



Equality Impact Assessment

On the

**Head and Neck Cancers, Ear, Nose and Throat
and Oral and Maxillo Facial Services Review**

(Access and use of the service by patients)

Version 1.0

Contents

Front Sheet	3
Identifying the aims of the service	4
Information and Intelligence	5
Key Findings	6
Race	8
Religion or Belief	14
Disability	16
Gender and age	20
Sexual Orientation	24
Action Plan	26

Equality Impact Assessment Front Sheet

Name of the service being assessed: Head and Neck Cancers Services Review

Directorate: Public Health

Date Impact Assessment completed: 15th June 2010

Is this a new or existing service?	New	N	Existing	Y
Is this a provided or a commissioned service?	Provided	N	Commissioned	Y
Is this EIA part of a service review or a service change?	Review	Y	Change	N

On which equality strands/target groups has this Impact Assessment been carried out?

Race Y Religion or Belief Y Disability Y Gender Y
Age Y Sexual Orientation Y Health

Names and roles of the people carrying out the Impact Assessment (ie the steering group):

This document has been produced as part of the Head and Neck Service Review. The project team meeting for this review has been used to discuss the document and the project board has signed it off. The Project Team comprises of the following members:

Ruth Hallett, Hoda Booz, Lucy Ellis – Brookes, Kate Cooke, Diane Cornish, Dany Bell, Serena Fazel, Trevor Foster, Ardiana Gjini, Daphne Havercroft, Ceri Hughes, Tony Jones, Emma Phillips, Amanda Saunders, Richard Smale, Claire Thompson, Paul Tierney, Tariq White

Service Manager	David Tappin
Signature	
Date	

1. Introduction

This is an equality impact assessment of the plans for a new hub, satellite and spoke configuration of head and neck cancer services across the Avon, Somerset and Wiltshire Cancer network and the centralisation of ear nose and throat services (ENT) and oral maxillo facial services (OMFS) inpatient services for Bristol. Clinicians have clearly stated in the clinical model that the centralisation of surgical head and neck services would require the centralisation of inpatient ENT and OMF services. Whilst ENT and OMFS are two related but distinct specialities, head and neck cancer services are a sub speciality of the two. Head and neck cancer services are delivered by a multi disciplinary team approach provided by both ENT and OMFS and surgeons have a shared case load to diagnose and treat head and neck cancers. It is also worth noting that the scope of the review only covers adult services (age 16+).

This equality impact assessment considers the six highlighted equality strands (race, religion or belief, disability, gender, age and sexual orientation) as well as additional factors around deprivation, risk factors and where people live. These have been included as it is recognised that most head and neck cancers can be attributed to lifestyle choices such as smoking and drinking alcohol and as it has been reported that there is a nine year difference in life expectancy between the most affluent and most deprived wards in Bristol (McMahon, 2008).

In November 2004 the National Institute for Clinical Excellence (NICE) issued 'Guidance on Cancer Services: Improving Outcomes in Head and Neck Cancers' promoting centralisation of services covering a population of one million people treating over 100 cases per year.

The Bristol, North Somerset, South Gloucestershire (BNSSG), Bath and North East Somerset (BaNES) and Wiltshire and Somerset health communities already benefit from high quality head and neck cancer services. Clinicians are keen to build on this to create the "South West Head and Neck Institute" - a regional centre, nationally and internationally renowned for world class patient outcomes and pushing the boundaries of clinical excellence in which a single team will work cohesively with the optimum mix of services co-located where possible.

2. Head and Neck Cancers Overview

There are over 30 specific cancer sites in this group and cancer for each particular site is relatively uncommon. Head and neck cancer as a group of cancers is uncommon and therefore the number of patients accessing the service is few, with only 182 new cases being registered across the Bristol Trusts in 2007.

Treatment of these cancers require similar skills and so services to treat a range of head and neck cancers can usefully be grouped together.

There are some differences between Equalities considerations Thyroid and upper aerodigestive tract cancers. For example there is a strong link between upper aerodigestive tract cancers and Social deprivation, but none has been found for Thyroid cancers (6)

There are also strong links between certain risk factors and some head and neck cancers. Some of these risk factors are widely practiced amongst certain Equalities groups and because of this; there is information under some equalities group section of

risk factors which are particular to this group. This is especially true of the “Race” equalities group where differences in lifestyle mean that there is an increased risk of some head and neck cancers for some groups.

3. Ear, Nose and Throat Services Overview

ENT services specialise in the diagnosis and treatment of ear, nose, throat, and head and neck disorders, including facial plastics and some cosmetic surgery.

Diagnosis and treatment of the ears commonly include hearing loss, ear infections balance disorders and tinnitus. When ear surgery is indicated, it involves microsurgical techniques including reconstruction of the bones of the ear, mastoid surgery and implant insertion.

Diagnosis and treatment of disorders relating to the nose include injuries and deformities of the nose, cosmetic surgery, adenoidectomy, sinus infections, seasonal allergies and tumours of the nose and sinuses. When surgery is indicated it may involve septoplasty, septorhinoplasty surgery or endoscopic sinus surgery utilising minimal access techniques with endoscopes and camera monitoring. Surgical navigation systems may be used for safety. In some circumstances more major nasal resections are necessary.

Inflammations of the throat and tonsillectomies, laryngitis, snoring, voice and swallowing disorders and tumours of the throat and larynx are also treated and diagnosed by ENT services. When indicated, surgery of the pharynx, larynx and upper digestive tract is either external or endoscopic. It may encompass major resections and primary reconstruction.

ENT services also treat and diagnose head and neck disorders including swelling of the neck, cysts and thyroid disorders and benign and malignant tumours of the lymph and salivary glands. A number of cosmetic procedures are also performed by ENT services.

ENT services are accessed from infancy to end of life. Because ENT covers such a wide range of conditions and such a high proportion of patients presenting to GPs have ENT symptoms, the referral rates from General Practice to ENT are very high; ENT consultations accounted for 4.4% of all NHS outpatient attendances in 2008/09 (<http://www.hesonline.nhs.uk>). Given that only 12% of these consultations result in hospital admissions, the outpatient consultation and its outcome is crucial for good practice in ENT.

For this reason, the diagnostic skills, the doctor patient interaction and often the reassurance given in the outpatient setting have a major bearing on the quality of the service in ENT – the “therapeutic consultation”. The 12% of patients referred to ENT who are admitted for surgery need a wide range of operations and so when surgery is necessary the variety of techniques used is extensive often requiring high technology and expensive equipment.

