

Head and neck cancer referral in England and The Netherlands: an international qualitative study of secondary care surgical specialists' views

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ABSTRACT

Background

One-year head and neck cancer survival in England has been reported as worse than that in the best-performing countries in Europe, despite 5-year conditional survival rates being similar, implying a later stage of presentation in England. One country with better 1-year survival rates is the Netherlands. There are many possible causes but one may be the system of referral from primary care to the specialist.

Aim

To study and compare the views of secondary care specialists in England and the Netherlands on their respective systems for the referral of suspected head and neck cancer from primary to secondary care and attempt to identify aspects that might have an impact on outcomes for head and neck cancer.

Design and setting

Semi-structured qualitative interviews of head and neck cancer surgical specialists in England and the Netherlands.

Results

Twenty-four specialists, 12 in England and 12 in the Netherlands, were interviewed about their national referral system for head and neck cancer. By far the most common theme was communication between primary care and specialists. Surgeons in England identified this as the aspect most lacking in the English 'two-week rule' system, whilst Dutch specialists felt strongly that the good communication that existed in their system was one of its best points. Other themes that emerged included varying views on the educational needs of primary care practitioners, criticism of 'tick box' referrals in England and the problem of managing large numbers of referrals that do not have cancer.

Conclusions

Overall, specialists in both countries identified good aspects of their respective primary care-specialist referral systems for suspected head and neck cancer. However, specialists in England strongly felt that the two-week rule/NICE guidance system could be improved with better direct communication between primary and secondary care and this in turn might improve speed of referral, the quality of referrals, reduce unnecessary referrals and assist with educating GPs. It is not clear whether such improvements would improve head and neck cancer survival rates but further research and piloting of such a system should be considered in England.

Keywords

Suspected cancer referral; head and neck cancer; fast-track cancer; international comparison

INTRODUCTION

There is a broad agreement that some cancer outcomes in England (and UK) are inferior to the European best, initially reported in the first 'EUROCARE' cancer studies¹. The fifth version of 'EUROCARE'² indicated that although UK improvements had been made, some outcomes remained inferior to the best in Europe. Many consider that the on-going relatively poor UK cancer outcomes are at least partly due to diagnostic delays resulting in a more advanced stage on diagnosis³.

Data from EUROCARE-5 indicate that for head and neck cancer UK 5-year conditional (on 1-year survival) outcomes compare well with the best in Europe, yet 1-year survival is still poorer than in several European countries⁴. One example is the Netherlands, where head and neck cancer 1-year survival for 2000-2007 was reported in Gatta's study to be 74.7% (95% CI 73.7-75.7) compared to 1-year survival rates in England of 70.3% (95% CI 69.7-70.9). 5-year conditional survival rates for the same period were very similar - Netherlands 65.7% (95% CI 64.1-67.5); England 65.6% (95% CI 64.6-66.6).

However, determining exactly why diagnostic delay occurs is a complicated problem for all cancers and probably has many components requiring different solutions^{5,6}. Furthermore, it is important that different cancer types are considered separately when attempting to determine the causes of diagnostic delay⁷. Many studies have attempted to identify factors causing delay in cancer diagnosis and the differences between developed European countries with comprehensive healthcare systems⁸. The International Cancer Benchmarking Partnership, initiated by the Department of Health in England⁹, has explored several possible causes of international variation in cancer outcome, including patient knowledge of cancer and willingness to consult a health professional¹⁰, international variation in primary care practitioners' willingness to refer¹¹ and socio-economic inequalities¹².

For the more common cancers, some work has focused on clinicians' views on the effectiveness of the diagnostic pathway¹³. However, there has been relatively little work studying clinicians' views on the fast-track diagnostic process for head and neck cancer¹⁴ and nearly all published work on clinicians' views focuses on studies conducted in single countries^{15, 16}

The purpose of this study is, therefore, to gain an in-depth insight into the views of head and neck cancer specialists in England and The Netherlands on their early cancer referral systems, with an emphasis on their perceived strengths and limitations and how the referral process might be made more effective. The study aims to compare the suspected head and neck cancer referral system in

each country through the views of the surgical specialists and to identify aspects of both systems of fast-track cancer referral that might potentially contribute to head and neck survival differences.

