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# Learning from patients with cancer and their spouses: a focus group study

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## Abstract

Guidelines, standards and protocols are now widespread in clinical oncology. Although based on randomized trial evidence where possible, most are based on professional consensus. However, the goal of incorporating patient and carer views meaningfully in such guidelines has proved elusive. We performed a qualitative, focus group study of patients with head and neck cancer, their carers and bereaved carers in the South and West of England. Patients and carers were asked to discuss their views on a series of professionally-derived standards for care. Pilot work showed that convening patient groups twice was more productive, allowing the first to discuss 'the patient story/journey' and the second to be more directed at specific standards, suitably translated into lay language. The results demonstrated that such methodology was applicable even to groups of patients traditionally viewed as 'difficult', such as laryngectomy patients, facially disfigured persons and bereaved carers. Participants were able to comment meaningfully on the standards and the process of head and neck cancer care as a whole. National (BAO-HNS) standards were modified with the results of the study. Focus groups, especially reconvened groups, are an effective way of gaining patient and carer views of professionally-derived standards in oncology. However, professional qualitative researcher help is required, and it is not necessarily 'easy' or cheap.

**Key words: Head and Neck Neoplasms; Patient Care Management**

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## Introduction

Despite growing pressures on the medical profession to listen to patients' perspectives, there has been surprisingly little direct research among patients with cancer. The principal focus of studies in this area has tended to be patient needs for information and support, particularly among those with breast cancer.[1] Yet there is much to be learned from both patients and their carers about their experience with all aspects of cancer care. As part of an exercise in developing standards for the care of patients with head and neck cancer in the South and West Region, we carried out a focus group study involving both patients and their carers. This took place under the umbrella of a multi-disciplinary group of clinicians and others.

The initial aim of this study was to learn the views of patients and their carers on a set of regional standards, developed by clinicians. Indeed, a number of changes were subsequently made to these standards and, following a process of consultation, to national standards as well. A separate article documents this process and discusses the methods employed in some depth.[2]

There is also a need to describe the particular concerns expressed, so that others can learn from them. The research enabled participants both to comment on specific standards (and suggest new ones) and to explore their own personal experiences with cancer services. Although the study involved solely people with head and neck cancer and their carers, many of the findings can be seen to have a wider application to people with other forms of cancer. This paper therefore sets out the responses for those issues with most general applicability, as well as calling attention to some issues specific to head and neck patients where appropriate.

## Methods

The initial plan was to hold a number of homogenous focus groups, some of which would be reconvened to allow sufficient time. A pilot study had shown that patients could contribute valuable comments on standards, but were best able to do so when they had told their own personal histories first. In all, nine sets of focus groups were held, of which three were reconvened, making 12 meetings in total. (Where groups were not reconvened, the same information was elicited within a single meeting.) Six groups involved patients with particular experi-

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ences (two each of those with a laryngectomy, radiotherapy and surgery resulting in altered appearance) and three involved spouses (two of patients who had experienced radiotherapy and one of patients who had died). In total, 39 patients and 18 carers were involved in the research; one interview was also held, where the person did not want to take part in a group of discussion.

Patients' names were obtained from consultants or others, such as a research radiographer, and spouses' names were requested from the relevant general practitioner (GP). Each person was sent an introductory letter, asking for their help with the research and enclosing a cover letter from their consultant, a short information sheet about the research, a reply slip and prepaid envelope. Those expressing an interest were telephoned to discuss the process and arrange the meeting. All meetings were facilitated by a highly experienced group moderator, using a topic guide to ensure that all key areas were covered. They were taped and transcribed to assist analysis.

Participant representatives is an issue frequently raised for such research. In the strictest sense, the participants were not representative, having been selected neither randomly nor purposively (because of insufficient numbers and little supplementary information). The only criterion for exclusion was a very long distance from the venue, to save excessive travel costs. But the study was not concerned with counting the *numbers* of people with different experiences or views. Its focus, instead, was to obtain a considered response to proposed standards, that could only be achieved by a qualitative process. Given the numbers of people involved (59) and the degree of consensus between them, we would argue that the views expressed were reasonably representative of those of people with the condition.