4. Oral Maxillo Facial Services Overview

Oral and maxillofacial surgery is the surgical specialty concerned with the diagnosis and treatment of diseases affecting the mouth, jaws, face and neck.

The specialty of oral and maxillofacial surgery is unique in requiring a dual qualification in medicine and dentistry and is a recognised international specialty.

The scope of the specialty is extensive and includes the diagnosis and management of facial injuries, head and neck cancers, salivary gland diseases, facial disproportion, facial pain, temporo mandibular joint (TMJ) disorders, impacted teeth, cysts and tumours of the jaws as well as numerous problems affecting the oral mucosa such as mouth ulcers and infections.

Oral & Maxillofacial (OMF) Surgeons are the specific experts on diseases affecting the mouth, face, jaw and neck. As a result of their training, OMF Surgeons diagnose and treat symptoms, pathology, deformity and trauma affecting the mouth, face, jaws and neck.

As a result of treating diseases located in this anatomical region, OMF Surgeons can provide advice on multi-system pathology where this affects the head and neck. Furthermore, advice is provided for specialities such as clinical oncology to minimise and treat complications in the head and neck, following therapies provided by these other speciality groups.

5. Information and Intelligence

List the available data (both quantitative and qualitative) which will support the impact assessment:

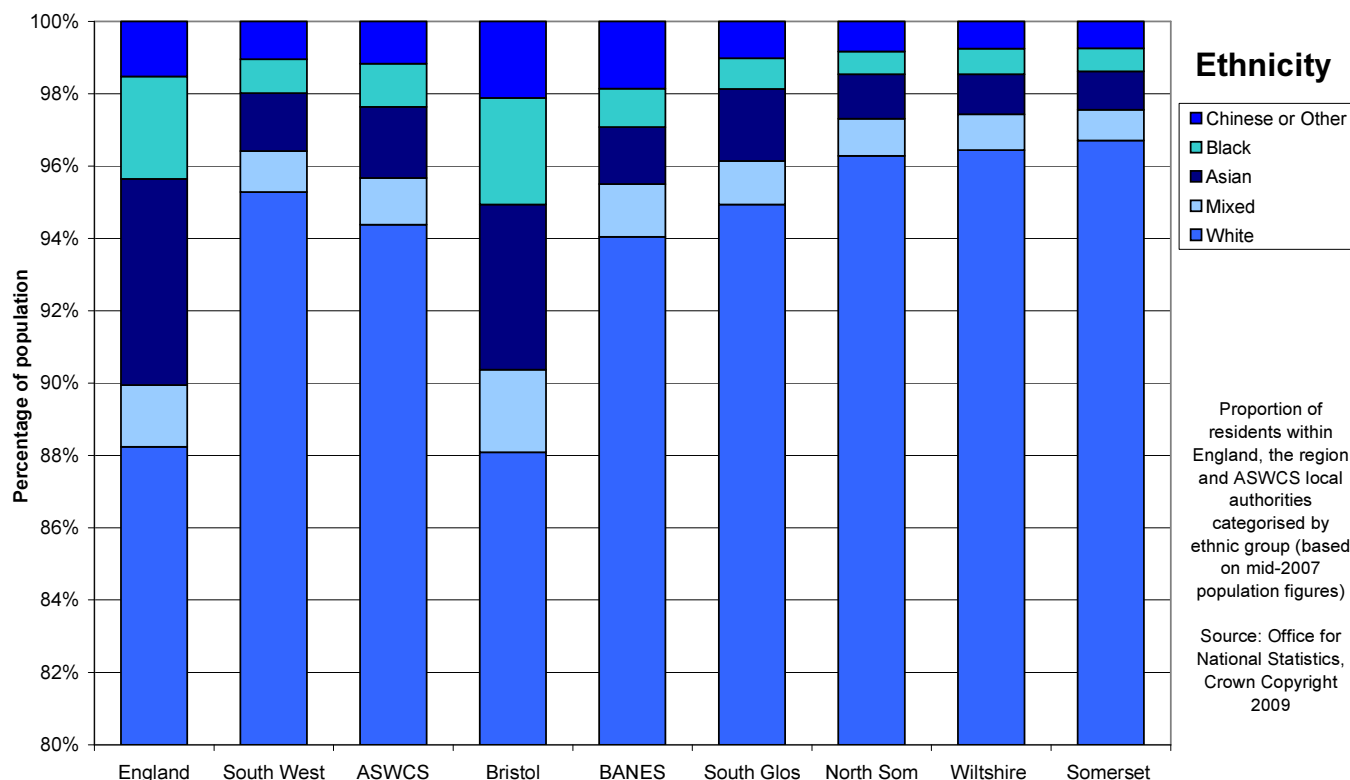
1. Head and Neck Cancers Services Review Health profile presentation
2. Head and Neck cancer patients engagement event on 27th April 2010
3. Department of Health Equalities Impact Assessment on Cancer Reform Strategy
4. Case Studies
5. Data from MDTs for 2009
6. Guidance on cancer services improving outcomes in head and neck cancers (IOG)
7. Lucinda Platt: *Parallel lives? Poverty among ethnic minority groups in Britain*, London 2002
8. Duleep Allirajah, Dr Katia Herbst and Dr Louise Morgan: *Free at the point of delivery: exposing the hidden cost of hospital travel and parking for cancer patients*, London, Macmillan Cancer Relief in association with Dr. Foster, 2005
9. National Audit Office: *Tackling Cancer Improving the Patient Journey*, London, National Audit Office, 2005
10. Census
11. Telephone conversation with Kate Mc Dermott, Health Facilitation Co-ordinator
12. Interviews with patients and patient relatives – names withheld.
13. Interviews with Speech and Language therapists
14. Interviews with ENT patients at St Michaels Clinic 22nd July 2010
15. Interviews with ENT patients at Southmead at clinic 27th July 2010
16. Bristol Joint Strategic Needs Assessment, NHS Bristol and BCC, 2008
17. Gale L, Naqvi H and Russ L (2008) *The Health of People with Learning Difficulties in Bristol*, Bristol Public Health Department
18. Scully C, Bedi R (2000) *Ethnicity and Oral Cancer*, *Lancet Oncology* Sep; 1(1):37-42

