
Head and Neck Cancers

Patient Views and Experiences

The National Cancer Alliance

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The NCA is a unique charity formed in 1994 which brings together cancer patients and healthcare professional, their relatives and friends, working together to improve cancer services, treatment and care throughout the UK.

The aims of the NCA are:

- To increase awareness of cancer diagnosis, treatment and care
- To encourage, monitor and promote standardised, high quality cancer treatment and care throughout the UK
- To influence cancer policy-making at national and regional levels
- To represent the interests, concerns and views of patients and their carers.

The NCA is a membership organisation and membership is open to anyone who wishes to join. Our members can, and do, get actively involved in the work of the NCA via its committees and sub-committees.

The NCA relies on contributions and donations to do its work. Any contribution, however small, helps us to achieve our aims.

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This project was commissioned by the National Cancer Guidance Group (NCGG), chaired by Professor Bob Haward, which is now under the auspices of the National Institute for Clinical Excellence. As part of this work, a national guidance document on the management of Head and Neck Cancers is now under development. The NCGG commissioned the National Cancer Alliance (NCA) to undertake a small-scale exercise to enable people who have had a diagnosis of head and neck cancer to input their views, knowledge and experience into the development of this guidance.

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1.0 INTRODUCTION

Following the publication in 1995 of the report of the Expert Advisory Group on Cancer, “A Policy Framework for Commissioning Cancer Services” (Calman–Hine), a number of national guidance documents have been produced on site-specific cancers for commissioners. This work is managed by the National Cancer Guidance Group (NCGG), chaired by Professor Bob Haward, and now under the auspices of the National Institute for Clinical Excellence. As part of this work, a national guidance document on the management of Head and Neck Cancers is under development. The NCGG commissioned the National Cancer Alliance (NCA) to undertake a small-scale exercise to enable people who have had a diagnosis of head and neck cancer to input their views, knowledge and experience into the development of this guidance.

1.1 Aim and Objectives

The overall aim of the exercise was to input patient perspectives into the development of the national guidance on head and neck cancers.

To achieve this aim, the following objectives were set:

- To provide patient perspectives about head and neck cancer services
- To provide patient feedback on the series of proposals that have been drafted to inform the development of the guidance.

1.2 Structure of Report

This report is structured in the following way. **Section 2.0** describes the research methods used, how recruitment was conducted, and details about the discussion group held. The profile of the respondents recruited to the discussion group is also given.

The main findings are then presented in Sections 3.0 to 6.0 and structured around the key themes identified in the series of proposals, namely: raising awareness, getting to a diagnosis, hospital-based tests and investigations, treatment and care, and follow up and after treatment.

In **Section 3.0** respondent perspectives on raising awareness are given, their views on their own presenting symptoms considered, and their subsequent experiences at the GPs or dentists are discussed.

In **Section 4.0**, respondents' experiences of hospital tests and investigations and receiving a diagnosis of cancer are explored.

Section 5.0. sets out findings relating to treatment choices, treatment and care and information and support issues.

Then, in **Section 6.0**, consideration is given to issues relating to follow-up and after treatment. Recommendations on each theme, based on respondent findings, are given at the end of each of these sections.

Finally, in **Section 7.0**, conclusions from the findings and their implications for developing the head and neck guidance are considered.

2.0 METHODS

As explained in Section 1.0, the broad aim of the project was to ensure patient input into the national guidance, through eliciting an in-depth response from patients who had recently, or were currently, receiving head and neck cancer services.

Qualitative research methods lend themselves to this approach and so, for this reason, holding a discussion group was the chosen method. This allowed a group of respondents to meet together in an informal environment under the direction of an experienced moderator. Using a discussion brief, themes identified in the series of proposals drafted to inform the guidance were discussed rather than specific questions asked. This greater flexibility allows issues considered salient to the members of the group to be explored in-depth. Due to the substantial overlaps in the proposals in how the different cancers of the head and neck should be managed, it was decided to hold a mixed discussion group, rather than having separate, cancer site-specific groups.

In order to augment the findings from the discussion group, those attending the group could additionally give written submissions and patients unable to attend the group were also given the opportunity to contribute in this way. To facilitate respondents giving written submissions, a summary of the proposals, with questions, was prepared by the NCA and sent to all respondents. The summary was also provided because the 25 discrete proposals total over 100 pages and are written with varying degrees of accessibility. It was emphasised to all that participated that they could write as much or as little as they wished and they should not feel constrained should they wish to write about issues that were not addressed in the summary.

2.1 Recruitment

The majority of the recruitment to the discussion group took place during an intensive recruitment process in August and September 2001. A variety of recruitment methods were used and included sending publicity information to: Head and Neck Clinics, Cancer Information Centres, national and local support groups, cancer charities and National Cancer Alliance (NCA) contacts. In addition, press releases were sent to local radio stations and local newspapers throughout England.

Using these methods, people who had had a diagnosis of one of the head and neck cancers were invited to participate in a discussion group and asked to contact the NCA if interested. The Project Consultant then contacted each of the respondents to tell them about the Project and establish their eligibility to participate in the discussion group. A standard recruitment form was used to confirm eligibility. All respondents were advised that participation in the discussion groups was voluntary and their contributions would be anonymised. Details of the respondent profiles are given in Section 2.3 below.

Prior to attending the discussion group all respondents received a letter of invitation and the summary of the proposals described in Section 2.0 above. Respondents were also given a list of all the proposals and offered copies of all the proposals or those that were specific to their cancer. Where reference is made in the report to respondents who made a written submission only, this is clearly indicated, otherwise, all references to respondents refer to those who participated in the discussion group.

2.2 Discussion group

The discussion group took place at the Novartis Foundation in London and was facilitated by Becky Miles, Director of the NCA, with Catherine Smith, Project Consultant. Nicky Vinton, NCA Research Associate, also attended as an observer. The discussion was tape-recorded for transcribing with the permission of the respondents.

2.3 Profile of Respondents

Using the recruitment methods described above, 10 respondents were recruited to the discussion group, nine patient respondents and one carer respondent who wished to attend with her husband. Numbers recruited were restricted in order to ensure an in-depth discussion.

Table 1: Patient Respondents' Profile – Discussion Group

SUMMARY PROFILE OF PATIENT RESPONDENTS IN THE DISCUSSION GROUP							
How they heard about the Project		Year of diagnosis		Diagnosis		Age Range	
Publicity via support group network	2	1995	1	Laryngeal Cancer	4	40 to 49	1
Head and Neck Clinics	5	1997	2	Tonsil Cancer	1	50 to 59	3
		1998	1				
		1999	3	Mouth Cancer	3	60 to 69	3
NCA Contacts	2	2000	2	Thyroid Cancer	1	70 to 79	2

Six of the patient respondents in the discussion group were male and three female. One female respondent, carer of one of the laryngeal patient respondents, also attended.