## Findings

The following information follows the logic of the initial standards, themselves based on the logic of patients' experience with cancer services. It starts, in short, with patients' initial contact with their GP and follows through their experience of treatment and palliative (and terminal) care. The principal focus is a specific standard, but additional information on patients' (or carers') experience is added as appropriate.

Some standards were discussed by all groups and some by only a few, depending on their relevance. Only those standards discussed by most groups are covered here. For fuller information on the study results, see the final report.[3]

### *Initial referral by the GP*

*'Any patient who has hoarseness, mouth ulcers or other oral lesions that last for more than a month should be referred to a specialist.'*

Virtually all patients agreed that this standard was appropriate. It was reasonable to have a period in which other more minor diagnoses were explored ('you've got to give your GP a chance to try and cure it from antibiotics or what-have-you before referring you to a consultant'). On the other hand, it was important to get referred promptly and GPs need to encourage patients to return if their symptoms do not clear. Dentists also needed to be aware of the problem.

Most patients had been referred within the month, but a few had periods of some months when the GP tried other diagnoses:

> 'My wife was having sinus – what we presumed it was. This went on with antibiotics and one thing and another for nearly nine months, until it got to a point where she was in so much pain...' (a spouse).

Laryngectomy patients seemed to experience particularly long delays in getting a proper diagnosis, including one woman who was told that her tendency to whisper was 'psychological'. Generally, little anger seemed to be directed to those responsible for the protracted diagnostic process.

Participants also noted that they had not always gone to the GP as quickly as they should have done. Older people were often reluctant to bother the doctor and it was suggested that there was a need for more publicity on this issue.

> 'I had hoarsenesss for six months and made a fortune for the patent medicine people, because I just thought I'd got a sore throat and it was traffic and other people's cigarettes' (a patient).

*'All patients should be seen at the hospital within 10 days of being told that they were being referred.'*

There was widespread agreement with this standard and most people felt they had been seen within the 10-day period. Patients were very accepting of the probability of some wait:

> 'By and large, the cancer's been in your body for a given period of time and, irrespective if you go in 24 hours or 10 days, it's not going to make that much difference to your life expectancy' (a patient).

Two groups suggested that the standard should be set at 10 days in total – not 10 working days. The waiting time was likely to be particularly worrying as the person knows there may be a problem ('all the time you're thinking cancer, cancer, cancer').

### *The first hospital visit*

*'Ninety-five per cent of first out-patient appointments should be with a consultant, not with a junior doctor.'*

Virtually all patients felt it was important to see a consultant at this stage and, in practice, nearly all had done so:

> 'I don't think you want to go in when you've had this worry on your shoulders and [be] told you're seeing a junior doctor' (a patient).

A few questioned the need for this standard, however. It might be better to see a junior doctor quickly than wait for a consultant. Some said they would not mind being seen by a junior person if they were assured that he or she would call in a consultant if needed. It was argued that at a minimum, a standard should require a consultant to be on the premises so that a junior doctor could seek out advice.

### The specialist head and neck clinic

*'Within 10 working days of diagnosis being confirmed, 95 per cent of new patients should be seen in a specialist clinic.'*

There was some disagreement concerning this standard. Of the five patient groups who discussed it, two felt it was about right ('we have to be realistic; they're very busy in there . . . ') In three groups, however, participants argued that the wait should be shorter ('once you been told, you don't want to be hanging around'). It was proposed that seven days in total (not working days) would be more reasonable, especially as this followed the 10 day wait for a hospital appointment in the first place. Their own experiences varied considerably, but many commented on how quickly they had been seen and treated.

