 11-15 7 16-20 5 21-25 1 <25 2 N/R 2

10 patients or less: 70%

Recording of Decisions?

Hospital Notes 30 Proforma 12 Electronic 1

63%

Communication with Primary Care?

Letter 37 Fax 1

Do you have a major organizational problem with your MDT?

Yes 24/52 No 28/52 54%

Give reason why there is a problem?

Radiology	5
Pathology	6
Radiation oncology	3
Admin support	2
MDT coordinator	9
No data collection	2
Not resourced/competition for MDT time	8

Are thyroid patients discussed at head and neck MDT meeting?

Yes 28/52 54% No 24/52

5 PRE-TREATMENT assessments

What percentage of patients have a pre-treatment assessment?

assessificate.				
	100%	>75%	>50%	>25%
Clinical Nurse				
Specialist	41/51 (80%)	3/51	2/51	3/51
Specialist	, ,			
Dentist	9/35 (26%)	12/35	5/35	19/35
Dietician	33/48 (69%)	5/48	5/48	7/48
Speech &	, ,			
Language				
Therapist	21/46 (46%)	8/46	12/46	5/46
Dentist Dietician Speech & Language	, ,	5/48	5/48	7/48

6 TREATMENTS:

Problems with beds?	No 28	Yes 2	N/R 21
Do you have access issues	with the	availab	oility of?
Theatre sessions	Yes 2	3	No 28
Intensive care beds	Yes 3	3	No 18

Do you have facilities in your Trust for:

Head and neck cancer ablation

& reconstruction	Yes	47	No	5
Complex reconstruction	Yes	42	No	10
Skull-base surgery	Yes	20	No	32
Laser resection	Yes	48	No	4
Voice restoration	Yes	50	No	2

Oncology service

What is the typical waiting time from referral to starting radiotherapy?

1–3 weeks	2	6 weeks	9
2 wks	2	6–8 wks	10
3 wks	3	6–10 wks	2
3–4 wks	1	8 wks	2
3–6 weeks	1	12 wks	2
4 weeks	5	12–16 wks	2
5 weeks	1	N/R	5
4–5 wks	1		
4–6 wks	3		
4–8 wks	1		

Does your trust have a joint clinic with an oncologist? Yes 45 No 4

Are patients seen jointly before radical surgery to discuss treatment and allow for pre-schooling of adjacent radiotherapy? Yes 48 No 1 N/R 1

7 SPECIALIST HEAD AND NECK NURSE:

Do you have specialist H&N nurses?

Yes 35 78% No 9 Shared 1 If yes how many are dedicated to cancer?

> 1 WTE 6 WTE 28

Do thyroid patients have access to a specialist nurse? Yes 25 No 13 N/R 3

8 FOLLOW-UP POLICY

As per BAOHNS policy: 5 years' minimum

9 LONG-TERM FOLLOW-UP AVAILABILITY? **Majority (more than 50%) have:**

Clinical Nurse Specialist

Speech & Language Therapist

Dietician

Dental Hygienist

Nurse Practitioner

10 WHAT IMPROVEMENTS WOULD BE EXPECTED WITH THE PUBLICATION OF THE IOG?

(See Discussion)