Respondents were from the following areas: Avon, Denbighshire, Devon, Buckinghamshire, West Midlands, and Somerset. All nine of the patient respondents in the group also gave written submissions. 6 respondents, one of whom was a carer, who were unable to attend the discussion group gave a written submission only.

Table 2: Respondents' Profile – Written Submissions only

SUMMARY PROFILE OF RESPONDENTS WRITTEN SUBMISSIONS ONLY							
How they heard about the Project		Year of diagnosis		Diagnosis		Age Range	
Publicity via support group network	4	1991	1	Laryngeal Cancer	2	40 to 49	1
		1992	1				
Head and Neck Clinics	1	1994	1	Adenoidal Cancer	1	50 to 59	1
NCA Contact	1	2000	2	Mouth Cancer	2	60 to 69	4
		2001	1	Neck Cancer	1		

Those giving written submissions only were from the following areas: Devon, Cambridgeshire, West Midlands and Yorkshire.

It is worth noting that compared to the two previous studies the NCA has undertaken for the NCGG, considerably more respondents in this study were recruited via publicity material given to health professionals (consultants and specialist nurses).

Copies of publicity materials, patient recruitment documentation, the summary of the draft guidance produced by the NCA and the focus group discussion brief can be obtained from the NCA on request.

3.0 PATIENT AWARENESS & RESPONSES TO ‘EARLY’ SYMPTOMS

With the aim of earlier diagnosis, the proposals drafted to inform the national guidance place emphasis on raising awareness about head and neck cancers with the public and GPs and dentists. As well, explicit reference is made about the importance of primary care professionals undertaking routine examinations or assessments and making rapid referrals to hospital-based diagnostic services. This section considers respondents’ views about raising awareness, their experience of presenting symptoms, consulting their GP’s, and being referred onto hospital.

3.1 Raising Awareness

The group as a whole seemed to be generally supportive of the idea of public health education strategies. A few suggested having “awareness” weeks to help raise the profile of head and neck cancers. Several suggested using leaflets and posters in GP and dental surgeries to raise awareness. One respondent, whose mouth cancer was initially picked up at a routine check-up at her dentist’s, said that she had noticed there were now posters and leaflets in his surgery. Another respondent commented that he thought there was enough health education but that it seems to be ignored, he cited as evidence of this the number of young people who smoke and drink heavily. A suggestion from another respondent was that awareness raising should start at school using a teacher trained in health education or a visiting nurse. This suggestion was echoed by a respondent who gave a written submission only, recommending that children at primary school should learn anatomy, physiology, and body awareness. Another respondent, who gave a written submission only, proposed advising the public to have regular dental check-ups.

3.2 Presenting Symptoms

Most respondents described having clear initial symptoms and a few had had concurrent symptoms. Symptoms mentioned were: loss of voice, on going sore throat, irritation in the throat, sensing an obstruction when swallowing, discovering a lump. One respondent was not aware of any initial presenting symptoms.

How respondents interpreted and acted upon their initial presenting symptoms varied. It appeared that a few first thought that their symptoms were possibly innocuous while others knew early on that, “*something was wrong*”. It may be that those who first thought their symptoms might have been innocuous did so because they could be linked to having a commonplace minor health ailment, for example, a sore throat, and this perhaps gave initial false reassurance. Whereas those that were more concerned at the outset, had symptoms, a lump or loss of voice, that were less easily explained away:

*“I knew there was something wrong with my voice, I was very worried ...
sometimes I could talk alright, sometimes I would be a bit hoarse”.*

Respondent, laryngeal cancer patient

3.3 Going to the GPs or Dentists

The prompt for deciding to go to the GPs or dentists varied. Two respondents had routine check-up visits at the dentists. The remaining patient respondents explained that they went to the GPs because of concerns about a range of presenting symptoms listed in Section 3.2 above. The time that had elapsed before consulting their GP varied greatly. Four respondents went to their GP's quite promptly, two waited several months, and one delayed for 5 years. The respondent who delayed for 5 years described himself as not in control of his life for that period due to heavy drinking. After 5 years, knowing that something was seriously wrong, he finally decided to go to his GP's.

3.4 GP/ Dentist Variation in Practice

The two patient respondents who attended their dentists for a routine check-up were referred straightaway to hospital:

“... he was very astute at picking something up”.

Respondent, mouth cancer patient

Of those respondents who consulted their GP, four were referred straightaway and three were not. Of those that had a speedy referral, one said he was scolded by his GP for delaying consulting her and another described his practice as:

"...marvellous,... tends to be ultra cautious".

(Respondent, mouth cancer patient)

All of the respondents who had a speedy referral were appreciative of the intervention of their primary care professionals even if some had a sense of foreboding of what was to happen next.

For those 3 respondents who did not have a speedy referral it seemed that the onus was on these respondents to get access to the tests and investigations that they needed. Two respondents described consulting another GP as they had been unable to get a satisfactory resolution from the first GP they had consulted. One of these respondents, who emphasised throughout the very positive view he had of the treatment and care he had received said:

"The only negative thing I've got about my treatment..., the first doctor I saw said it was a virus and gave me treatment for five days and then when I said I wasn't any better, he said, 'Well it's something you have to live with' ...I love to sing and I found that I couldn't keep the notes...I didn't have any pain but it was just something. So I went to another GP and he took a swab and found nothing, and eventually, they referred me to a surgeon, but not as urgent".

Respondent, tonsil cancer patient

Another respondent related consulting another GP at her practice with a sore throat she had had for 10 days as her own GP was away. She said that she was advised that she had a sore throat and to return in 2 weeks if it had not gone. In the interim, a family member noticed that she had a lump on her neck and this prompted her earlier return to the practice. Her own GP still being away, she then saw a different GP, at her insistence, to the one she had first consulted. She described this GP as 'panicking', she thought in response to seeing the lump on her neck, and referring her straightaway to the hospital. The third respondent whose referral was delayed said his GP treated him for laryngitis for 3 months:

"Some weeks I had loss of voice, it lasted 2 or 3 days and then it would come back... Swallowing was like I had a piece of phlegm stuck and I couldn't get rid of it. I went to my GP, three months he treated me for laryngitis.