6. Key Findings

- The new service needs to gather, analyse and report equalities data and this requirement should be built into the service specification
- There is an increased risk for certain ethnic groups e.g. South Asians
- There should be partnership work with other agencies and services to raise awareness of Head and Neck cancers and risk
- Some groups may not understand what cancer or ENT and OMFS disorders are and the service should take care when communicating with all patients
- There should be more information about the cancer, treatment, the effect on quality of life and how long a patient has to live
- Recognition that different groups use English in different ways
- “end of life” planning and care is important
- The service must plan communication and feeding for the immediate post operative period needs planning in advance
- The route via a dentist is less accessible for patients with Learning Difficulties
- Transport needs of older and disabled people need to be considered
- To support patient choice, the service should consider giving the option of either savory or sweet Percutaneous endoscopic gastrostomy (PEG) feeds
- There should be more proactive signposting to cancer help for minority ethnic communities
- The service should consider allowing patients to pre order food in advance of their operation with support from a dietician where appropriate
- Patients and family members should be provided with a quiet space as part of the ward/ space design for the newly centralised service
- There needs to be some consideration to allow family members to stay and support patients, when appropriate
- A shuttle service between North Bristol Trust and University Hospital Bristol sites need to be investigated which could be used by both patients and staff
- A leaflet needs to be produced which explains access to the University Hospital Bristol sites including public transport and parking facilities nearby
- There needs to be a follow up of the health check for patients with Learning Difficulties for those who are identified as not being registered with a dentist
- Commissioners should consider giving dentists similar Learning Difficulties training as that offered to General Practitioners
- Providers should ensure that translation and interpretation services are offered to every patients for whom English is not a first language

7. Assessing the Impact – Head and Neck Cancer

7.1 Race

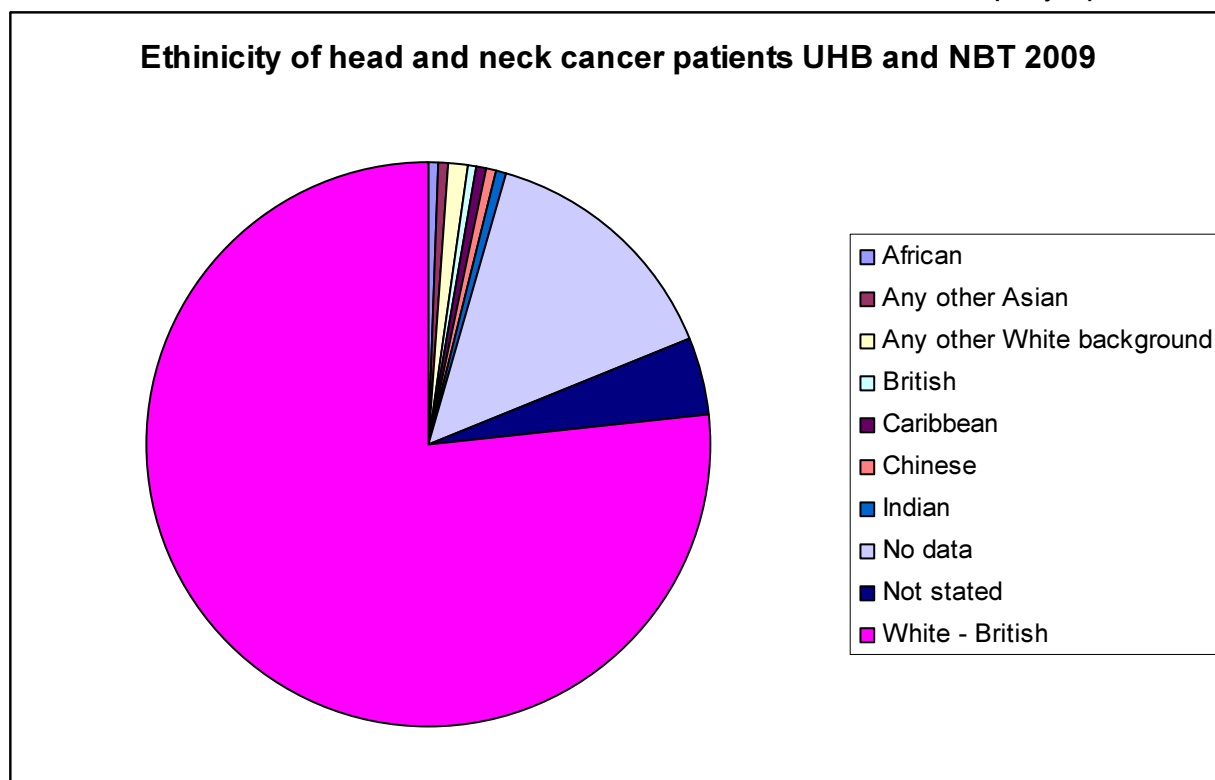


The above graph shows the ethnic profile of the local population (not just patients with cancer).

We can see from the graph that Bristol has a larger Asian and Chinese population than its neighbours within the Avon, Somerset and Wiltshire area.

There are a number of ethnic groups which are recognised as having a higher risk of certain head and neck cancers and these directly relate to lifestyle factors common to these groups.

It is vital that race is monitored, recorded and reported on in the new service to ensure that people from higher risk groups are engaging with the service.



The above graph shows that the majority of patients who have come through head and neck cancer services have classed themselves as White – British. It also shows that there is a considerable number of patients (15%) for whom there is no data.

The development of a centre of excellence should be seen as an opportunity to develop innovative partnerships. The centre should aim to work with local community groups, health trainers, faith communities, to improve awareness of risk factors.

Rates of Oral cancer are higher among people from a South Asian background and the risk of dying from cancer of the pharynx is five times higher for immigrants from the Indian sub continent than for British natives.

Betel quid chewing is a strong independent risk factor for pharyngeal cancer (cancer of the back of the throat). A World Health Organization study has found that chewing betel nuts can cause oral cancer and that the rate of these malignant mouth tumours was highest in Asia where the betel nut is a widely used stimulant. Betel nut, which contains an addictive stimulant similar to nicotine, is widely used in parts of Southeast Asia, India, Pakistan and the South Pacific as a breath freshener, a hunger antidote, a substitute for cigarettes.