Cancer Referral in the English and Dutch Health Systems

In 2018, the English and Dutch health systems provide for populations of 53 million (66 million all UK) and 17 million, respectively. The Netherlands spent 12% of GDP on health care whilst the UK spent 8.8%. In the UK, most funding is derived from general taxation. In the Netherlands an insurance-based system provides funding; all residents are required by law to purchase statutory health insurance. In both countries, the GP provides a 'gatekeeping' service and refers, when required, to secondary care¹⁷.

The English system for fast-track cancer referral, including suspected head and neck cancer, is the 'two-week rule' (TWR) which requires that referrals from a GP are seen by a specialist within 14 days. GPs are provided with a list of signs and symptoms of potential cancer to assist with referral¹⁸.

In the Netherlands there is no specific fast-track cancer referral system. Hospital and specialist care (except emergency care) are accessible only upon GP referral. GPs are guided with an on-line evidence-based guideline system (NHG-Standaarden) and refer to a specialist if alarm symptoms are present. Both secondary and tertiary centre specialists are set to assess new cancer patients within a week, and, if necessary, the same day after consultation by telephone. Head and neck cancer cases in a secondary ENT centre setting may be referred to a dedicated outpatient clinic in a tertiary head and neck centre the same week.

METHODS

Ethical approval for the study was obtained in England from the Medical Sciences Interdivisional Research Ethics Committee of the University of Oxford (CUREC reference R52175/RE001) and in the Netherlands from the Medical Ethical Committee of the VU University Medical Centre Amsterdam (reference 2017.116). In accordance with good clinical practice, a formal presentation was delivered to a group of PPI volunteers who were invited to comment on and discuss the study. Secondary care surgical specialists that received referrals for head and neck cancer were chosen for this study. Such specialists have extensive experience of head and neck cancer referrals compared to GPs¹⁹. The Netherlands was chosen as the comparison with England as the Netherlands has superior 1-year survival yet an almost identical 5-year conditional survival.

Recruitment

Purposive sampling was employed to obtain consistency across the Dutch and English samples with respect to:

- ENT and maxillo-facial specialists.
- Sex
- ‘Secondary’ care specialists (general ENT and maxillofacial surgeons) and ‘tertiary’ (head and neck only specialists).
- Age and experience of participants.

Potential participants in the UK and the Netherlands were identified from national lists of specialists and through professional networks. Participants were accredited surgical specialists; trainees were excluded. Participants in each country were provided with a participant information sheet, in English, describing the nature and purpose of the study. Recruitment and interviews continued to the point of data saturation.

Interviewing and data collection

A semi-structured interviewing technique was used. A flexible interview template was developed, based on existing published literature (*Appendix 1*), together with an iterative approach to further question development as interviews progressed. Interviews were conducted in English in both countries by a single researcher, an experienced head and neck surgeon. Interviews in the Netherlands took place between June 2017 and October 2017, whilst those in England were conducted from August 2017 to February 2018. Interviewees were contacted and interviewed at a convenient time and place of their choice, including, in some instances, their own homes. All participants were issued with an information sheet and signed an appropriate consent form. All interviews commenced with the same broad question: ‘*Could you describe the typical referral process of a suspected head and neck cancer patient to your out-patient clinic?*’. Interviews typically lasted 30 to 40 minutes and were conducted in English. All interviews were securely audio-recorded.

Although interviews were not restricted to pre-determined questions, several important issues were included in the interview template:

- Strengths and limitations of the referral system in the participant’s country;
- View of the effectiveness of the system and how it might be improved;
- Referrals that only have a small possibility of cancer and the effect on the system;
- The quality of referrals and the quality of the information provided by primary care;
- The need for education of primary care practitioners and what form it might take.