(Respondent, laryngeal cancer patient)

After this time he insisted on being referred to an ENT specialist and although the respondent related that his GP was quite confident that there was nothing wrong, the GP agreed and instigated his referral. The respondent also stated that at no point had his GP undertaken any examination.

A carer respondent, in a written submission only, related that his wife had consulted her dentist and was treated by gingivectomy without success. His experience had led him to conclude that dentists needed improved awareness of the appearance of cancerous lesions.

3.5 Referral

For clarity, it is re-iterated that this is a small-scale qualitative study that is not representative of head and neck cancer patients. Nonetheless, for these respondents, the elapsed time before being referred by the GP for specialist investigation ranged from a matter of days to several months. This would indicate that, as suggested in the proposals, to use elapsed time before a referral is made by the GP as a performance measure would be of real value.

Once the GP or dentist had made a referral, the time it took to be seen at the hospital varied a good deal. Several respondents were seen within a matter of days. One respondent waited several weeks and another 4 months and then, on the morning of the appointment, he was notified that it was cancelled and would be re-scheduled 5 weeks later. His GP, finding out about the cancellation by chance, intervened and arranged a hospital appointment for him a few days later. Another respondent, who had been given a non-urgent referral was offered an appointment 8 months later, this prompted him to seek a private consultation.

3.6 Information and Support for Patients

There was limited discussion in the group of information and support needs of patients at the GPs and dentists. It appeared that the consensus was information and support needed to be offered and tailored to the needs of the individual. There was also agreement that too much information at this stage, prior to diagnosis, could be precipitative and unhelpful. It seemed that the priority was for the GP or dentist, in response to patient need, to be supportive of the patient as, at this stage, they play a critical role as patient advocate and gateway to diagnostic services.

3.7 Summary of Recommendations

All respondents were in agreement that **early diagnosis** of cancer was of paramount importance. They believed that it was essential, therefore, for **GPs and dentists to have an improved awareness of presenting symptoms** and **to make speedy referrals to hospital-based diagnostic services.**

Raising Awareness - General Population

- Health education strategies, including “awareness weeks”, should be used to help raise the profile of head and neck cancers. Leaflets and posters should be displayed and be readily available in GP and dental surgeries. Health education in schools, using trained personnel, should be considered.

At the GPs - Patients

- Patients should be encouraged to go back to their GP if symptoms persist and supported, if needed, in having an assertive dialogue with their GPs.
- Patients, if dissatisfied with their GP, should be able to seek a second opinion from another GP.

Clinical Practice and Organisational Issues

- GP and dentist awareness of the symptoms that could be related to a diagnosis of head and neck cancers needs to be raised.
- GP management of the patient consultation needs to be improved. In particular GPs should be trained and encouraged to take a more systematic and holistic approach to investigations, using protocols or checklists, and drawing them to a ‘conclusion’. If GP investigations are inconclusive, GPs should be able to consult a specialist for advice and patients should be encouraged by their GP to return if symptoms persist and further investigation or a referral for specialist investigation should then take place.
- GPs need to listen more to their patients and the medical reasons for any presenting symptoms should be discounted before social or psychological reasons are presumed.

- Once a GP has made a referral this needs to be monitored to ensure that their patient has access to a specialist diagnostic service within a reasonable time scale.
- GPs need easy and speedy access to and information about specialist diagnostic services.

4.0 HOSPITAL BASED ASSESSMENT AND DIAGNOSIS

This section outlines respondent responses relating to:

- hospital-based tests
- investigations and assessment
- the point when they were given their diagnosis of cancer
- the general response to the proposals relating to this phase.

The proposals advocate the need for a rapid, systematic and streamlined approach to assessment and diagnosis. Another aspect of the service emphasised in the proposals is the importance of multi-disciplinary teams at the diagnostic phase. The proposals also recommend that a consultant should tell the patient their diagnosis with a trained nurse specialist present and that information and support should be available for both patients and their families.

4.1 Hospital Based Tests, Investigations and Assessment

All respondents referred to the need for speedy referral and a rapid diagnostic service so that the very difficult state of limbo experienced at this stage is as brief and as well managed as possible. Respondents wanted this approach in order to alleviate stress and ensure a diagnosis is given promptly and treatment and care started.

At this stage, respondents described a range of experiences of hospital services. One respondent saw a registrar, all the others a consultant. A few described their consultant as not obviously being part of a team, several were aware that they were being managed by a team. Some respondents commented on staff seeming to be over-stretched and this constraining the service that could be provided. The degree to which GPs or dentists were kept informed seemed to vary widely.

Reflecting respondent priorities, this part of the discussion was dominated by their recall of how this stage was managed, especially being given a diagnosis of cancer, rather than in depth discussion of the tests and investigations that they underwent. However, one respondent stressed the need for mouth biopsies to be done under a light general anaesthetic as she had found it terrifying to be awake during this procedure.

4.1.1 Communication, Information and Support

The degree of communication and information that respondents received at this stage varied considerably. Nearly all respondents were told what tests would be undertaken and two respondents received written information at this point. Some had the reasons for the tests explained to them but were not always given as much information as they wanted, even if they actively sought it. One respondent said her consultant had been supportive but that he was reluctant to answer her many questions, saying that, “...*he was paid to do the worrying*”. For this respondent, this response heightened her fears and anxieties. Where information was given this was valued and respondents generally expressed a need to be kept informed. Several related being treated in a very sympathetic and supportive way and this seemed to make this stage easier. A few who had little support or information described how difficult this time was. This was especially so for those who waited for their test results and they described feelings of stress, worry, and isolation at this time. All felt that written information and ready access to support, for example, specialist nurses and counsellors, was needed at this stage.

From both the discussion group and written submissions, it is apparent that at this stage of assessment, information and support services need to be an integral part of the treatment and care provided. The management of this is clearly a sophisticated process as it needs to be tailored to the needs of the individual, delivered by personnel with specialist expertise, offered in an incremental way, and in no way pre-empting patients receiving a definitive diagnosis of cancer.

4.2 Receiving the Diagnosis of Cancer

As was reported in the NCA's urological and haematological patient experience studies, the moment when patients are told they have cancer is often recalled vividly. All members of the discussion group and all those who sent written submissions highlighted that how their diagnoses of cancer was given, and whether information and support was available and readily offered, was for all of the utmost importance.