The use of chewing tobacco was most prevalent among the Bangladeshi BME group. (3)

There is an NHS Asian tobacco helpline, website and leaflets which are available in Urdu, Punjabi, Hindi, Gujarati and Bengali. The helpline is available every Tuesday 1-9pm and the same spoken languages are available. The leaflets and website both mention the link between chewing tobacco in paan and oral cancer:

“People chewing tobacco in paan are over 5 times more likely to be at risk of oral cancer”

There are a number of issues around race which are highlighted well by the story of one patient relative who told the story of her mother who was first diagnosed with mouth cancer when she was 78 and died when she was 80. In this case, the patient was of Indian origin and had been born in India. The patient relative told us that she has chewed betel nut back in India but that there was some mystery surrounding her childhood and youth. The patient was deaf and had speech, but did not speak English. All communication with medical professionals was via family members. She was treated in Bristol at St Michael's hospital.

7.2 Communication

When first told about the cancer diagnosis, the relatives did not understand what cancer meant. It seemed as though this was something that could be fixed by surgery.

“When we went to the dental hospital and they saw it there, straight away, they said it was cancer. I didn't know what cancer was. No one in my family had cancer.”

“I didn't have the true picture of the cancer. It's Important to tell us “we do not know the state of the cancer on your mothers tongue”. “

“I think the first things we need to do is for there to be someone to talk to and take care of us and give information – I didn't have that.”

During the time immediately after the operation, the patient used a pen and paper to communicate. This communication was in Kachi which only one member of the family could read. Relatives stayed with the patient all the time that she was in hospital and the fact that they were able to do this was valued greatly.

During the patient's final stay in hospital, the relative strongly feels that the medical professionals knew that her mother was going to die soon but this was not communicated to relatives. Ideally they would have liked for the patient to be allowed to die at home, but if this was not possible, to be told clearly how long the patient has to live so that the relatives can gather together to say goodbye.

In this case, a new baby had recently arrived in the family. As this happened in the same hospital, the patient was taken to visit the baby and was able to hold her.

But the rituals for this family (who are Muslim) around the birth of a new baby also took up their time.

“So then when we talked about how to take my mum home again, they said they didn't think she would make it.

It didn't strike me what she was really telling me. And they had taken the oxygen out because they knew she was only going to be there for a couple of hours or so.”

The storyteller had gone home to wait in for a sling for her mum to pull herself up on at home and during this time, her mum died.

There is a tendency in some English cultures to skirt around issues such as death but this story highlights how there is a need for families to be told in a straightforward way when a patient is expected to die.

There is support available for patients from BME communities with Cancer from “Cancer Help for Minority Ethnic Communities” hosted by Bristol Community Health. This family did make contact with them, but this was only after they had seen the information in the Oncology waiting room. This support was not mentioned to them by the medical professionals treating the patient.

As with all services, the communication needs of people whose understanding of English is limited needs to be considered. Information on how best to communicate with the patient also needs to be passed over to the service from the referrer to ensure the first contact with the services is as productive as possible. E.g. if the patient requires an interpreter, this needs to be arranged in advance.

Communication needs were raised by patients an involvement event and a specific case mentioned was that during the post operative period when communication is already difficult, when patients and staff use English in a different way, this may form an additional barrier at a time when it is important for the patient to be able to communicate medical needs.

The following is from a patient interview which highlights how we may use English in different ways. This patient is White British and female.

“So there was one nurse who had English as an additional language and her English was too perfect and one time she asked about some medication and she said she could give me a suppository and I asked what it was for and she assumed I didn’t know what a suppository was so she said “it’s for your bottom” so I thought that was to help me go to the toilet and I said I didn’t need that. She looked a bit surprised but she didn’t say anything. So I was having chronic diarrhoea and I can laugh about it now but obviously at the time it wasn’t funny. Then the night nurse came on and asked if I wanted some pain relief I had a choice of it going through my nose tube or in my bottom and I was so sick then of things going down the tube that I asked for it in my bottom. So I turned over expecting to have an injection in my bottom and she actually gave me a suppository! But I didn’t realise that you could have pain relief as a suppository and that’s what the previous nurse had been talking about.

I turned down a painkiller but stayed on a laxative via the nasal tube, which I didn’t realise they were giving me.

She was black (the nurse) and I think she got upset because I’d mentioned the situation to another nurse and I think she told her and she thought I didn’t like her but she was a lovely nurse and I was happy with her nursing. I wish I could have explained to her afterwards when I could talk properly. She was so upset. I think the other nurse told her in an insensitive way. Once I could talk it would have been fine. “

This highlights that we all speak English in different ways and this may apply to people of different races and have English as an additional language or people who have English as a first language. We use language differently around the country and around the world and medical professionals may use terminology that is not familiar to the patient. When communication is more difficult – for example when someone cannot talk, it can make the situation even more difficult.

It is important that the staff in the service do not make assumptions about what a patient or relative can or cannot understand.

“Because they’re good at their job and they know, its second nature to them so they forgot to say things sometimes and unfortunately when you get to the 20th patient and

you've had to say it 20 times you might forget to say something. For every single patient its new so they still need to know.”