*'This clinic should have an ENT consultant and an oncologist for head and neck cancer present 100 per cent of the time. In half the clinics, there should also be a palliative care consultant and a plastic or reconstructive surgeon. In the case of patients requiring radiotherapy, there should be both a surgeon with a special interest in head and neck cancer and a radiotherapist present 100 per cent of the time.'*

There was general consensus that a surgical consultant and oncologist should be present and, for those requiring radiotherapy, a radiotherapist. Many suggested that the standard should also specify an option for a specialist (or Macmillan) nurse to be present, especially important for patients living on their own, to provide support:

> 'I was really shocked with [my diagnosis], I wasn't expecting it at all . . . [The Macmillan nurse] could see I was a bit upset, she understood how I was feeling, so we could have a chat outside the room as well.' (a patient)

But the main issue was not so much *who* should be present, but *how* the discussion should be handled, particularly the desirability of a large multidisciplinary meeting involving all the key specialists. Some found this helpful as a means of meeting all people who would be concerned with their care right at the outset ('I had two specialists, the nurse and some others. I felt a VIP. Everything I asked, they told me'). Others thought that this was too intimidating, with the feeling of being in a crowd ('this sea of doctors') making it difficult to ask questions. Patients might prefer to meet the relevant personnel in the course of time. It was agreed that where there was a large meeting, patients should be given some warning of what was coming and all those present should be fully introduced.

There was considerable agreement that a standard should explicitly offer patients the choice of such a meeting.

### Breaking the bad news

*'Bad news should be broken sensitively, in line with well recognised guidelines, which state that news should be given both at an appropriate time, when someone is with the patient, and in an appropriate place. Time should be available for discussion and a follow-up appointment offered. The news should not under normal circumstances be given to carers alone.'*

All groups discussed this issue in some detail. The most common response that it was difficult to set a standard, because people varied in how they would like it handled. Consultants simply needed to be sensitive to individual patients ('how can you tell a man who's got cancer in a "good" way? There's no right time or right place').

Generally, it was argued that the bad news should be told in a doctor's office, with sufficient time to ask questions or just sit and weep. There should be no delay in passing on such information, which should be given in a kind but honest and clear manner, with no euphemisms:

> 'They should say these are your options, this is what we can do . . . as much information as they can give you. They should be prepared to sit there and talk with you. Knowledge is power and to share that knowledge is to share power. It's my body – I want to know all about it and have a voice' (a patient).

> 'There's so many words now . . . . And half the people don't understand what they're talking about. I think it should be told that it's cancer' (a carer).

Many patients spoke very warmly of how they had been told. There was particular appreciation for the practice of being offered a room where they could talk together afterwards. A few, however, were less happy. Some had been told too abruptly ('he sat me down, said the biopsy was wrong, you've got cancer') one was told on the telephone and another was told when by his wife's bedside in an open ward. It was suggested that consultants should be offered training in how to break the bad news sympathetically.

Virtually every group felt that it was important for a spouse or friend to be present when such news was given. This was both to provide support and to provide an additional ear for information, as patients were often unable to take in much detail at that point. It was widely recommended that a standard should require patients to be advised that they should be accompanied to the consultation, despite the practical problem that the letter would, in effect, be giving the bad news already:

> 'Well, if you're asked to bring your husband or your wife and when you get there there's a box of tissues on the table, you're going to get bad news' (a patient).

*'Treatment plans should be made and documented at this first clinic visit in 50 per cent of cases.'*

This issue was discussed by four patient groups. They tended to stress the importance of an early treatment plan to give a sense of some response. One group were concerned that patients should be offered a small amount of time to think about it, as it was difficult to make important decisions quickly. Two groups proposed that the standard should apply to 75 per cent of cases.

It was also argued that the treatment plan should not be sent out by letter, but telephoned by the doctor directly to the patient (in the absence of a face-to-face consultation, which would be the ideal). This should be followed up by a face-to-face discussion between the consultant and the patient, preferably within a week or so.