There seem to be two key and inter-related reasons why the point of diagnosis was such an important juncture for respondents. Firstly, it was again very evident and important to continue to reiterate, from the discussion group and written submissions, that receiving a diagnosis of cancer is a life-changing event. Therefore respondents explained that they needed to be told in privacy and in a clear, sensitive, and supported way, and to be allowed time to assimilate the diagnosis. A few described these elements as being present when they were told their diagnosis and they were positive about how it had been managed. It seemed that where these elements were present it had helped these respondents and their families to better manage their diagnosis emotionally. Secondly, it appeared that how a diagnosis is given may impact on how, at least initially, respondents viewed their treatment and care. The words frequently used by respondents to describe what they needed following the diagnosis were 'reassurance' and 'confidence'. It appeared that where the giving of a diagnosis was well managed, it was then easier for respondents to feel reassured and to have confidence in the treatment and care they were about to receive.

Most respondents were told by a consultant their diagnosis of cancer, one was told by a registrar, and one by a GP at her request. Several recalled a nurse specialist being present when they were told. Although respondents said they appreciated being told in a clear and straightforward way, one respondent, who was very positive about the support and treatment he received subsequently, related how difficult it was when he was told in a very stark way:

“My surgeon said well you have cancer, but you have a choice. We can do nothing and it will kill you or you can have surgery”.

Respondent, mouth cancer patient

Another recalled her diagnosis consultation being handled badly:

“My husband and I were told that I had a tumour and it would mean surgery. Cancer, the word was not mentioned, and no-one offered counselling or any assistance just we would hear when surgery could be performed...I was scared to death, I was fighting not to break down and did not, as I did not want to embarrass any of us, but I broke down as soon as I got outside”.

Respondent, mouth cancer patient

Two respondents, both in written submissions, said that how they were given their diagnosis, in both cases by registrars, was not well managed. One wrote that she was given her diagnosis alone by a registrar, although he was aware that her husband had attended the hospital with her. She described feeling emotionally traumatised and isolated at the time the diagnosis was given and that this led to her feeling overwhelmingly out of control. She wrote that her predicament was compounded by a lack of information and for the moment she has decided not to embark on treatment. Another respondent wrote she was told her diagnosis by a registrar on a ward. She explained that she was asking about some of the drugs she had been prescribed, as she was breastfeeding at the time and she was anxious about whether she should continue to breast-feed. The registrar then told her, in anger, that she had cancer.

From the discussion group and the written submissions it was again apparent that those involved in imparting a diagnosis of cancer usually need to be consultants, specialist nurses need to be present and those involved, wherever possible, should have a stake in the patient's on going treatment and care. Respondents needed those imparting the diagnosis, to be able to give them, or at a later point according to individual needs, specialist information about the diagnosis and how treatment and care was to be managed.

A few respondents said how important it was for their spouses to be supported at the point of diagnosis and this was highlighted by 2 respondents' contrasting experiences:

“The support and the back up was tremendous, there was even a head and neck specialist nurse. I am glad she was there because my wife wasn't with me, she came afterwards and so the head and neck nurse had to look after her and coming away from hospital we knew that if we had any questions whatsoever to phone this number”.

Respondent, mouth cancer patient

“I felt so sorry for her. She was walking outside crying her eyes out. I did warn her. I think that is one of the things that should be there, a nurse or somebody who actually specialises in cancer and it should be a room set aside where you can go and have a consultation, where you can get it out of your system”.

Respondent, larynx cancer patient

4.2.1 Post- Diagnosis Information and Support

For all, it was clear that this was a crucial time to know that information and support was there:

“You are frightened aren’t you. And you do feel alone”.

Respondent, larynx cancer patient

“...the word ‘cancer’ shouldn’t be the only thing a patient is given at this stage”.

Respondent, larynx cancer patient

Respondents’ had mixed experiences of the level of information and support they were given following their diagnosis. Respondents said they needed those giving the diagnosis to provide: easy access to specialist support (including counselling), written information about the cancer and its treatments (tailored to individual needs), and advice on who to contact for further verbal information and with queries/ questions/ concerns after the consultation. For several this provision was made routinely, for a few, even if the diagnosis consultation had been well-handled, this information and support was absent and much needed.

At one end of the spectrum, a respondent said:

“From the minute I was diagnosed I have nothing but positive comments to make. All staff who dealt with me were clearly experts in their field and time was never a problem.”

Respondent, tonsil cancer patient

Whereas another respondent, who had a more mixed experience said:

“It’s the lack of information. I mean I didn’t know they had a support group, ...why didn’t anyone tell me? And I found out quite by accident..., I phoned and this man that answered said we’ve had this support group for 7 years”.

Respondent, thyroid cancer patient

This respondent received no written information and tried to get more information from her consultant, she then resorted to seeking help from a library:

“All my consultant kept saying was he was going to do a good job on me, and stop worrying. But it’s easy for them to say when it’s your body, and the word cancer is very frightening”.

Respondent, thyroid cancer patient

Another respondent explained:

“I would like to think right back to when you are told ‘cancer’ and then you are left alone; I would like that stopped. I would like for that person who is told cancer, to know what I know now, to put it in a package, ...and it should be given to that person.... You know you’re going on a journey. You want a map. You want a few clues, whether to turn left or right”.

(Respondent, larynx cancer patient)

Two respondents, from different parts of the country, mentioned how useful they had found a booklet, that they had come across at a later point, called, “Managing the Stress of Cancer” produced by the Bristol Haematology and Oncology Centre.

4.3 Summary of Recommendations

Hospital based Assessment

- Once the need for specialist hospital based investigation is decided, the patient and GP need to be kept fully informed of the process.
- The overall time scale for completing tests and investigations should be as rapid as possible and closely monitored by the hospital.
- The purpose of tests and investigations and what they will entail should be explained to the patient and written information made available.

Breaking the news of a diagnosis of cancer

- It should be suggested that patients bring a relative or friend to the ‘getting your results’ consultation (irrespective of the potential good or bad news) and the patient, if unaccompanied, should not be left alone once the diagnosis is given unless they ask to be.
- The diagnosis should always be given in a private, quiet setting.
- The diagnosis should always be given face-to face, in person (rather than by phone) unless the patient states expressly otherwise.
- Health professionals need to have very good communication skills and experience to impart a diagnosis of cancer.
- Senior specialist medical staff, who preferably will have an on going role in the patient’s treatment and care, should give the cancer diagnosis.
- During the ‘breaking bad news interview’, the number of health professionals present should be restricted to as few as absolutely needed.
- The diagnosis and its implications need to be fully explained, unless patients do not wish this, and time needs to be given to patients to understand and assimilate the diagnosis.
- An appointment for the patient to return again to discuss the diagnosis together with any possible treatment plans, should be made before the patient leaves.
- A trained and experienced clinical nurse specialist should be present at the diagnosis consultation and able to provide on going information and emotional support tailored to the needs of the patient and their partners.
- Written information, ideally talked through by health professionals – at the time or later according to the needs of the patient, should be freely available and offered.
- Information about professional support available, for example, social work support, should be provided routinely.
- Information about help lines, information and support centres, support groups and patient to patient support should be readily available.
- A key contact name and number should always be given at the point of diagnosis so the patient knows who to contact with queries or for further information.