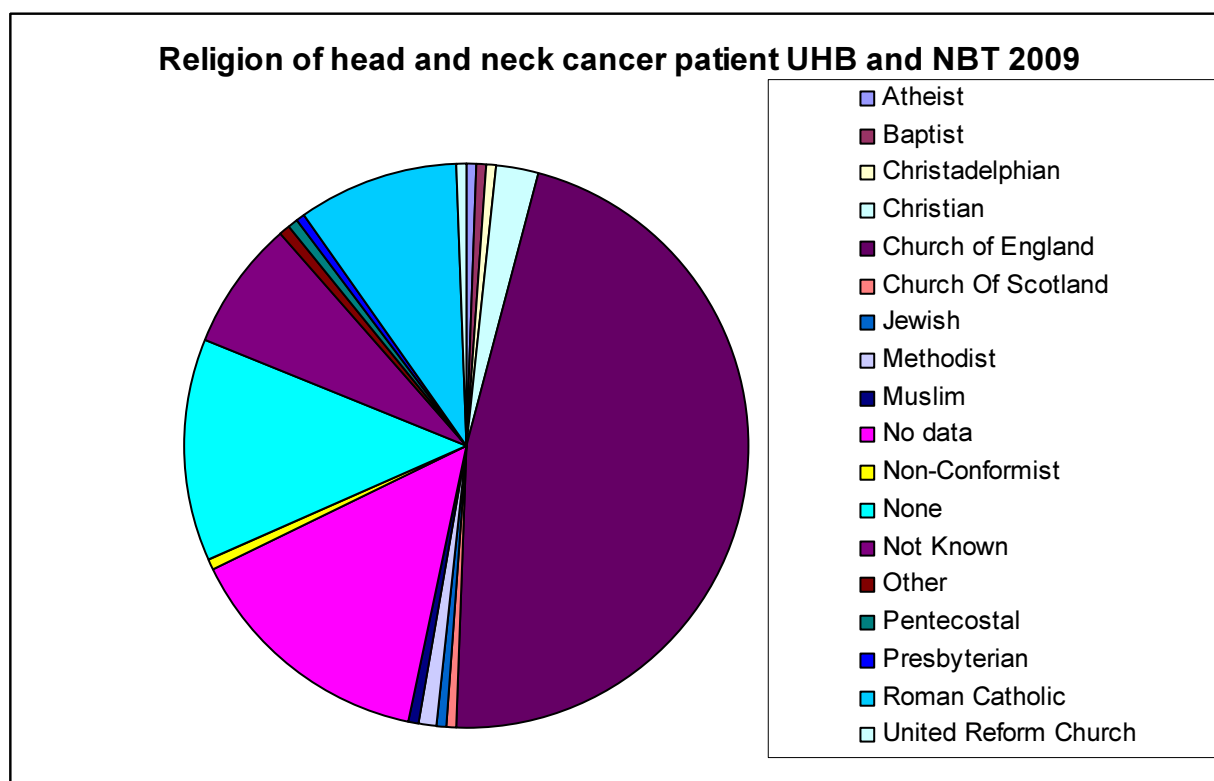
From other documents

Race has historically been poorly recorded in the NHS limiting the quality of available data. It is difficult in some cases to differentiate between the influence of race and that of deprivation. (3)

The lower than average socioeconomic position of some Black and Minority Ethnic groups is the main reason behind their worse health outcomes. Most Black and Minority Ethnic groups have higher rates of poverty (lower income, less benefits, more unemployment, fewer necessities and more deprivation).(7)

When receiving treatment and care Black and Minority Ethnic patients, particularly those outside large urban conurbations, can have problems with communication of cancer diagnosis and information, particularly when the first language is not English. (9)

7.4 Religion or Belief



A quiet space to grieve, pray or for quiet contemplation was needed for people of all or no religion. It was raised in discussion at an involvement event that is lacking in the newly built Bristol Heart Institute, and it was felt a lesson should be learnt from this. It was felt that as over half of all head and neck cancer patients die a space for either patients or family members is an important consideration when designing the space for the centralised service.

The chaplains are available as a point of contact for all faiths at the hospital. Patients and relatives should be made aware that they are available and can contact officials or representatives from other faiths on the family's behalf.

Religion should not be assumed based on race, for example Indian census data shows that 2.33% of the population are Christians which is higher than the 2% figures for Sikhism.

End of life care is particularly relevant for this patient group as there is a high mortality rate for head and neck cancers of over 50%. Where patients are not well enough to go home to die, a flexible environment which can be adapted for different patients and families from different religions and beliefs is needed. For example, comfortable chairs and pull out beds so that families can stay with a patient while they are dying. As previously mentioned under Race, it is important that relatives are clearly communicated with if medical professionals know that the patient is dying. This will allow them time to gather together to say goodbye and perform whatever cultural or religious practices are appropriate.

Food was mentioned as an issue particularly that supplied in the immediate post op period. This is detailed further under the “Disability” section. Consideration of different religion and beliefs will need to be considered as part of menu planning. For example some people do not eat meat either for religious or other reasons and there needs to be food choices available which take this into account.

7.5 Disability

We have not been able to access a breakdown by disability of either those patients who access the service or those who work in the service. The standard equalities issues around accessing a service such as physical building access, leaflets available in accessible formats, longer appointments for patients with learning difficulties, all apply.

Additionally, there are some issues which apply specifically to head and neck cancer treatment and some disabilities which are caused by the cancer and/or the treatment.

There are a number of issues around communication which are particularly relevant to this group.

Firstly, communication between professionals. When a General Practitioner or Dentist refers a patient over to head and neck services, there needs to be a way to communicate any particular needs that the patient may have in addition to details on the medical condition they are being referred to. For example a patient with Learning Difficulties (LD) may need a longer appointment; a Deaf patient may need a British Sign Language interpreter. Ensuring these needs are communicated will mean that the patient's first appointment with the service can be as productive as possible.

Communicating with the patient also needs consideration as people with Learning difficulties may need extra time to explain information to them and leaflets and other information in an accessible format. People with sensory impairments also have specific communication needs and this need to be taken into consideration. Head and neck cancer and the associated treatments can be complex and this needs to be fully communicated.

The following is from a patient who was treated 15 years ago at Southmead Hospital. She had a laryngectomy operation.

Diet

"I believe it was a Sunday. I had been informed that my solid diet would commence that day. Breakfast I was offered 3 choices. Bread and jam, bran flakes or ready brek. I chose the latter as the easier option. I could not eat it because it was lumpy and the flakes and lumps were spilled over the sides of the dish, it looked awful so I sent it back.

Dinner I was given roast beef potatoes and veg. I tried but could not swallow the bit of veg. The nurse commented that I had not eaten breakfast nor dinner and this was "worrying", I asked if there were any soup or ice cream but she could only offer me a crumble for desert which I could not eat. This went on for five days.

The speech therapist came to see me and asked me to take a drink of water. I could not swallow in one gulp because the liquid would sit for a few seconds in my throat and it took a couple of swallows before it went down. She said this combined with my inability to eat was concerning. I asked for a soft food diet and she said that some of the food I had received was soft such as mashed potato.

Eventually a dietician came to me. She was very cross. She told me that she should have visited me the day before my solid diet commenced, but she had not been informed

and they had only contacted her because I was not eating. She said that everything would change now and she was in charge of my diet; she said that she would send up double of everything and she did. I had yogurts, ice cream and soups, jelly and rice, ready brek which was very well mixed and creamy. This was wonderful and gradually by the time I left the hospital I was able to eat rice with sauce and pasta etc. I had no further trouble and found within a short time that there is no foods that I could eat but it takes time and to expect a patient, who has undergone the kind of surgery that I had, to eat a normal diet is ridiculous. It needs a common sense attitude. I do hope other patients are not having to endure the same treatment but I imagine that attitudes have changed; at least I hope they have.”

Language and Communication

The following is from another patient who was treated at both Royal United Hospital and St Michaels.