Analysis

Recorded interviews were transcribed verbatim and the transcribed files were imported into *NVivo 11 Pro* qualitative analysis software (version 11.4.1.1064, QSR International, 2017). Qualitative thematic analysis, using the constant comparison method²⁰ was carried out concurrently with the on-going interviews. Analysis started following the first interview and continued throughout the study. Following multiple readings of the transcriptions, codes were initially assigned by one researcher (SL) to phrases and sentences that identified concepts described by the clinicians. Coding was reviewed in a sample of interviews by a second researcher (CB). Codes were subsequently organised into groups of common themes. New codes and themes were developed iteratively as the interviews progressed. Data were analysed to identify different perspectives amongst the participants, including a focus on similarities and differences between Dutch and English participants and their perceptions of the effectiveness of their suspected cancer referral systems.

RESULTS

12 participants were interviewed in each country. A summary of the participants' profiles is given in table 1.

Table 1 – profile of participants

Variable	England	Netherlands
Age range	43-60 years	36-59 years
Mean age	52.7 years	46.3 years
Male	11	10
Female	1	2
ENT-based	6	8
Maxillofacial-based	6	4

From the interviews several themes emerged:

COMMUNICATION *'The other thing that's largely broken down is the inter-personal contact between specialists and general practitioners' (English head and neck surgeon)*

By far the most common theme in this study amongst the English participants was the lack of direct communication between primary and secondary care practitioners during the referral process. Many English specialists, particularly those aged over 50, felt that this had been better in the past and the two-week rule system did not facilitate inter-clinician discussion. There was a strong view that improved communication between primary and secondary care would improve the effectiveness and efficiency of head and neck cancer referral. Specialists in the Netherlands, on the other hand, reported very close and direct communication with their primary care colleagues and often commented on the importance of this relationship (table 2)

Table 2 - Comments on communication

ENGLAND
<i>'It is just a shame to me that we are encouraged not to pick up the phone. The general practitioners don't pick up the phone and refer any more. I genuinely feel that that's a quicker way forward for a lot of the patients'</i>
<i>'We have lost the direct contact with primary care practitioners, which historically was a phone call. Dr Smith phones you up and says, listen, I am worried about Mrs Jones who I think has got a cancer. You see the patient that afternoon and you can use a lot of the filtering systems through the direct patient, doctor to doctor contact.'</i>
<i>'It's all based on that person to person communication. You can run a healthcare system in as protocolised way as you choose. That doesn't overcome that human interaction aspect of this. I cannot speak too strongly that that is important especially in something as complex as head and neck. I think it's critical.'</i>
<i>'In the 17 years I've been a consultant I have seen GPs and secondary care clinicians move further and further and further apart in a general sense. We don't really interact socially. We don't really interact academically.'</i>
NETHERLANDS
<i>'I think it's very important that the GP must feel confident to call the specialist. It must be easy for them to call. They don't know. That is an important thing. Of course, we make time for those people. The first weeks are important to do it quickly.'</i>
<i>'It's necessary that you have short lines. And you only have short lines if you know the names and you know the person and you have them on the phone every now and then. I think this system works.'</i>
<i>'If they want they can always talk to us. They have got a special telephone number to call the department'</i>

REFERRAL SPEED *'If I see the letter myself or have talked to the GP, I let them come the same day or the day after.'* (Dutch ENT surgeon)

Whilst both English and Dutch specialists agreed there was a need to see suspected cancer patients rapidly, English specialists commented on the lack of influence they had on both the process and speed of referral of suspected head and neck cancer. On the other hand, Dutch clinicians were often able to see patients much more quickly than in England and had substantial influence on the referral process (table 3).