### *Information*

*'Ninety per cent of out-patient clinics and wards should have written information sheets providing information on support organizations, general ward topics, general treatment issues and specific head and neck problems.'*

There was virtual consensus that written information sheets should be available on the issues mentioned. Additional suggestions included the provision of information on local support groups and on complementary medicine. It was not generally thought that there was a need for a special leaflet for carers.

Participants also argued that information should be available early on. However much information people are given at the time of diagnosis, there is a need for reinforcement via the written word ('you're a bit shocked at the time, you're not going to take things in'). Most thought this should be provided as soon as a treatment plan had been decided. On the other hand, one group questioned whether very technical information would be appropriate, for instance the details of tracheotomies, right from the start. It was also suggested that someone should specifically *give* the information to patients – not simply assume that they would find it if it was placed on racks.

Most people felt that they had been given all the information that they needed and that it had been easy to read. The one exception was information about radiotherapy and it was agreed that a standard should require the provision of detailed information to help people prepare for the treatment and its after-effects. Both patients and spouses were concerned that they did not know whether they should be alerting the doctor to new symptoms, because it was unclear whether they were arising from the treatment or the cancer. One group suggested that a telephone helpline should also be available at this stage, to enable people to obtain reassurance and information on how to cope:

*'Ninety per cent of outpatient clinics and wards should have written information sheets.'*

No one could understand why this standard was limited to 90 per cent and it was universally proposed that the standard should apply to *all* centres.

*'A register of local people who have had head and neck cancer and who are willing to talk to new patients should be kept on the ward and a visit from such a person should be offered to patients prior to the treatment.'*

This idea was discussed by four groups of patients. It was widely welcomed and, indeed, had been implemented in some hospitals. Talking to someone who had 'been through' the experience served to provide both a lot of information and hope for their own prognosis:

> 'It's fine reading the books, I was given all the pamphlets . . . , I could read them till kingdom come, but it doesn't mean anything until you're actually spoken to somebody' (a patient).

This idea was particularly well liked by patients with altered appearance. After having been told of the complex details of their operation, they were very apprehensive and speaking to someone ahead of time might have allayed some fears.

Three participants had been involved in undertaking such visits and most said they would be willing to now or in the future:

> 'Eventually I would very much like to do that . . . . I'm very lucky and I hope I could be very positive for them in a time when it's a complete void and unknown and a dread' (a patient).

### *Radiotherapy*

*'A nationality accepted timescale suggests that radiotherapy should be planned within 10 days of attending the specialist clinic and treatment started within one month of the diagnosis being made.'*

This timescale was generally viewed as reasonable, although one group proposed that the standard should be amended to read 'treatment started within one month of the diagnosis being made, unless the diagnosis suggests earlier'. Patients should be offered reassurance that waiting periods were not causing any detriment to their long-term prognosis.

One group proposed that patients should be given a firm date as early as possible, as waiting was particularly difficult when a date had not been set:

> 'To the authorities, another day or two might seem quite trivial, but when you're waiting for a biopsy report and you're stood by the door waiting for the postman to come up the road another day, that day can be horrendous' (a carer).

Most patients had experienced treatment within the given time, although there was the occasional exception. There was also general agreement that the treatment had been handled well, although some had found it decidedly difficult.

*'All patients should have a named consultant radiotherapist.'*

There was general agreement that patients should have a named consultant radiotherapist, although not all did. Patients felt much more secure when there was someone they felt they knew ('it feels more like a personalized service, if you have a name').

### *Hospital admission and care*

*'In 90 per cent of cases, patients should be notified of the admission date within two days of attendance at the Head and Neck Clinic.'*

The three groups of patients with whom this standard was discussed all felt it was reasonable. One suggested that this information should be in the treatment plan, itself to be passed to the patient within three days. Early notification was vital to enable patients to prepare themselves.

The initial document did not include any standards concerning patient care in hospital, but one group proposed that a standard should require pain nurses to visit patients on the ward following an operation ('when you've got a hole in your head and a rib gone, it hurts so much, you just want to die') as well as a dietician prior to discharge.