“They said I wouldn’t be able to talk and they said it was alright because we’re very good at understanding what you want and there was actually one nurse who was very good but of course she wasn’t on all the time. She was good at anticipating. The others were good once I could start writing stuff. I hadn’t realised how much you do rely on talking. When you’ve got a traci when you’ve first had the operation you can’t talk. One of the nurses was really good at lip reading so that was good. I used a notepad to write things down and then I got my daughter to bring in one of those children’s drawing boards – you know that you can wipe off and that was good because if you didn’t have the energy to lift up your arm properly you could scratch on it with a nail or something.

When I was going up in ambulance in St Michaels from intensive care at UHB and I couldn’t talk. I was put on one of those slide under, lift off things. I was strapped down and my elbow kept on bashing against the side and my elbows were bare because I just had a nightgown on but I couldn’t say anything because I couldn’t talk at that time. I couldn’t say it was hurting and I couldn’t move my arms because I was strapped in. From their point of view I was safe because I was strapped in but I don’t think they realised how scary it was for me to be bounced about in an ambulance and not be able to say anything – it was traumatic. The ward is actually on site now (at UHB) so they’re fixing that. You want to be able to say ouch, ouch but you can’t!

At the BRI I mean I knew it’s a few years on but they have a specialist ward and that’s what they do all the time so they were really skilled at cleaning out the traci and knowing what to do and also they took my off it really quickly. So my partner left on the Friday night I couldn’t talk and he had to go away for the weekend. So the next day I was talking with the finger on and then I had it removed so by Sunday night when he came to see me, I was talking normally and he couldn’t believe it was like a miracle! The first time I didn’t speak for a long time. It was two different situations so it’s difficult to know if the technology has moved on or if it’s because of the specialist nurses. “

For patients undergoing surgery, there needs to be a plan in place in advance which details their food and communication needs during a time of temporary disability when needs may be different. This point was highlighted during an interview with one cancer patient who had also had surgery on his leg:

“After the operation the nurse who looked after me didn’t have very good English, I couldn’t understand her and I couldn’t make her understand me. I kept sliding down the bed on to my bad leg and I couldn’t communicate this or reach the buzzer so I had to keep setting the alarm off to get attention. I had pain from trapped wind because of the anaesthetic and I couldn’t explain to anyone and no body told me about this before the operation”

The planning for this period should include the speech and language therapist (SLT) and the dietician. Communication methods need to take into account the needs of both the patient and the members of staff who each may each use English and/ or other languages in different ways. Sensory impairments and other disabilities also need to be considered e.g someone with a learning disability may need to use pictures rather than writing words down. A number of communication tools can be explored before surgery so that the patients and SLT are confident that the patient will be able to communicate their needs during this period if they are not able to speak in the way they are used to. It is especially important that they are able to communicate any acute medical needs at this time.

One idea talked about with patients was to have a picture board which was introduced before surgery:

“The picture boards would be great for non English speakers and Special needs so that would suit a lot of people. You’d need a symbol for pain and things like that and feeling sick.”

However, the use of communication boards should take into consideration the individual patient needs. One patient criticise explained they were given a writing board during their inpatient stay at UHBristol “but I couldn’t hold a pen”.

Such communication tools may already be used by speech and language therapists (SLTs) in other work.

For food and nutrition needs, patients may have difficulty either chewing or swallowing solid foods directly after their operation. At this point they may also have difficulty communicating. It would be possible for a dietician to work with on site staff to develop a menu which took in to account patients nutritional needs, their possible limitations in chewing or swallowing and gave choices to take in to account their beliefs and preferences around food. The patient could then choose from this menu before their operation.

Some patients may need to use Percutaneous endoscopic gastrostomy (PEG) feeding as a primary or additional feeding method following surgery, usually on a temporary basis. One patient commented that he wanted a savoury feed for his feeding via Percutaneous endoscopic gastrostomy (PEG) but was told that only there was only sweet available. He disliked the sweet versions and has since found out that savoury versions are available but were not offered while in hospital.

Both head and neck cancers and their treatment can have an effect on long term eating, speaking and breathing abilities and can leave patients with a long term disability.

Learning Difficulties (LD) – from telephone conversation with Kate Mc Dermott, Health Facilitation Co-ordinator

There are Community Learning Difficulties Teams (CLDT) in each area covered. These teams include Speech and Language therapist and would be able to help with pre appointment planning before the first appointment with the service.

Once a patient is at United Hospital Bristol Trust, support is available from the Learning Difficulties liaison nurses who can communicate with the community team and support the patient.

The recent Direct Enhanced Service (DES) has seen more people with Learning Difficulties register with General Practitioners. In Bristol, 48 General Practitioners have received training to raise awareness of Learning Difficulty issues. This has not been checked across other areas. An annual health check will be conducted for patients with Learning Difficulties and one of the questions will ask whether they are registered with a dentist. However, currently there is no system whereby registration with a dentist is then followed up. People with Learning Difficulties are less likely to be registered with a dentist and those who have come from institutions where health care is provided are especially unlikely to be registered as they have been used to dentistry being organised for them.

So currently a General Practitioner is more likely to be aware of the Community Learning Difficulties Team and can refer to them as part of the referral to the service.

The route via a dentist is less accessible for patients with Learning Difficulties at the moment. This firstly because they are less likely to be registered with a dentist and therefore less likely to be referred in to the service by them and secondly, the dentist is less likely to be aware of the support offered by the Community Learning Difficulties Team because they haven't received training in the way that many General Practitioners have.

