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Review

Referrals for head and neck cancer in England and The Netherlands: an international qualitative study of the views of secondary-care surgical specialists

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Abstract

One-year survival after head and neck cancer in England has been reported to be worse than that in Europe, despite five-year conditional survival being similar, which implies that patients present later in England. One country with better rates is The Netherlands. There are many possible causes, one of which may be the system of referral from primary to secondary care. We have compared the views of secondary care specialists in the two countries about their systems for referral, and identified aspects that might have an impact on outcomes. We organised semistructured qualitative interviews of surgical specialists in head and neck cancer in England and The Netherlands (n = 12 in each). The most common theme was communication between primary care and specialists. Surgeons in England identified this as the aspect most lacking under the English "two-week" rule, while Dutch specialists felt that the good communication in their system was one of its best points. Other themes included the educational needs of primary care practitioners, criticism of "tick box" referrals in England, and too many patients referred who do not have cancer. Overall, specialists in both countries identified good aspects of their respective referral systems, but those in England felt strongly that the "two-week" rule/NICE guidance system could be improved with better direct communication between primary and secondary care, which might improve the speed and quality of referrals, reduce unnecessary ones, and assist in educating primary care physicians. It is not clear whether such improvements would improve survival, 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 broad agreement that the outcomes of some cancers in England (and the rest of the UK) are inferior to the European best, initially reported in the first "EUROCARE" cancer studies.[1] The fifth version of EUROCARE indicated that though improvements had been made in the UK, some outcomes remained inferior to the best in Europe.[2] Many consider that the UK's relatively poor outcomes result at least partly from diagnostic delay, so the patient has a more advanced cancer at the time of diagnosis.[3]

Data from EUROCARE-5 indicate that, for head and neck cancer, five-year conditional (on one-year survival) outcomes in the UK compare well with the best in Europe, yet one-year

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survival was still poorer than in several European countries.[4] One example is The Netherlands, where one-year survival after head and neck cancer in 2000–2007 was reported by Gatta et al to be 74.7% (95% CI 73.7 to 75.7) compared with one-year survival in England of 70.3% (95% CI 69.7 to 70.9).[4] Five-year conditional survival rates for the same period were similar: Netherlands 65.7% (95% CI 64.1 to 67.5) and England 65.6% (95% CI 64.6 to 66.6).

However, finding out exactly why diagnostic delays occur is complicated for all cancers, and probably has many components that require different solutions.[5,6] It is also important that different types of cancer are considered separately when we attempt to find out the causes of delay.[7] Many studies have attempted to identify both the factors that delay the diagnosis, and the differences between developed European countries with comprehensive healthcare systems.[8] The International Cancer Benchmarking Partnership, initiated by the Department of Health in England,[9] has explored several possible causes of international variation in the outcome of cancer, including patients' knowledge about it and willingness to consult a health professional,[10] international variation in primary care practitioners' willingness to refer,[11] and socioeconomic inequalities.[12]

For the more common cancers, some work has focused on clinicians' views on the effectiveness of the diagnostic pathway.[13] However, there has been relatively little study of clinicians' views on the "fast-track" diagnostic process for head and neck cancer,[14] and nearly all published work on clinicians' views has focused on studies done in single countries.[15,16]

The purpose of this study, therefore, was to gain in-depth insight into the views of specialists in head and neck cancer in England and The Netherlands about their referral systems for suspected early cancer, with an emphasis on the perceived strengths and limitations, and how the process of referral might be made more effective. We aimed to compare the referral system for suspected head and neck cancer in each country through the views of the surgical specialists, and to identify aspects of both systems of "fast-track" referral for cancer that might potentially contribute to differences in survival after cancer of the head and neck.

Referrals for cancer in the English and Dutch health systems

In 2018, the English and Dutch health systems provided for populations of 53 million (UK = 66 million) 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, while in The Netherlands it is an insurance-based system, and all residents are required by law to have health insurance. In both countries, the general practitioner (GP) provides a "gatekeeping" service and refers patients, when required, to secondary care.[17]

The English system for "fast-track" referral for all suspected cancers, including those of the head and neck, is the "two-week" rule, which requires that referrals from a GP are seen by a specialist within 14 days. GPs are provided with a list of potential signs and symptoms of cancer to assist with referral.[18]

In The Netherlands there is no specific fast-track referral system for cancer. Hospital and specialist care (except emergency care) are accessible only by referral from GPs, who are guided by an on-line, evidence-based, guideline system (NHG-Standaarden), and refer to a specialist if alarm symptoms are present. Specialists at both secondary and tertiary centres will assess new patients with cancer within a week – and if necessary the same day – after consultation by telephone. Patients with head and neck cancer in a secondary ENT centre may be referred to a dedicated outpatient clinic at a tertiary head and neck centre to be seen the same week.