5.0 TREATMENT

The proposals drafted to inform the development of the national guidance recommend planned and coordinated treatment provided by a specialist multi-disciplinary team, with specialist equipment and facilities. The core team who will have weekly team meetings and keep patient notes, and treatment plans – which are also sent to the GP and, if appropriate, the patient. All patients should undergo pre-operative assessments. Side effects of treatment should be fully explained to patients and written guidance and support should be provided.

Most respondents, once they had received a definitive diagnosis, started treatment fairly promptly except for one respondent whose radiotherapy did not commence until several weeks later. One respondent, who gave a written submission, decided not to embark on treatment, the reasons for this are referred to in Section 4.2 above.

5.1 Deciding on Treatment Options

It seemed that most respondents were steered into a particular course of treatment by their consultant. One respondent said she was told about a clinical trial. How much respondents were told about their proposed course of treatment and its ramifications appeared to vary a good deal. A few described their consultants as simply telling them what the treatment would be:

“They said to me this is going to happen”.

Respondent, mouth cancer patient

“I was informed by the surgeon that he would take a slice off my tongue, and remove the floor of my mouth, and the skin for the graft, would be taken from my leg”.

Respondent, mouth cancer patient

“I was told I couldn’t have radiotherapy because it was too big, it wouldn’t do me any good and I could be wasting their time. The only option that was left was a laryngectomy which I jumped at because I knew it was going to save my life”.

Respondent, larynx cancer patient

One respondent described her consultant as being reluctant to elaborate on the treatment she required and, when she was told that she would have to have a period in isolation she explained that she was initially fearful of what this would entail. She therefore asked to see the room where she would have to stay in isolation, her consultant was surprised at this request but agreed that she could see it:

“I didn’t go in for about six weeks, but at least in that six weeks I didn’t have a vision of this horrible room, with big bars on the window”.

Respondent, thyroid cancer patient

Another respondent recalled her surgeon telling her quite explicitly what her treatment would entail and all the possible side effects. This respondent spoke very highly of the treatment and care that she received but this description of her treatment by the surgeon was so daunting that she initially delayed undergoing surgery. It was prompting by a family member that encouraged her to rethink:

“Well the surgeon ... was a marvellous man, but he made it sound so terrible, that I really didn’t have the will to live after that. It was his style to tell you everything that could happen, but as it was, half the things he mentioned didn’t happen”.

Respondent, mouth cancer patient

One respondent described in very positive terms how he and his wife were told about his treatment and that the consultant took some time to explain the treatment and what would happen subsequently. It seemed that this approach helped the respondent and his family to prepare for treatment.

5.2 Multi-disciplinary team working

Most respondents were aware of there being a team, although many had worked this out for themselves rather than being told about their team or receiving written information. Most of those who thought they had a team felt their team worked in a reasonably planned and coordinated way. Having a team that took a consistent approach and had a common purpose was clearly important:

“...from diagnosis to aftercare, nurses to consultant, everybody worked as a team and the consultant was always available if I had any queries”.

Respondent, larynx cancer patient

A few respondents highlighted not having access to a specialist nurse and felt this was a significant gap. Others were able to relate how important access to a specialist nurse had been to them:

“Mine actually came to my house, before the surgery...and spent two hours drawing diagrams, showing what was going to happen, what was going to happen afterwards”.

Respondent, tonsil cancer patient

In the discussion group, one respondent described having access to a social worker and had found this invaluable in terms of having a caring professional to talk to and also having the expertise to give benefits advice.

The other most frequently mentioned members of the team were speech therapists and dieticians. However, access to these professionals appeared to vary widely and some had sought out this help for themselves. This is discussed further in Section 5.5 below.

5.3 Patient Information

All respondents wanted information and wanted it to be readily available, although it was also suggested that this might not be the case for all patients. All respondents received information verbally about their treatment and felt this information needed to be provided by ‘specialists’, professionals who were able give a truly informed response and had good communication skills. A constraint identified by several respondents was that their health professionals did not really have the time to give full explanations or respond to queries. A few visited cancer information centres and had found this helpful. Some respondents said they also received written information but several said this did not meet their needs. A couple had received individually tailored patient information – one in the form of a patient held record, and another, a copy of their treatment plan. All respondents were very positive about the idea of receiving a copy of their treatment plan.

It appeared that all respondents needed to know, at least in outline, what their overall treatment plan was and what the estimated time scales might be, both for treatment periods and recovery.

It seemed that for many there was a need to explain the overall treatment plan at the outset and to give detailed information incrementally or as required by the patient. There appeared to be several reasons why having this information was important. First and foremost, at a psychological and practical level, respondents and their families needed to know the scale of the challenge they faced. One respondent, having undergone one operation was unaware that further surgery was likely to be required although it became clear that her surgeon knew this from the outset and she found this approach unhelpful. Another who needed radiotherapy was given no indication of what this would entail:

“... no counselling and warning me of what was to come, with the making of the mask, fitting etc”

Respondent, mouth cancer patient

This series of NCA studies has indicated that some health professionals, possibly in order to try and protect the patient, may have a tendency to understate how long treatment and recovery will take or the possible severity of side-effects and how long these will last. The studies have also suggested that it is perhaps inevitable for patients to want to ‘benchmark’ their side effects and recovery. Therefore, it seems that if they are told that side effects will wear off fairly quickly or that the period of recovery is likely to be relatively brief and this does not happen, patients then worry that the treatment has “gone wrong” or “failed”. This also has an impact on families and carers as they are likely to have underestimated the length of time for which active support is going to be needed. One respondent illustrated this when she said she was advised she would lose her sense of taste for 2 to 3 days after radiotherapy. However, her loss of taste lasted for over 6 weeks and this led her to worry that something was wrong and she anxiously followed it up with her hospital team.

5.4 Support

In the discussion group, respondents used the term, ‘support’ to describe both the emotional support and practical inputs a patient might need at different stages. Descriptions of support included: receiving emotional and psychological support in the form of advice and counselling from professionals, emotional and practical help from other patients, and practical inputs from professionals – specialist nurses, social workers, complementary therapists, so that patients could manage the treatment process as well as possible.