Comments on treatment were almost wholly positive. There were, however, some exceptions, in particular problems concerning inexperienced nurses unfamiliar with the details of a laryngectomy. Some people with altered appearance also felt that hospital care was too medically driven, neglecting both psychological aspects of recovery and practical matters, such as help with camouflage.

### *Discharge from hospital*

*'Seventy-five per cent of patients should see a primary health care team worker (usually the district nursing sister) on the ward less than a week before discharge.'*

This standard was discussed by four groups, of whom two felt it could be dropped because the key issue was what happened *after* discharge. Most were primarily concerned about this period, particularly the need for a contact name and telephone number when there were anxieties. Many had been told that they could telephone the ward if they needed help and this was proposed as an additional standard:

> 'You've got a built-in insurance policy, you can come up to this ward day and night, 365 days of the year, and they will see you. At three o'clock one morning my catheter came out, I couldn't get it back in – I was received as if it was the middle of the afternoon – no problem. To me this is brilliant after care' (a patient).

It was argued that a standard should also require a district nurse or other health worker (possibly the specialist nurse) to visit once immediately following discharge, to see that patients were settled in, particularly important for those who lived on their own. The transition between hospital and home was difficult:

> 'While you're in hospital, you feel you've got an umbrella of somebody looking after you all the time, but when you go home and you're on your own, you're apprehensive of every little pain' (a patient).

Quite a few had seen no one following discharge ('I was just left to me own devices'). There were, however, some stories of an excellent service, with both hospital and community staff keeping an eye on patients. Several people who had had a laryngectomy argued that their district nurse was too unskilled to do more than provide support and they should be better trained.

*'The GP should receive a discharge summary saying what had been done, when, complications and follow-up arrangements within four working days of discharge.'*

This standard was discussed with four groups and there was general agreement that it was reasonable. A few felt that GPs – both their own and in general – were not as well informed as they might be about their circumstances; indeed, one man said that his GP not only did not receive a discharge summary but did not know that he had had an operation.

### *Follow-up*

*'Patients should be followed up in the combined Head and Neck Clinic within one month of their initial treatment and then at these intervals: year 1: at least two monthly; year 2: at least three monthly; year 3: at least four monthly; year 4: at least six monthly; thereafter: annual review.*

These standards were discussed by four groups of patients. The follow-up reviews were welcomed to obtain reassurance that the cancer had not spread, especially the one-month visit to the consultant immediately after the operation. Three groups argued that follow-up in the first six months or year should be on a *monthly* basis, both for support and for practical information ('you have all sorts of peripheral problems you want to discuss'). A variety of alterations to the standard were proposed, generally to provide greater frequency where desired by patients. Views differed about whether patients should be discharged altogether, but there was support for a choice to be given to patients on this issue.

### *Palliative and terminal care*

*'Ninety per cent of medical and nursing staff should be aware of existing guidelines for the appropriate management of pain and should know where to refer patients if they need specialist palliative care.'*

*'As part of crisis planning, 90 per cent of ward nurses should know what to do in the event of a tracheotomy blockage or heavy life-threatening bleeding.'*

These two standards were discussed together by the group of carers of people who had died. It was argued that any standard in this area should pertain to all staff ('if the 10 per cent happened to be on when you need it, that's very important'). It was felt that this standard should also apply to district nurses, given the number of people being cared for at home.

The palliative care received was seen as very good. A number of participants commented favourably on help from their district nurse as well as the local hospice. Some, in contrast, felt that they did not have the support they would have liked at this time, as all attention was given to the patient but not to the needs of the spouse.

With respect to terminal care, it was suggested that a standard should require advice to be provided by the consultant or GP about where such care might take place. Participants generally reported favourably on care from hospices, but less so on care in hospital.