Methods

Ethics 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 Ethics 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 (Patient and Public Involvement in Research) volunteers, who were invited to comment on and discuss the study. Secondary care surgical specialists who dealt with referrals of patients with head and neck cancer were chosen for the study. Such specialists have extensive experience of referrals for head and neck cancer compared with GPs.[19] The Netherlands was chosen to compare with England, as they have superior one-year survival yet an almost identical five-year conditional survival.

Recruitment

Selective (non-probability) sampling was used to obtain consistency across the Dutch and English samples with respect to: ENT and maxillofacial specialists; sex; "secondary" care specialists (general ENT and maxillofacial surgeons); "tertiary" (specialists in head and neck only); and the age and experience of the participants.

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

Interviews and collection of data

A semistructured interviewing technique was used. A flexible interview template was developed, based on existing publications (Appendix 1), together with an iterative approach that we used to question development further as the interviews progressed. Interviews were conducted in English in both countries by a single interviewer, who was an experienced head and neck surgeon. Interviews in The Netherlands took place between June and October 2017, and in England from August 2017 – February 2018. Interviewees were contacted and interviewed at a 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 process of referral of a patient with suspected head and neck cancer to your out-patient clinic*?" Interviews (all in English) typically lasted 30–40 minutes and were securely audiorecorded.

Although interviews were not restricted to prearranged questions, several important issues were included in the interview: the strengths and limitations of the referral system in the participant's country; the participant's view of the effectiveness of the system and how it might be improved; referrals that have only a small possibility of cancer and the effect on the system; the quality of referrals and the quality of the information provided by the primary care practitioner; and the need for education of GPs and what form it might take.

Analysis

Recorded interviews were transcribed verbatim and the transcribed files imported into NVivo 11 Pro for Windows qualitative analysis software (version 11.4.1.1064, QSR International, 2017). Qualitative thematic analysis, using the constant comparison method[20] was made concurrently with the on-going interviews. Analysis started after the first interview, and continued throughout the study.

After multiple readings of the transcriptions, codes were initially assigned by one researcher (SL) to phrases and sentences that identified concepts that had been 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 among the participants, including a focus on similarities and differences between Dutch and English participants and their perceptions of the effectiveness of their respective systems for referrals of patients with cancer.

Table 1
Profile of participants (n = 12 in each group).

Variable	England	Netherlands
Mean (range) age (years)	53 (43–60)	46 (36–59)
Sex:		
Male	11	10
Female	1	2
Specialty:		
ENT-based	6	8
Maxillofacial-based	6	4

Results

Twelve participants were interviewed in each country (Table 1). Several themes emerged from the interviews:

Communication

"The other thing that's largely broken down is the interpersonal contact between specialists and general practitioners" (English head and neck surgeon).

By far the most common theme among the English participants was the lack of direct communication between primary and secondary care practitioners during the referral process.

Table 2
Comments on communication.

ENGLAND

"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."

"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."

"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."

"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."

THE NETHERLANDS

"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."

"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."

"If they want they can always talk to us. They have got a special telephone number to call the department."

Table 3
Comments on speed of referral.

ENGLAND
"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."
"These patients ought to be seen very quickly, much quicker than the 14 days allocated, perhaps two or three days."
"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."
THE NETHERLANDS
"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."
"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."

Table 4
Comments on patients referred who do not have cancer.

ENGLAND
"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 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."
"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."
THE NETHERLANDS
"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."
"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."
"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."

Many English specialists, particularly those aged over 50, felt that this had been better in the past, and the "two-week" rule did not facilitate discussion between clinicians. There was a strong view that improved communication between primary and secondary care would improve the effectiveness and efficiency of referrals for head and neck cancer. Specialists in The Netherlands, on the other hand, reported close and direct communication with their primary care colleagues, and often commented on the importance of this relationship (Table 2).

Speed of referral

"*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).*

While both English and Dutch specialists agreed that there was a need to see patients with suspected cancer rapidly, English specialists commented on the lack of influence that they had on both the process and speed of referral of patients with suspected head and neck cancer. Unlike them, Dutch clinicians were often able to see patients much more quickly, and had substantial influence on the process of referral (Table 3).

Patients referred who 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, while on the other there was an acknowledgement that a system such as the "two-week" rule casts a wide net by design. English clinicians expressed concern that other routine cases might be disadvantaged by the large number of patients with suspected cancer but only a small risk of having the disease. They also suggested that GPs in some instances used the "fast-track" pathway when the prospect of cancer was low for fear of missing a diagnosis of cancer. Specialists in The Netherlands, particularly "general" ENT/maxillofacial surgeons, who get the bulk of GP referrals rather than those consultants in tertiary centres, also had many patients referred who had only a small risk of cancer, but they were more inclined to view this as inevitable. They also felt that direct discussion with the GP was helpful in deciding the urgency of the case (Table 4).