In terms of emotional support, all respondents agreed it was important for all patients to be aware of what support services were available and how they could be accessed. A couple of respondents said that their own families had met their emotional support needs but they knew how to get support elsewhere if needed. It was again agreed that, at least in part, the support available also needed to be specialist – that is, offered by professionals who understood head and neck cancers and the psychological and physical impact of these diseases and their treatments. Practical support, such as advice about benefits or help with travelling to and from hospitals for treatments, was also felt to be needed.

In addition to specialist professional support, all agreed that there was potential value in receiving support from other patients, either on a one-to-one basis, or as part of a support group. A few respondents had been able to join patient groups where others had had the same diagnosis and treatment and they felt this had been very important. The complexities of patient to patient support were readily recognised but it seemed that most felt making ‘befriending’ or ‘buddy’ schemes available was valuable and important. There was general agreement that any such scheme needed careful management to ensure all those recruited worked within clear boundaries. A couple of respondents commented that laryngectomy clubs at local hospitals were starting to close as specialist nurses moved to work in large head and neck teams at regional centres. There was general agreement that specialist support needed to be maintained at a local as well as at a regional level.

A few respondents also gave particular emphasis to the importance of families getting the support they need during periods of treatment. The carer respondent agreed that she had found it important to be able to have other carers to talk to at the hospital while her husband was undergoing treatment.

5.5 Undergoing Periods of Treatment

The main themes that emerged during the discussion around undergoing treatment were: the need for specialist medical, nursing and related inputs and the importance of treatments and their side effects being managed in a patient-centred, holistic way. Wherever possible, respondents were keen to praise their professionals and express their appreciation for the treatment and care that they had received.

There was also a high level of awareness of the burdensome workload many professionals face and several commented on the impact of staff shortages, especially in nursing. Where there were criticisms, the majority of these related to the absence of specialist care or where professionals did not seem to take a responsive, holistic approach. In describing the need for a holistic approach, there was no expectation of professionals to have professional knowledge on all issues but that they should be able to signpost or provide access to other professional expertise or support as needed. It was apparent that any criticisms were given because they had been of immediate, short-term or long-term consequence.

“The surgeons only really seem interested in their particular area of expertise. They seem to show little interest in after effects such as difficulty in swallowing and eating”.

Respondent, tonsil cancer patient

5.5.1 Specialist Input

The need for ‘specialist’ medical and nursing input was an on going and much emphasised theme throughout the discussion. Once in receipt of specialist care, this made respondents very much aware of the knowledge, skills and experience their professionals needed to give effective treatment and care for their cancer. Hence, respondents often spoke very highly of their specialist professionals:

“And they were experts, all the nurses were absolute experts on what they had to do, nothing was too much trouble”.

Respondent, tonsil cancer patient

It was also clear that respondents were very much aware if specialist input was not available:

“My first operation, I was in a ward that specialised in head and neck surgery. All the nurses and doctors involved were specialists in that area and it gave you a lot of confidence knowing that they were so specialised. By the time my second operation came along ...I was in a general surgical ward and the difference was quite remarkable, it was nowhere near as good, the nurses were nowhere near as expert in my particular disease”.

Respondent, larynx cancer patient

Another related being on a newly opened specialist ENT ward:

“None of the staff had been through a laryngectomy before... One ENT sister, who’d worked in London, knew what to do”.

Respondent, larynx cancer patient

One respondent, in a written submission, said she experienced particular difficulties due to the lack of specialist nursing care post-operatively and, she wrote that as a consequence the pain relief she needed was not administered:

“I came round in terrible pain, rang my bell again and again, ...a nurse came, she was an agency nurse, she did not know what I could have so she went away and never came back...”

Respondent, mouth cancer patient, written submission only

The few respondents who had a dedicated nurse specialist thought that it was not just desirable, but essential that every patient, as suggested in the guidance proposals, should have a key worker.

5.5.1.1 Dietetics

Prior and during treatment several respondents mentioned receiving varying levels of dietetic advice and support. Several had found that their consultants were simply not interested in this area although it was causing them significant difficulties. All felt that this was a very important area of care and for most it was not systematically or well provided:

“I think something ought to be done about food, because I think a lot of trouble is caused by diet”.

Respondent, mouth cancer patient

Several respondents mentioned their eating difficulties being compounded by the poor quality of the food available in the hospital and/ or it being unsuitable for their needs:

“The irony was that the catering department couldn’t cater for the food, they didn’t seem to understand what liquidised food was, whatever came up..., it was always solid, and we kept sending it back. In the end they were sending up these same drinks, day after day”.

Respondent, tonsil cancer patient

One respondent had found that he experienced intense pain on eating certain foods but was unable to get professional advice, his surgeon said he could do nothing about it. The respondent proceeded to keep a record of his diet himself in order to establish what foods triggered this adverse reaction.

5.5.1.2 Speech Therapy

All respondents agreed that speech therapy had a key role to play in their rehabilitation after treatment. Respondents explained that this was for speech and determining whether oesophageal speech would be possible, as well as for learning swallowing techniques. Most respondents had access to speech therapy in hospital, some described having a very good service but others had found it less satisfactory. One respondent sought out speech therapy support for himself once he had returned home.

The need for this specialist input seemed especially important for head and neck cancer patients. This was because, for some, having undergone radical surgery, the difficulties they faced could be compounded by a sense of isolation due to being unable to communicate freely:

“I seemed all alone as I couldn’t talk, so no-one spoke to me”.

Respondent, larynx cancer patient

5.6 Patient Centred Treatment and Care

Several respondents described the emotional and physical energy it took to undergo treatment, especially if they had to summon up the stamina to embark on further treatment once one course was finished. It was felt by some that their consultants, even where they held them in the highest regard, needed to be more aware of the overall impact and consequences of treatments. It was also felt important for health professionals to be mindful of the physical and psychological consequences of the cancer and/ or its treatment to ensure that patients received medical help, not necessarily oncological, and the support that they needed. Where this was present it was appreciated greatly:

“all the staff I had looking after me were very aware of what I, as a patient, was going through, and made every effort to assure me of the success of my op”.

Respondent larynx cancer patient

“... the whole team went out of their way with patient’s care and sensitivity, especially for cancer care. This special treatment or caring attitude included the team’s attitude to family and friends, it is difficult to explain, but very special and certainly did not go unnoticed”.