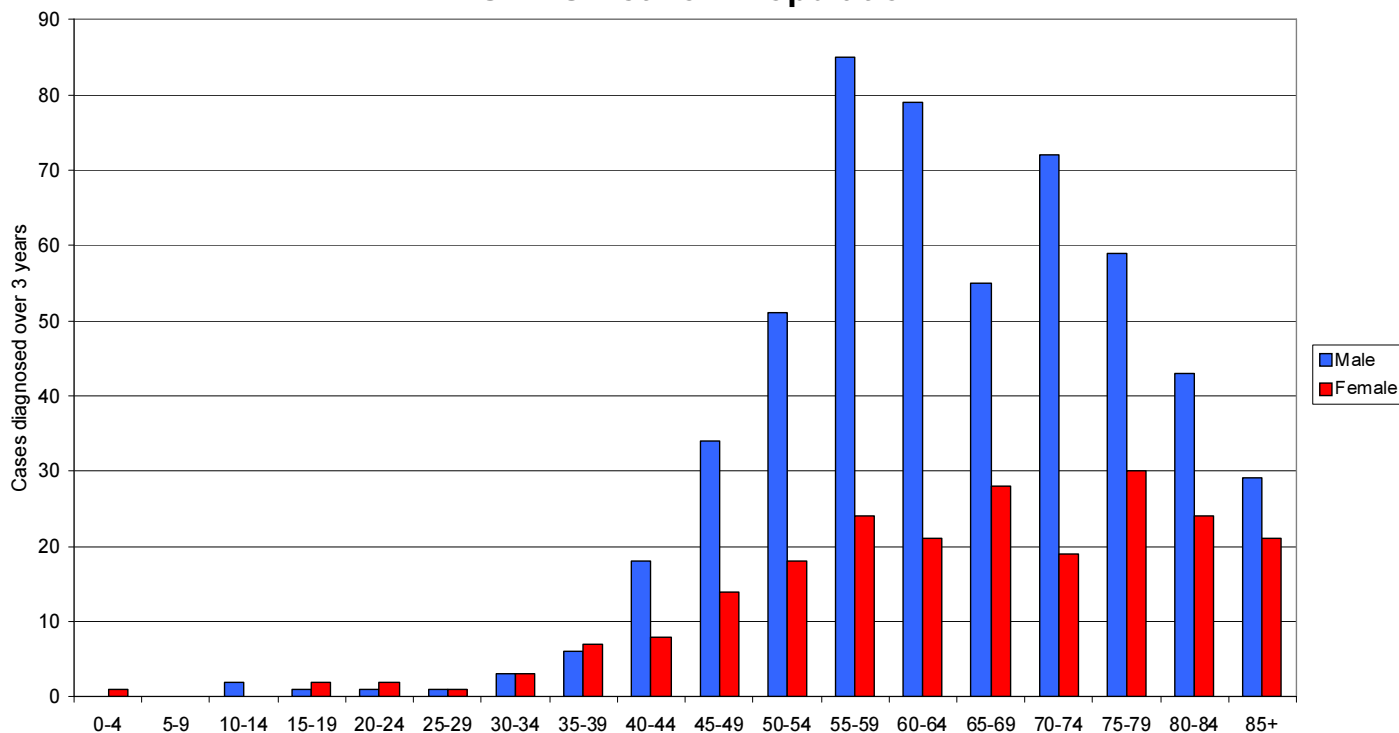
To help rectify this, there needs to be some follow up of the annual health check questions whereby patients who are identified as not being registered with a dentist are followed up.

Assuming this leads to more people with Learning Difficulties registering with dentists, better links are then needed between the Community Learning Difficulties Team and dentists.

7.6 Gender and Age

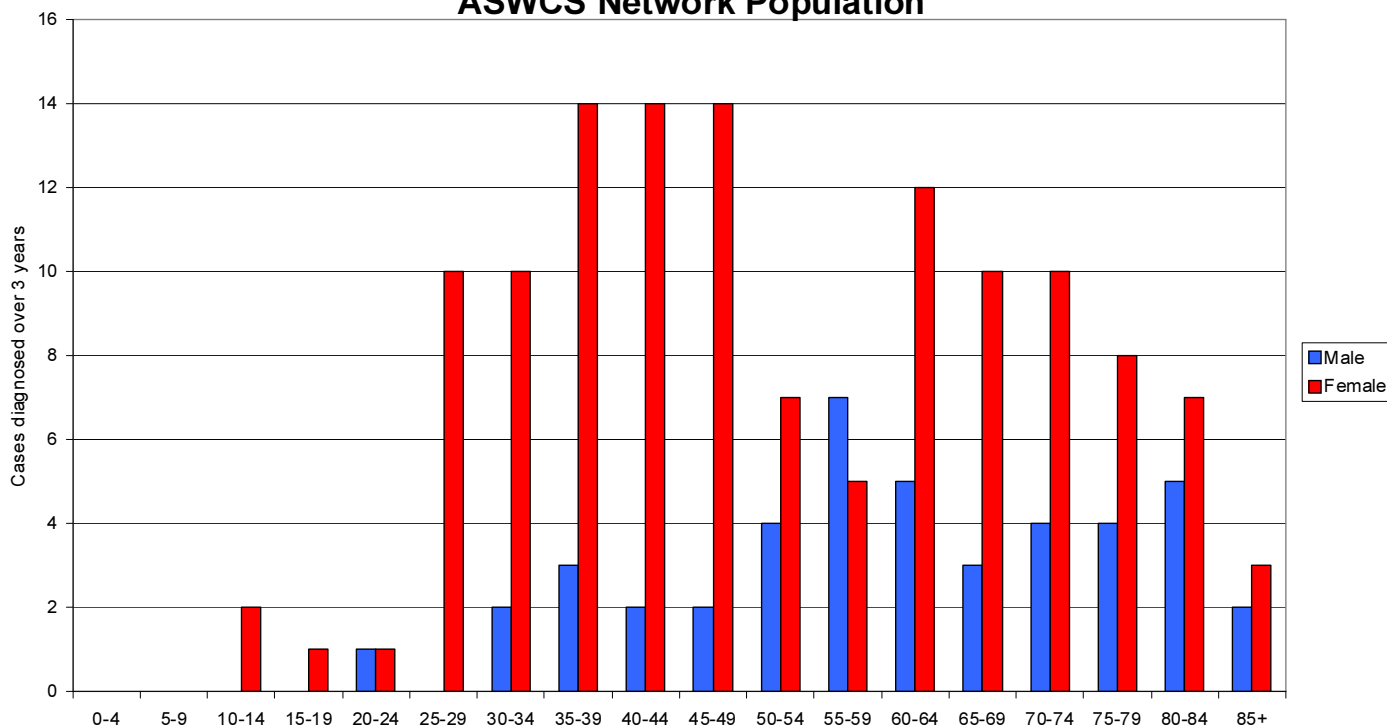
The graph below show the age distribution for those patients with Upper Aerodigestive Tract Cancers throughout the Avon, Somerset and Wiltshire Cancer Network Area. As you can see these cancers are more common amongst men and is more likely to affect those who are over the age of 44.