Table 3 – Comments on referral speed

ENGLAND
<i>'The typical referral process is a standard two-week referral form, which comes in a standard proforma. We actually have no interaction with the process prior to the patients arriving at the clinic.'</i>
<i>'These patients ought to be seen very quickly, much quicker than the 14 days allocated, perhaps two or three days.'</i>
<i>'If you were referred to the neck lump clinic on Tuesday afternoon, you have to wait eight days for an appointment. I aim to see most patients at less than seven days and currently that is only about 50% of patients. As a rule, I think we could be quicker.'</i>
NETHERLANDS
<i>'I always offer to see the patient the same day. Same day or the day after. As soon as possible. Patients appreciate it if they can come the same day and well, just meet the surgeon and to get started with all the diagnostics.'</i>
<i>'We call the patients and invite them for a visit on the outpatient clinics on Monday or on Wednesday so that's twice a week, so they never have to wait longer than five days.'</i>

REFERRALS THAT DO NOT HAVE CANCER *'So you sort of see a 25-year-old, the history says they get mouth ulcers once every two months for the last two years. They have ticked oral cancer and they have got a two-week referral. In my experience it is fairly common.'* (English head and neck surgeon)

This was a common theme in the English interviews. There was a mixed view – on one hand, frustration at the perceived 'inefficiency' of large numbers of patients referred with only a remote chance of cancer whilst on the other hand an acknowledgement that a system such as the two-week rule by design 'casts a wide net'. English clinicians expressed concern that other 'routine' cases might be disadvantaged by the large number of suspected cancer with only a very small risk of the disease. They also suggested that GPs in some instances referred on the fast-track pathway when the prospect of cancer was low for fear of missing a cancer diagnosis. Specialists in the Netherlands, particularly 'general' ENT/maxillofacial surgeons, who received the bulk of GP referrals rather than those in tertiary centres, also experienced many referrals with only a small risk of cancer but were more inclined to view this as inevitable. They also felt that direct discussion with general practitioners was helpful in deciding the urgency of the case (table 4).

Table 4 – Comments on referrals that do not have cancer

ENGLAND
<i>'I think it is inevitably going to be part of a process where screening occurs and you are going to have to look at a lot of people with symptoms before you actually find the cancers. In some respects, from a patient's perspective and population perspective I think it's good because they are getting seen quicker. But from a resource perspective, I think it's appalling.'</i>
<i>'I think our colleagues in the primary care sector are quite acutely aware of that. I think they would rather send something which they probably know in the back of their mind that it probably isn't, but they are not willing to take that chance and put it in a routine referral and so they will just put it on a two-week referral and I think that probably accounts for a lot of why we are getting a lot - 80-90% of them - that are just benign disease.'</i>
<i>'But currently the way things stand, it penalises people in the routine pathway and encourages patients, doctors and dentists to use the two-week rule pathway for non-malignant conditions.'</i>
NETHERLANDS
<i>'It's part of the job. It's better that we do the whole work up and get to say, lucky you, you haven't got cancer.'</i>
<i>'You have patients who are referred with either a bit of a bulk at the tongue base which might just be lingual tonsil which is a bit bulky and all the alarm bells are sounding and you try to figure out if it's cancer or not. We get the lateral neck mass which turns out to be a bronchogenic cyst and not the lymph node from the unknown primary. We get them. We all get them.'</i>
<i>'If I speak to a general practitioner, I tell him what I think of his story and then I tell him, we will see the patient within one hour the same day, a few days or a few weeks. We agree. He follows my suggestion, nearly always. It's seldom a general practitioner thinks the sense of urgency is larger than I suspect. We will tend to stay on the same side, of course.'</i>

QUALITY OF REFERRALS *'I think it's utterly awful that patients can be referred with a diagnosis of a suspected malignancy with a tick in a box.'* (English head and neck surgeon)

Amongst the English specialists there was a wide range of views on the quality of referrals. One prominent theme was a dislike for 'tick box' referrals without any additional information and many felt that the referrals were better when some further clinical information was included. However, other participants noted that often symptoms did indeed require urgent investigation. On the other hand, Dutch specialists had very few criticisms of the quality of referrals (table 5)