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).*

Table 5
Comments on the quality of referrals.

ENGLAND
"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."
"Just ticking a box that says, you know, hoarse voice with no duration of symptoms or anything like that."
"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."
THE NETHERLANDS
"I really think that the quality of the general practitioners here is fairly good."
"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."

Table 6
Challenges in primary care.

ENGLAND
"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."
"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."
"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."
THE NETHERLANDS
"I think the GP is a busy man or woman here in the Netherlands, they have a lot of busy practices."
"The GPs, they have to know so many things, but they are not specialists."

Among 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 more clinical information was included. However, other participants noted that often symptoms did require urgent investigation. Dutch specialists, however, had few criticisms about the quality of their referrals (Table 5).

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

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 about the need for education of GPs about head and neck cancer. On the one hand, some practitioners advocated regular primary care education (either face-to-face or internet-based) while others suggested that such education was of limited value. Participants in England suggested that – while primary care education was potentially useful – the practicalities of delivering it were challenging. In The Netherlands several views emerged, broadly similar to those in England. Dutch 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, diverse, and ranged from marked enthusiasm for training sessions to the opinion that such training was of little value (Table 7).

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, while being aware of shortcomings in the "two-week rule/NICE guidance" system, did think that it had benefits. The Dutch specialists were, overall, 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).

Discussion

Summary and main findings

In this study we have highlighted both similarities and differences in the views of English and Dutch specialists about their systems of "fast-track" referral for patients with suspected

Table 7
Primary care education.

ENGLAND
"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 premalignant 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 resources 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."
"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 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."
"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 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."
THE NETHERLANDS
"The GPs here don't have a lot of ENT knowledge."
"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."

Table 8
Perceived benefits in England and The Netherlands.

ENGLAND
"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."
"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 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."
"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."
THE NETHERLANDS
"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 think one of the big advantages of the Dutch system is the fact that its 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 think that is very important that there is a telephone number which you can get easily and they arrange it very fast."

head and neck cancer. In several respects the two countries face similar problems, such as GP's limited experience of head and neck cancer, the large number of suspected cases referred who do not have cancer, and the uncertainty about the best approach to the education of GPs.

However, there are aspects where clear differences exist, one important area of which is communication between GPs and specialists. The most common theme among the English participants was the diminishing direct communication between the two, often to the point of being non-existent, about referrals for head and neck cancer. There was a broadly-held view that professional discussion would be helpful both to reduce the number of referrals with benign conditions, and to allow urgent cases to be seen more rapidly. Interestingly, the importance of good, direct, primary-care-to-specialist communication was also the most common theme among the Dutch participants. In 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, rapid referral. They often saw the patients on the day of referral, and felt that this brought several benefits, including the ability to begin investigations at the earliest opportunity and to reduce the patient's period of anxiety. In England specialists noted that while 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, which met the prescribed target but with little or no input from the experts in head and neck cancer up to that time. Nearly all the English participants emphatically disliked "tick box" referrals, with no further information in the correspondence.

In both countries participants mentioned that a large proportion of patients referred did not have cancer. A systematic review by Langton et al[21] reported that 8.8% of English "two-week" rule referrals for head and neck cancer were diagnosed with cancer, and positive predictive values of this order are typical for many types of cancer referred through the English "two-week" rule system, including gastrointestinal,[22] breast,[23] colorectal,[24] central nervous system,[25] and gynaecology.[26] Similarly, in The Netherlands, van Boven et al[27] reported low positive predictive values for symptoms of potential cancer in patients who presented to primary care, including haemoptysis (2.7%), rectal bleeding

(2.6%), and haematuria (2.2%). However, we found that it was notable that specialists in The Netherlands were more inclined to accept that the investigation of patients who did not have cancer was "just part of the process". Several of their English counterparts commented that the presence of many patients who were suspected to have cancer, but did not, 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 patients who did not have cancer.

Participants from both countries commented on the difficulties that a generalist in primary care with limited time had in diagnosing a relatively uncommon malignancy such as cancer of the head and neck. However, many English specialists felt the "two-week" rule was being used (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 about head and neck cancer, although in both countries the delivery of training was considered challenging.

Despite criticism of several aspects of the "Two-week" rule/NICE guidance in England, there were many comments on its benefits. These included the patient-centred process, the development of clinics organised in a timely manner around the need to see patients who might have cancer, and the importance of an established access target to promote focus.