Strong views were expressed about support at the time of bereavement. It was felt that a standard should require preparation for bereavement, preferably by a district nurse. Help following a bereavement should ideally come from those who knew the person who had died. There was little interest in going to organizations, such as Cruse, with no familiarity with the family's situation. Most had had little or no contact with any of the professionals looking after their spouse following the death, but any kindness shown from such people was very strongly appreciated.

### *Living with cancer*

No standards had been offered about the long-term needs of patients with cancer or their carers, but many people spoke about their needs. Support was the major issue. Many felt profoundly changed as a result of their experience:

> 'There's a difference between cancer and say 'flu or even typhus. They are illness which you're over with . . . Cancer is with us forever either in its after-effects or in its recurring stages . . . You're no longer the person that used to be an air traffic controller and a singer in the local choral society. You are a person who's got that funny thing in his throat and that we all feel sorry for . . . It changes your life' (a patient).

Emotional difficulties were particularly common among those with altered appearance, as facial surgery was very traumatic. They could feel very awkward appearing in public or even eating out in company:

> 'It's very hard to go out and face the world. When I had my pedicle hanging I didn't go out, I didn't open the door, I didn't want anyone to visit' (a patient).

There was strong support for a standard requiring a specialist or Macmillan nurse to be available for support during this period. Patients should be informed that these were not solely concerned with terminal care, as was a common impression. Help from a clinical psychologist should be offered to those with altered appearance, possibly starting when they were in hospital.

It was also very important that both patients and carers were aware of local support groups and how to contact them. Many such groups existed, but people did not always know about them. They were seen to perform a number of important functions, both helping people to come to terms with the condition and providing tips about how to cope:

> 'You can relate on a different level than you can with your husband, you wife or your family' (a patient).

> 'Little problems that you can't ask a doctor – a doctor doesn't know – you can ask someone else and they say "oh, yes, I had that" (a patient).

Two people with altered appearance said that our focus group was the first time they had spoken to anyone about their anxieties and were very grateful for the opportunity to explore their feelings with others who had been through a similar experience.

A number of people also stressed the need for practical help, such as advice on financial matters. A standard should require attention to the social situation of patients, such as people looking afer elderly relatives or children on their own.

Many participants were very positive about the care received, both patients and carers:

> 'I think they've been absolutely marvellous all the way through the treatment. They fall over backwards trying to help you – everybody, from my doctor at home, district nurses in the clinic, everybody's marvellous. Soon as you walk in tothe receptionist, all the way through, everywhere' (a carer).

Finally, one person suggested that all patients should have a copy of the standards:

> 'You need these standards nailed up on the wall and you need a number underneath, like this is your Crimewatch number or your Helpline number. You really need to know where to go, don't you, if you're not getting the standards that you require' (a carer).

## Discussion

The information collected in this study raises some subtle and complex issues. Firstly, it suggests that patients and carers are both more understanding and more sophisticated than might be anticipated by many health professionals. The comments suggest an awareness of the complexity of the diagnosis and treatment process, so that attention is not expected instantly and some waiting is accepted as reasonable.

Secondly, however understanding patients may be of the system by which their care is provided, they feel they are entitled to be treated with respect and openness. Clear appointments should be given, explanations offered of problems and full information available to assist them to understand their diagnosis and treatment. Indeed, the standards themselves should be available to patients, so they know the means by which the system is being assessed.

Thirdly, an impression is conveyed of people being highly dependent on health professionals for their treatment and care, conscious of being always on the margins in terms of understanding what is happening. Time and again, the need for explanations and clear appointments is signalled.

Such is the need for cancer patients to 'tell their story' that it was clear in our pilot studies that we need to have a reconvening technique in some groups. Although such discussions are less focussed on the objective of the research, valuable, sometimes surprising, information can still be gained and it clears the way for more targeted discussion second time round.

It was clear that this technique was not only applicable to persons with communication difficulties or altered appearance and to recently bereaved carers, but that it was actually an enjoyable and therapeutic experience for many as well. For some, it was the first time they had ever had a chance to discuss their feelings about their cancer and its care. Although the regional ethics committee had asked us to set up a telephone 'hot-line' for persons who might become distressed, only one patient felt the need to call the nurse responsible.