Table 5 – Comments on quality of referrals

ENGLAND
<i>'Essentially what we've created is a tick box exercise, so you tick a box in terms of where you feel that they might follow the criteria with actually very little in the way of free text and actually, as you and I know, the free text actually gives you more information. Very few people actually put any free text in now at all.'</i>
<i>'Just ticking a box that says, you know, hoarse voice with no duration of symptoms or anything like that.'</i>
<i>'I think if you referred an unresolved lump in the neck that is actually a fair cop. That is exactly what secondary care should be dealing with, because unless you have got access to an ultrasound scan and aspiration services you aren't going to get a diagnosis on that.'</i>
NETHERLANDS
<i>'I really think that the quality of the general practitioners here is fairly good.'</i>
<i>'It's only rarely that I really think, okay, this is really a late referral by somebody and so I think, in general, everything is doing okay.'</i>

PRIMARY CARE CHALLENGES *‘But again, I am aware of the pressures GPs are under, where they haven't got much time, six, seven minutes to really see a patient and then sort things out.’ (English head and neck surgeon)*

Specialists in England and the Netherlands commented on the difficulties faced by primary care practitioners. English specialists commented both in terms of pressure of time and the difficulties of identifying head and neck malignancy in the primary care setting. The overall view in the Netherlands was very similar, with specialists also commenting on the volume of work in general practice and the difficulties identifying head and neck cancer (table 6)

Table 6 – Primary care challenges

ENGLAND
<i>‘The GP is overworked. They are not having adequate time to see patients. They are ticking boxes and getting them off the plate as quickly as possible.’</i>
<i>‘What we used to have was ‘urgent’, ‘soon’ and ‘routine’. We don't stratify the referrals any more. So, if a doctor or a dentist wants to have somebody seen quickly they just use that pathway.’</i>
<i>‘The difficulty with head and neck cancer diagnosis is that the GP can't nasendoscope the patient. To a certain extent that diagnostic test is not available to them and therefore, the need for somebody to examine the larynx and pharynx becomes the issue.’</i>
NETHERLANDS
<i>‘I think the GP is a busy man or woman here in the Netherlands, they have a lot of busy practices.’</i>
<i>‘The GPs, they have to know so many things, but they are not specialists.’</i>

PRIMARY CARE EDUCATION *‘A typical graduate who comes through UK medical schooling would have done, at the most five days of ENT, if they are lucky’ (English ENT surgeon)*

In both England and the Netherlands there was a broad range of views regarding the need for education of general practitioners in head and neck cancer. On one hand some practitioners advocated regular primary care education, either face-to-face or internet based whilst others suggested that such education was of limited value. Participants in England suggested that whilst primary care education was, potentially, useful the practicalities of delivering it remained challenging. In the Netherlands several views emerged, broadly similar to those in England. In the Netherlands specialists generally agreed that primary care practitioners' knowledge of ENT cancer was not extensive. The views on the need and type of education were, however, very diverse ranging from marked enthusiasm for training sessions to the opinion that such training was of little value at all (table 7)

Table 7 – Primary care education

ENGLAND
<i>'The logical idea is that if we take a chunk of our time to educate primary care about what oral cancer looks like and what pre-malignant areas are and all that kind of stuff that will reap the benefits, because they won't refer as much unnecessary stuff that is filling up the clinics using resource that could otherwise be used more appropriately. My experience of that is that it doesn't work. All that happens is they send in more.'</i>
<i>'The most important thing would be to make the doctors and the dentists more aware of the clinical signs and symptoms and to be able to educate them and tell them about which would be the appropriate cases and what cancers looks like.'</i>
<i>'I have done myself a few sessions and teaching sessions and lectures to the primary care physicians. Unfortunately, I must admit that there was a very poor response in attending these sessions.'</i>
<i>'One of my roles is about making sure examination of the oral cavity is in the curriculum for every doctor. It's hard to get it in, but I have insisted it goes in.'</i>
<i>'I teach the GP ST3s every year for the region. I get two hours to teach them about head and neck cancer. So we do try and put the information out there. But we know that because head and neck cancer is not that common, most GPs will only look after one or two head and neck patients in their whole career'</i>
NETHERLANDS
<i>'The GPs here don't have a lot of ENT knowledge.'</i>
<i>'You know that it's just as common as leukaemia or whatever and everybody knows about that but nobody knows about head and neck cancer, which is strange.'</i>