Comparison with existing publications

The most prevalent theme was the importance of communication between primary care and specialist. The English participants thought that this was inadequate – particularly since the introduction of the "two-week" rule/NICE guidance – while Dutch participants often had direct contact, usually by telephone, to facilitate rapid referral and assist with stratification of urgency. The primary-secondary care interface has long been recognised as important in the management of patients in general,[28] and many studies have emphasised the importance of close communication in the effective treatment of cancer.[13,15,16] There is evidence that primary care practitioners also greatly value the sharing of information in the care of patients with cancer.[16] 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 Leftwick,[14] and our study strongly supports this view.

We found that specialists in both countries considered that knowledge about head and neck cancer in primary care was not extensive, which has been shown in several studies.[29,30] However, in agreement with other studies, Mansell et al[31] noted there was little consensus on the value or type of education that might be helpful. Interestingly, their systematic review, which included studies that used lectures, a training session, or internet/video sessions, found that no educational intervention produced an effective long-term outcome.

We found that in The Netherlands patients were, in many instances, seen more rapidly for secondary care than in England. In some other countries, such as Denmark, patients with cancer attend secondary care typically in about two or three days.[32] Patients often consider quality of care to be related to rapidity of diagnosis and treatment,[33] but it is by no means certain that reductions of a few days in waiting time translate into superior outcomes for patients with head and neck cancer,[34] although a shorter interval may lead to a reduction in the patient's anxiety.[35]

Clinicians in both countries identified good aspects of their respective systems. The Dutch specialists emphasised rapidity of referral and a close relation with GPs, whereas the English specialists thought that their system was patient-centred and quick, and that targets provided a means to achieve focus. In a qualitative study of the referral of patients with colorectal cancer,[13] participants also commented on the benefits of the "two-week" rule/NICE guidelines, including speed of referral and reduction in anxiety for patients.

Strengths and limitations

This study is, to our knowledge, the first to compare the views on their referral systems of specialist surgeons in the field of head and cancer in two European countries with different survival outcomes for the disease. A cancer such as one in the head and neck is seen only rarely in primary care – perhaps only once or twice in a GP's entire career. The views of specialists on the referral of the condition are therefore valuable, as they will have many referrals every week of their working lives, and 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 in each country) but it was judged that data saturation was achieved in both countries after the interviews. The sample in England included interviews in Yorkshire, Lancashire, Greater Manchester, Merseyside, and Cheshire. Clinicians in The Netherlands were interviewed in many parts of the country, but in both countries participants worked in a range of large cities and smaller towns, and we interviewed clinicians in academic and non-academic posts.

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

Conclusions

The objectives of this study were to compare the systems of referral of patients with head and neck cancer in The Netherlands and England from the point of view of secondary care clinicians, and to attempt to identify aspects

that might improve its early diagnosis. 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 of this aspect), the large number of patients referred who do not have cancer (particularly in England), and variable views on the need for education in primary care in both countries. Specialists in The Netherlands were satisfied with their system and, while English specialists identified many good points in the "two-week" rule, there was an overall view that improvements could be made.

Implications for practice and research

We suggest that improved direct communication between primary and secondary care practitioners would improve efficiency and effectiveness of referral for patients with head and neck cancer (and possibly outcomes) in England. Better communication might also improve other aspects of the referral system that we identified – speed of referral, the quality of referrals, unnecessary referrals, and assistance with educating GPs.

However, with increasing pressure on both primary and secondary care, any such system would need to be carefully piloted to ensure safety, effectiveness, and practicality. It is arguable that improved efficiency of the referral system and reducing unnecessary referrals might prove cost-effective, and we suggest that these aspects require further research for all types of cancer.

Conflict of interest

AP reports grants from the National Institute for Health Research (NIHR), and grants from NIHR School of Primary Care Research, during the study; and occasionally receives expenses for teaching evidence-based medicine.

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

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Ethics statement/Confirmation of patients' permission

University of Oxford (CUREC reference R52175/RE001) and VU University Medical Centre Amsterdam (reference 2017.116). Formal written signed consent was obtained from all participants.

Appendix 1.

Template for semistructured interview.

1. Could you describe the typical referral process of a patient with suspected head and neck cancer 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 patients with potential head and neck cancer 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, is provided by the written referrals that you receive?

(a) Would you like to see this changed, and if so how?

4. We know that 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 when 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 referrals with suspected head and neck cancer?

(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 patients with head and neck cancer?

8. Could you describe your experience of communication between primary and secondary care (in relation to referrals for head and neck cancer)?

(a) How do you think this could be improved (if at all).

9. What else might improve timing/quality of referrals of patients with suspected head and neck cancer?

10. Is there anything else on which you would like to comment in relation to fast-track referral of patients with head and neck cancer?

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