Respondent mouth cancer patient

It was also very clear, especially where several respondents had just undergone radical surgery and were at their most vulnerable, just how important the human touch was:

“You are drifting in and out of consciousness because the anaesthetic is wearing off and you see all these machines and then a smiling face which is reassuring, you know somebody is taking care of you”.

Respondent larynx cancer patient

“The surgeon came night and morning to see me to make sure all the nurses knew exactly what they had got to do if something went wrong... He never said very much, but he was just there”.

Respondent mouth cancer patient

In contrast, a few respondents had instances where they had been treated less sensitively in the period prior to treatment or in the post-operative period and these events had clearly stayed in their minds. One respondent described how difficult it was when she was having her mask fitted prior to radiotherapy:

“the screws and mask would not align up in my case, the eyes of the mask were not cut out at that time, and for 2 hours I was frightened to death with not being able to see... The nurses, at one time 3 and 4 trying to fit my mask, were naturally getting very frustrated and cross, ... when they certainly should have been considering the patient”

Respondent mouth cancer patient

Another respondent, who felt that overall his treatment and care had been good, still recalled vividly the first time a suction tube was used to clear his lungs:

“I’ve been frightened in my life several times. But that absolutely had me coming off the bed – screaming, trying to scream. For me, that’s the worst thing”.

Respondent larynx cancer patient

This respondent then explained that a difficult procedure had been made worse because he felt it had been administered badly and he had not been told what was to happen:

“...not knowing what they’re going to do next is one of the most frightening parts”.

Respondent larynx cancer patient

Many respondents spoke of the routine communication difficulties they experienced with staff post-operatively. A couple of respondents commented on nursing staff trying to guess what they wanted, before they had finished their sentence, and invariably getting it wrong. Another said he had been reluctant to write his requests as he was embarrassed by his writing skills and as a result had been unable to communicate his needs adequately.

5.6.1 Hospital Environment

Several respondents commented on the hospital environment where they received treatment. Some had attended out patient clinics where they had had to wait, often for considerable periods of time and sometimes having travelled long distances, in areas that were bleak and depressing. A few suggested that there should always be access to beverages, even if just via a vending machine, and that using volunteers could create a friendlier environment. A few respondents had attended the same hospital for radiotherapy treatment and a couple described this experience as quite isolating as facilities were dispersed across different floors and this also meant waiting in different areas.

Several respondents, as in-patients, had had private rooms and appreciated this, one commented that having had radical surgery, a general ward would not have been appropriate.

A respondent in a written submission emphasised the need for neutropenic sepsis beds having access to a tv, radio, and telephone to ease the isolation.

5.7 Side effects

Many of the respondents said they had been advised about most of the short-term side effects of their treatments and appreciated that side effects could vary greatly from patient-to-patient.

One respondent, in a written submission, said she found out by chance that she would have ulcers as a side effect of the treatment. One respondent mentioned suffering a great deal from receiving too much radiotherapy treatment but the GP and the radiotherapy department had been unable to help. Eventually, after 18 months of trying to get help, she resorted to contacting a network of mouth cancer patients for advice. Another related being warned that as a result of radiotherapy he would lose his sense of taste for a time, he said that this still did not prepare him for just how strange this was:

“I’ll tell you what, they never prepare you for it. It is the weirdest thing in the world and its horrible. I couldn’t have anything, no food, it’s horrible”.

Respondent, tonsil cancer patient

Other respondents then echoed this statement, agreeing that losing sense of taste is very strange.

All respondents displayed a stoical and often pragmatic approach to their treatments and side effects. Despite this being a common overall attitude to treatment, several had still found it difficult to cope with some of the side effects they had experienced. It was clearly very important that professionals are responsive and sensitive and make available any additional professional input that was required.

5.8 Summary of Recommendations

Deciding Treatment

- Regardless of where you live, the most effective and up-to-date treatments, including those on clinical trial, should be offered and available to all.
- Treatment options should be clearly presented to patients in a sensitive way. The evidence base for those options clearly stated, and written information on the options and evidence supporting those options should be readily available and always offered.
- Technology should be used to ensure that doctors have speedy and easy access to nationally accredited and regularly updated information on cancers, available treatments, and clinical practice.
- Trained and experienced clinical nurse specialists, or similar, should be available to provide information and support, including psychosocial support, when deciding treatment, and throughout periods of treatment.

Undergoing Treatment

- A designated **key worker**, probably a clinical nurse specialist, should be provided for every patient.
- An overall treatment plan, outlining what the treatments entail and the estimated time scales involved should be discussed with the patient and a written copy given.

- Known side effects of proposed treatment options (short and longer term) should be given to patients in a considered and straightforward way. (If side effects of a treatment are unknown or uncertain but considered likely, this should be stated clearly.)
- Professionals should take full account of the potential physical and psychological impact of side effects on a patient and provide ready access to relevant professional expertise and support as required.
- Monitoring of side effects should take place and, where present, should be actively managed and patients referred for relevant professional expertise.
- All ‘in –patients’ should be treated on a specialist ward with specialist nurses.
- Systematic access to specialist dieticians and speech therapists should be made available prior and during treatment.
- Hospital catering services should be obliged to be able to routinely cater for the needs of head and neck cancer patients.

Support and Information

- Systematic access to experienced counsellors and complementary therapists should be made available and routinely offered to all patients during the treatment process. Counselling should also be available to patients’ families.
- Befriending schemes, so that people can be in touch with others who have undergone the same treatment, should be offered and facilitated by the hospital.
- Access to benefits and housing advice should be facilitated by the hospital and routinely offered to all patients at an early stage.
- Patient information should include a list of who is in their team, a summary of how the clinics and doctors function together, their various responsibilities, a written explanation of the appointment system, and who a patient or carer can contact if necessary. The use of patient held records should be encouraged.

6.0 FOLLOW-UP AND AFTER TREATMENT

For follow-up, the proposals drafted to inform the guidance propose that follow-up should be for up to 5 years. In terms of post treatment care, the proposals suggest that there should be a dedicated service for the provision of post-treatment care for patients. Post-treatment care should include: speech and swallowing support, nutritional support, oral care support, physiotherapy, pain control and psychosocial help. It is also proposed that non-head and neck professionals should be educated on the special needs of patients with tracheotomies and speech difficulties.

6.1 Follow-Up

There was limited discussion of follow-up within the group. However, all saw on going follow-up as important and reassuring. Some thought follow-up should continue for life whereas others felt that up to 5 years was quite adequate. There was also a mixed response as to how follow-up had been managed, with some who felt that their follow-up was well organised and planned and others who felt there follow-up was virtually self-managed.