THE ENGLISH AND DUTCH SYSTEMS OF REFERRAL: PERCEIVED BENEFITS

'It works well. I think it does, anyway just from my experience over the last ten years. It's not perfect by a long shot, nothing is. Certainly, it's getting better.' (English maxillofacial surgeon)

'I am quite happy with the way the admission to the hospital is working. I am quite happy with it. I don't see - I rarely see -problems' (Dutch maxillofacial surgeon)

Many English specialists, whilst being aware of shortcomings in 'two-week rule/NICE guidance' system did believe that it had benefits. The Dutch specialists were, overall, very happy with their system of referral and considered GP-specialist communication, speed of service and highly centralised secondary treatment centres to be key benefits (table 8)

Table 8 – Perceived benefits in England and the Netherlands

ENGLAND
<i>'I think there is no question that it's a very patient-centred process. It is valued by patients that come and use it and they certainly appreciate the speed at which things are done.'</i>
<i>'The best points? Probably the fact that we now have designated two-week cancer referral slots in our clinic, so we are not looking to crow bar them into an existing clinic'</i>
<i>'I am not against targets. I actually think targets concentrate the mind and where they work really well is actually in the hospital care setting. It's a thing that concentrates minds.'</i>
<i>'Pathways gave us a lever and we forget that we had a huge ridiculous waiting list in the 80s and 90s to access to care for all sorts of things. Two-week wait emphasised cancer.'</i>
NETHERLANDS
<i>'I think it's good. There is a quick referral from the GP and also quick referral from the general ENT to the head and neck.'</i>
<i>'I think one of the big advantages of the Dutch system is the fact that it's head and neck oncology is restricted to the eight academic centres and three or four maybe preferred partners as we call them that really, I think that is the biggest advantage in achieving a good outcome.'</i>
<i>'I think that is very important that there is a telephone number which you can get easily and they arrange it very fast.'</i>

DISCUSSION

SUMMARY AND MAIN FINDINGS

This study highlights both similarities and marked differences in the views of English and Dutch specialists of their systems of fast-track head and neck cancer referral.

In several respects, both countries face similar problems, such as the limited head and neck cancer experience of primary care practitioners, the large number of suspected cases referred that do not have cancer and the uncertainty regarding the best approach to GP education.

However, there are aspects where clear differences exist. One important area identified in this study is primary care to specialist care communication. The most common theme amongst the English participants was the diminishing direct communication between the GP and specialist, often to the point of being non-existent, in the referral of head and neck cancer. There was a broadly-held view that professional discussion would be helpful in both reducing the number of referrals with benign conditions and allow urgent cases to be seen more rapidly. Interestingly, the importance of good, direct primary care to specialist communication was also the commonest theme amongst the Dutch

participants. In marked contrast to England, telephone discussions about patients were common, often using dedicated telephone numbers. Such communication was reported to facilitate both stratification of urgency and, when appropriate, very rapid referral. They frequently saw the patients the same day as referral and felt that this brought several benefits including the ability to commence investigations at the earliest opportunity and reduce the period of patient anxiety. In England, specialists noted that whilst nearly every patient referred with suspected head and neck cancer was seen within the required 14 days there was no 'stratification' of urgency and nearly all patients were seen after 12 or 13 days, thus meeting the prescribed target but with little or no input from head and neck cancer experts up to that time. Furthermore, nearly all the English participants emphatically disliked a 'tick box' referral with no further information in the correspondence.

In both countries participants mentioned that a high proportion of referrals did not have cancer. A systematic review by Langton et al²¹ reported that 8.8% of head and neck English TWR referrals were diagnosed with cancer and positive predictive values of this order are typical for many cancer types referred via the English TWR including gastro-intestinal²², breast²³, colo-rectal²⁴, CNS²⁵ and gynaecology²⁶. Similarly, in the Netherlands, van Boven et al²⁷, reported low positive predictive values for symptoms of potential cancer presenting to primary care including haemoptysis (2.7%) rectal bleeding (2.6%) and haematuria (2.2%). However, in this study it was notable that specialists in the Netherlands were more inclined to accept investigating 'negative' cases as 'just part of the process' in contrast to their English counterparts, of whom several commented on the impact that many negative suspected cancer cases had an adverse effect on other patients. In contrast, several Dutch specialists commented on the 'need to see patients' and the risks of them being sent to 'rival' hospitals – presumably a financial need - which may, at least in part, explain the Dutch relative enthusiasm for seeing many cases where cancer is absent.