The present UK Government initiative on a two-week waiting time limit was given considerable support in these groups (which were held more than a year before such a limit was imposed on head and neck cancer warning symptoms). Patients seemed to have no patience with GP's who held onto patients with suspicious symptoms for too long. The comments also serve to emphasize the diagnostic dilemma faced by many GP's and specialists as many early symptoms described herein were very vague ('sinus trouble', 'throat problem'). This difficulty seemed to be recognized by the patients, at least one of whom appeared to have understood very well the biology of the disease ('24 hours or 10 days, it's not going to make that much difference to your life expectancy'). This is one of several comments in the study which teaches doctors that patients can gain much better insight than they are often given credit for. The argument that 10 days should mean exactly that and not 10 working days, as in the standards, echoes precisely what was eventually enshrined in the Government's directives. Interestingly, they were very practical about the difficulties of all patients seeing a consultant at the first hospital visit, and only asked that they be seen by at least a competent junior who had access to the consultant on site if need be.

The original standard of 10 working days between diagnosis and specialist clinic was arrived at as the result of an audit in the mid-90s which showed that few units had weekly multidisciplinary clinics. Subsequent standards have changed to make this a one week gap, and patients supported this strongly. This argues for a cancer network to have access to a weekly combined clinic opinion in all cases.

It was sad to hear of some of the ways in which a few people had had the cancer diagnosis broken to them. At this moment, above all, patients and carers require careful consideration as to the right time and place. They supported the idea of avoiding euphemisms and calling cancer 'cancer'.

The problems of allowing doctors time to consult fully and prepare a reasoned plan as well as the inability of a patient in the combined clinic setting to take in sufficient information led to the suggestion that a period of perhaps three days should be allowed for the plan, arrived at by multidisciplinary consultation, to be communicated to the patients and carers, but that this should be face-to-face by a doctor with plenty of time for questions. They also raised the standard from 50 to 75 per cent. There was limited discussion as to whether a GP should be informed quickly, although it had obviously helped a lot in one case.

Information sheets were applauded, and one group commented on the plethora of such information, suggesting that there should be two sheets at first: a general one on head and neck cancer, and a second one describing where to get information on specific topics. This is now in national standards. They also reiterated the common advice that such information should be delivered both verbally and in writing, and that they should be given the opportunity to phone/call back for more information over the next few days.

At present there are considerable national difficulties with waiting times for radiotherapy, due to lack of radiographers and machines. Many areas have little hope of meeting the standards which patients agreed were reasonable. However, as a minimum, they should be told what their actual start date will be as soon as possible.

The central position of specialist liaison nurses was a continuous thread throughout the groups, even extending to the bereavement setting discussed by one group. Those patients from areas not having such a service felt abandoned in a sense. A recent study showed wide variations in the presence and workload of such nurses in the UK. They should be universally available for pre-treatment and aftercare of head and neck cancer patients, and there should be a mechanism for centrally reviewing their roles and workloads.

Although not specifically asked their views on centralization of care in fewer, regional centres, patients acknowledged that there would be differences in what might be available between hospitals, and merely asked that they be told there were such differences and given the chance to choose for themselves. Travelling to distant centres as opposed to local hospitals was not discussed.

The implications of these studies for healthcare provision are many. Foremost are the need for specialist liaison nurses to be part of the cancer journey for every patient with head and neck cancer. Resources need to be targeted into those areas which will reduce unnecessary delays, such as the radiotherapy services. The question of centralization of services is not conclusively addressed, but the suggestion is that patients and carers accept that care cannot be the same in every hospital. Above all, however, this study reinforces the importance of actively seeking the views of patients and carers when planning our cancer care services. The present method seems to provide an effective way of doing just that.

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Professor M. Birchall takes responsibility for the integrity of the content of the paper.
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