A couple of respondents said, if they needed to they could go straight to their ENT clinic or ward if they were experiencing problems. This direct and flexible approach was valued.

6.2 After Treatment

One respondent, in a written submission, described the period after treatment as a state of “nothingness”, and went onto write:

“...this is a common cancer patient experience. People feel as if they are ‘in-limbo’, suddenly left to their own resources”

Respondent, adenoid cancer patient, written submission only

A few respondents in the discussion group described feeling alone at this point and one described the difficulty of adjusting back to daily living:

“I was happy the op was over but at the time did not know just how back to normal I would get...”

Respondent, larynx cancer patient

In this study, almost all respondents had found their speech had been affected as a consequence of their treatment, for some the treatment had also affected their physical appearance, and many had faced radical changes in their diets. These significant changes meant that on a day-to-day basis most respondents were continually reminded, often in a quite overt way, of living with the consequences of having a head and neck cancer and how this had also impacted on how others related to them. Several respondents related how these differences, for example, in speech, could be easily misunderstood by others and that this ignorance could be an added strain. One respondent, in a written submission, wrote how in her dreams she had ‘normal’ speech, but had to face reality when she awoke.

It seemed that some respondents had quite limited contact with their GPs both before and during and after treatment episodes, and several respondents felt their GPs needed more knowledge about their post treatment needs:

“The GP could have benefited from after care information”.

Respondent, larynx cancer patient

It appeared that how this after treatment stage was managed varied a great deal for respondents. At one end of the spectrum were a couple of respondents whose transition home was actively managed and supported, with the involvement of their specialist nurses. Another had the help of a district nurse although he had to guide her in what to do, and others seemed to access help and services through a mix of planning and chance or had had to actively seek out what they needed for themselves:

“The District Nurse said would I like a palliative care nurse to come in. And she is uper, absolutely super, but why didn’t somebody else tell me about her before, she could have elped me or my family, for four years I have had no one”.

Respondent, mouth cancer patient

Another respondent, who had sought out speech therapy and physiotherapy help for himself, said that he thought what was needed at this point was,

“written information, access to head and neck nurses, list of information and support services, and a diary to note: symptoms, progress, questions for visits etc”.

Respondent, mouth cancer patient

A couple of respondents had had particular difficulties relating to the removal of peg tubes. Both had returned home with the peg tube still inserted and for one, this had been the cause of considerable discomfort and stress, it was removed only when she threatened to pull it out herself.

It was again agreed that patient to patient support and support for families and carers needed to be readily available at this time.

6.3 Summary of Recommendations

- Follow up should be provided by the specialist team and be planned and managed by a key worker in consultation with the patient.
- Information on how to access the specialist team between appointments, if needed, should be given to all patients.
- Particular attention should be paid to supporting patients to adjust back to daily living in the period immediately after treatment. A priority should be to address the speech and dietary needs of every patient.
- Primary care professionals need to be educated in the after treatment needs of head and neck cancer patients so that they can play an active role in managing and supporting their after treatment needs.
- Information about palliative care services and its potential value from diagnosis onwards should be given to the patient

7.0 CONCLUSIONS

This section draws together overall conclusions. Specific recommendations on the drafting of the head and neck guidance, based on the collective experience of all the respondents who participated in the project, are given at the end of each of the previous sections.

It is important to note that although we talked to patients with different head and neck cancers, who had received different treatments at hospitals around England and Wales, many expressed similar needs and views. The strong, underlying themes in the discussion group and in the written submissions was the need for services to be **patient-centred and systematic, specialist and holistic**. Retrospectively, all in the discussion group felt that to **get a diagnosis as speedily as possible**, necessitated that a systematic approach was taken from the GPs or dentists onwards. As well, when exploring what patients needed, **the need for specialist services** staffed by specialist professionals was repeated frequently and with great emphasis. This emphasis was perhaps a direct result of many being able to compare and contrast their experiences of dealing with specialists and specialist services and non-specialist services. Relating to the themes identified above, the key issues that were repeatedly raised related to the need for:

- good communication and information between health professionals and their patients
- good communication and information between health professionals within the hospital and between the hospital and the community
- services to be well organised and for treatment and care to be planned and delivered in a patient centred and holistic way
- all health professionals to be aware and remain aware of the impact a diagnosis of cancer can have on the patient and to understand that it is frightening and some treatments may also be frightening and an ordeal for the patient
- all health professionals to be aware and remain aware of the short and longer term consequences of undergoing treatments for head and neck cancer and the whole life impact that this may have for the patient. For example, changes in appearance, changes in speech, eating difficulties.

Respondents reflected in a measured and considered way about the services they had received. All respondents wanted to be constructive as possible about their experiences and, wherever possible, wanted to relate **positive examples**. They were therefore very keen to give praise where they felt praise was due and to note any improvements they had seen. However, it seemed that for all the greatest shortfall in their overall experience of head and neck cancer services was the lack of a holistic approach to their needs. As the diagnostic process and subsequent treatment and care got underway, the need for **professionals to take a holistic approach** came to the fore. Even those respondents who, overall, had a positive experience and expressed very positive views about their health professionals still found that some of the day to day problems they experienced during and after treatment, for example dietary matters, were neglected or simply ignored.

If these needs are ignored, this may well affect a patient's emotional and physical well being and therefore may undermine the effectiveness of their treatment and care. Respondents clearly did not expect their professionals to be able to address all their needs but needed them to be able to refer or sign-post them to the help or support they needed. This need for a holistic approach links back to the need for a systematic and co-ordinated approach to be taken so that the best use of the multi-disciplinary team, including the wider team, and existing services and resources can be utilised.

Again, as was found in the previous NCA studies commissioned by the NCGG, patients and carers who participated in this project gave very generously to share their knowledge and experience of head and neck cancer services and their views on developing guidance for these cancers. This was demonstrated by all those who attended the group, many travelling some considerable distance to do so, and those unable to attend but still contributing by sending a written submission. The driving reason for this generosity was a strong desire to help improve health services and a real concern and willingness to directly help other patients.

On the basis of these findings, it is appropriate to partially re-iterate the final conclusion given in the previous studies. If the overall aim of the head and neck guidance is for commissioners to provide patient-centred, efficient and effective services, it will need to not only address the detailed ‘content’ of the services, but to also focus as much on the structures, systems, and professionals needed to deliver the service, together with the linkages between them. Staying focused on the needs of the patient and the patient perspective is the most likely way of achieving this successfully. This approach will help ensure that the specialist services needed are accessible, the content of the services remains appropriate and patient-centred, and service delivery is successful.

National Cancer Alliance

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