In both countries, participants commented on the difficulties of diagnosing a relatively uncommon malignancy such as head and neck for a generalist in primary care with very limited clinical time. However, many English specialists felt the TWR system was being utilised, in some instances, to gain access to secondary care when the risk of malignancy was remote. In both countries there was a wide range of views on the need and type of education for GPs in head and neck cancer although in both countries the delivery of training was considered challenging.

Despite being critical of several aspects of the TWR/NICE guidance system in England, there were many comments on the benefits. These included the patient-centred process, the development of clinics organised around the need to see potential cancer patients in a timely manner and the importance of an established access target to promote 'focus'.

COMPARISON WITH EXISTING LITERATURE

The most prevalent theme in this study was the importance of communication between primary care and specialist. The English participants felt this was inadequate – particularly following the introduction of the TWR/NICE guidance system - whilst Dutch participants often employed direct contact, usually by telephone, to facilitate rapid referral and assist with ‘stratification’ of urgency. The primary-secondary care interface has long been recognised to be of importance in patient management in general²⁸ and many studies have emphasised the importance of close communication in effective cancer care^{13, 15, 16}. There is evidence to indicate that primary care practitioners also greatly value information sharing in the care of cancer patients¹⁶. The importance of such communication in relation to head and neck surgery was emphasised in a questionnaire study of English primary and secondary clinicians by Bethell and Leftwick¹⁴ and our study strongly supports this view.

In this study specialists in both countries considered that primary care knowledge of head and neck cancer was not extensive, which has been demonstrated in several studies^{29, 30}. However, in agreement with other studies, Mansell³¹ noted there was little consensus on the value or type of education that might be helpful. Interestingly, Mansell’s systematic review, which included studies that employed lectures, a training session or internet/video sessions, found that no educational intervention produced a long-term positive outcome.

Our study found that in the Netherlands patients were, in many instances, seen more rapidly in secondary care than in England. In some other countries, such as Denmark, cancer cases attend secondary care in typically 2 or 3 days³². It is known that patients often consider quality of care to be related to rapidity of diagnosis and treatment³³. However, it is by no means certain that waiting time reductions of a few days translate into superior outcomes for head and neck cancer³⁴ although a shorter interval may lead to reduced patient anxiety³⁵.

Clinicians in both countries identified good aspects of their respective systems. The Dutch specialists emphasised rapidity of referral and a close relationship with GPs. The English specialists felt that their system was patient-centred, quick and that targets provided a means to achieve ‘focus’. In a qualitative study on the referral of colorectal cancer¹³ participants also commented on the benefits of the TWR/NICE guideline system, including speed of referral and reduction of patient anxiety.

STRENGTHS AND LIMITATIONS

This study is, to our knowledge, the first study to examine and compare the views of specialist surgeons in head and neck cancer in two European countries, with different survival outcomes for the disease, on their referral systems. A cancer such as head and neck is seen only very rarely in primary care, perhaps only once or twice in an entire GP's career. Therefore, the views of specialists on the referral of the condition are valuable as they will receive many referrals every week of their working lives and have an in-depth understanding of the process. However, the perspective of both primary care practitioners and patients could possibly be valuable.

The sample in this study is relatively small (12 interviews in each country) but it was judged that data saturation was achieved in both countries following the interviews. The sample in England included interviews in Yorkshire, Lancashire, Greater Manchester, Merseyside and Cheshire. Clinicians in the Netherlands were interviewed in many different parts of the country. In both countries participants worked in a range of large cities and smaller towns and clinicians in academic and non-academic roles were interviewed.

The study was restricted to two countries. Studying further countries with different health systems may shed further light on the primary to specialist referral process for suspected head and neck cancer.

CONCLUSIONS

The overall objective of this study was to compare the systems of head and neck cancer referral in the Netherlands and England from the point of view of the secondary care clinicians and attempt to identify aspects that might enhance the early diagnosis of head and neck cancer. The most prominent theme was primary care-specialist communication. Interestingly, this was identified by the English clinicians as the aspect most lacking in the English referral system and by the Dutch clinicians as the most useful feature of their system. Other important themes included speed of referral (often much quicker in the Netherlands), the lack of ability to identify the urgency of referrals in England (good communication in the Netherlands allowed professional discussion to assist with this aspect), the large number of referrals that do not have cancer (particularly in England) and very variable views on the need for education in primary care in both countries. Specialists in the Netherlands were very satisfied with their system and while English specialists identified many good points in the TWR system there was an overall view that improvements could be made.

IMPLICATIONS FOR PRACTICE AND RESEARCH

We would suggest, in the light of our study, that improved direct communication between primary and secondary care is a factor likely to improve efficiency and effectiveness in head and neck cancer referral and, possibly, outcomes in England. It is also, of course, arguable that better communication might improve other aspects of the referral system identified in this study – speed of referral, the quality of referrals, unnecessary referrals and assist with educating GPs. However, with increasing pressure on primary and secondary care, any such system would need to be carefully piloted to ensure safety, effectiveness and practicality. Nevertheless, it is arguable that improved efficiency of the referral system, reducing unnecessary referrals, might prove cost-effective. We would suggest that these aspects require further research, for all types of cancer.

CONFLICT OF INTEREST

AP reports grants from NIHR, grants from NIHR School of Primary Care Research, during the conduct of the study; and occasionally receives expenses for teaching Evidence-Based Medicine.

CB receives funding from NIHR PGfAR, NIHR School of Primary Care Research, Cancer Research UK and the Oxford Centre for Biomedical Research.

FINANCIAL SUPPORT

This study was partly supported by a travel grant from Kellogg College, University of Oxford and a Small Project Initiative from the British Association of Oral and Maxillofacial Surgeons.

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APPENDIX 1

SEMI-STRUCTURED INTERVIEW TEMPLATE

- 1. Could you describe the typical referral process of a suspected head and neck cancer patient to your out-patient clinic?**
 - (a) What are the good points?
 - (b) What areas could be improved?
 - (c) Can you describe some examples from your experience where things have gone well and not so well?

- 2. Could you explain your view of the effectiveness of the system, overall, in identifying and referring potential head and neck cancer patients as early as possible?**
 - (a) What modifications in the referral system – if any are needed – would help improve efficient early diagnosis of head and neck cancer?

- 3. What kind of information, both in quality and quantity, does the written referrals you receive, provide?**
 - (a) Would you like to see this changed, and if so how?

- 4. We know only a small percentage of referrals actually have cancer. What do you think of this?**
 - (a) Is it necessarily part of the process?
 - (b) Can you describe how it influence your/the clinic's efficiency?
 - (c) Can you describe how this affects patients? (Do they welcome being seen or does it cause anxiety?)
 - (d) Does it need to be changed in any way? If so, what do you suggest?

- 5. What is your experience of patients being referred where cancer is extremely/very unlikely?**
 - (a) (If this happens), why do you think this is?
 - (b) Could you describe some examples?

- 6. Could you describe your view of the overall quality of suspected head and neck cancer referrals?**
 - (a) In what way(s) are they (good/poor/indifferent)? Please explain your view.

- 7. Could you describe your view of the training needs, if any, of primary care practitioners, in the early referral of head and neck cancer?**

- 8. Could you describe your experience of communication between primary and secondary care (in relation to head and neck cancer referral)?**
 - (a) How do you think this could be improved (if at all).

9. What else might improve timing/quality of suspected head and neck cancer referrals?
10. Is there anything else on which you would like to comment in relation to fast-track referral of head and neck cancer?