**Age distribution of patients with UAT Cancer (3 years 2004-06)
ASWCS Network Population**

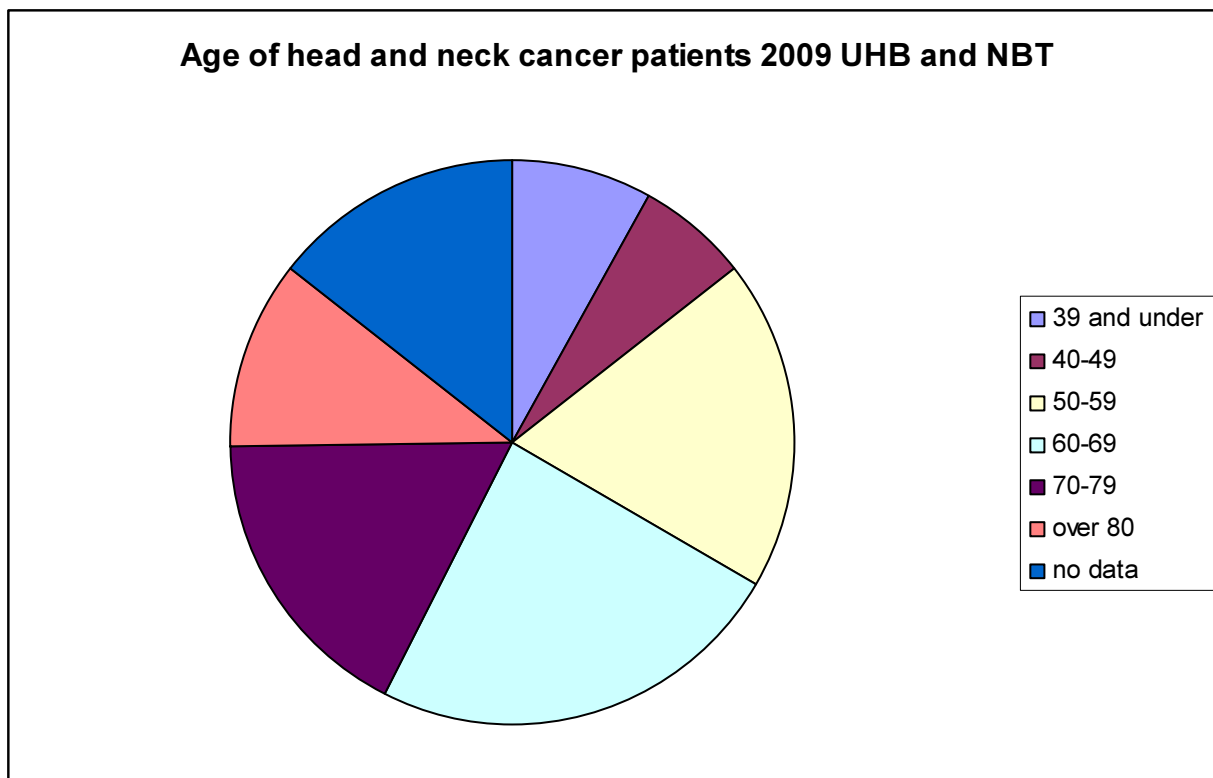


The graph below show that Thyroid cancer is more common in women than in men and the risk is more evenly spread throughout the age range. However, the number of overall cases is lower than for UAT cancers.

**Age distribution of patients with Thyroid Cancer (3 years 2004-06)
ASWCS Network Population**



The graph below show that in 2009 that the majority of patients discussed at the multi-disciplinary team meeting were over the age of 49. However, there were still a number of patient who did not accurately have their age recorded.



We didn't have any specific issues raised about gender either by the user reference group or individual patient interviews, apart from that there should be separate female and male wards. However, it should be noted that the majority of patients involved in both the user reference group and the all individuals patients and relatives interviewed, were women.

Thyroid cancer is more common in women, among whom new cases peak between the ages of 30 and 54. Other head and neck cancers are more common in men.

Head and Neck Cancer treatment can significantly affect the way a person looks and one patient commented that younger people may be more worried about how they look after surgery.

"If I was younger and I had small children I might be more worried. [about my appearance] It's quite an important part of your rehabilitation. So I've been waiting quite a while [to have new teeth put in]."

Patients relatives were mentioned a number of times in interviews. Because head and neck cancers tend to affect older people more, relatives are also likely to be older and this needs to be considered. Small things can make an important difference.

"Jeremy [the surgeon] said to the nurse you couldn't get her a cup of tea could you? And mum always remembers that."

Looking after relatives at a time when the patient is unable to consider them themselves is seen as important by patients.

It is planned that inpatient services will be centralised whilst diagnostic, follow-up and rehabilitation services should be provided closer to home. Travel arrangements therefore are an important consideration due to wide geographical coverage of this

service. It is important the service develops a clear supportive approach to ensuring patients understand the various ways they can access the service. Free bus passes are available for people over 60 and public transport links to the hubs are important. However, the service should be public transport may not be suitable for everyone and some treatments are likely to leave people feeling unwell, so parking options also need to be communicated effectively to patients and relatives.

The speech and language therapists expressed concerns for their older patients which patients had raised with them. One solution discussed was a shuttle bus that went between North Bristol Trust and University Hospital Bristol sites:

“Access is a concern. This is a real worry for both us and patients. I would need to be able to drive to University Hospital Bristol and know that I will have a space. And my patients need to know that too. So a really clear leaflet about where they can park is needed. They need to feel confident that they will be able to park when they get there. For vulnerable patients with head and neck cancers, standing around on a bus stop is really difficult.

It may be that patients could actually choose to park at Southmead and then take a shuttle down to University Hospital Bristol.

They are worried about getting there and then having to walk from where they've parked their car, especially patients with respiratory problems. So if it was reliable and door to door that would work well for everyone and we would prefer to use that. Because then you don't need to worry about parking when you get there and it would be better for the environment too.”

There are two suggestions from this:-

1. One is that a shuttle service between North Bristol Trust and University Hospital Bristol sites is investigated. This could be used by both patients and staff.
2. A leaflet is produced which explains access to University Hospital Bristol sites including public transport and parking facilities nearby.

Neither of these ideas is specific for head and neck cancer services and would need wider input and possibly partnership work with Bristol City Council and First Bus.

During patient interviews the relative of a head and neck cancer patient also expressed her concern for older patients accessing services particularly around having to 'chase' appointments;

“The system is not sensitive to the needs of anyone on their own or who may be old and vulnerable. I am concerned about people who can't chase things themselves or use the internet to find things out”. I feel sorry for any one older, or who is on their own, it would be hard for anyone to ask for what they need”

The patient himself also expressed concern:

“There was a communication breakdown along the way, if I hadn't chased it I don't know what state I would be in now that is what worries me, especially about people who can't chase things up”

7.7 Sexual orientation

We do not have a breakdown of patients by sexual orientation.

The issue of assumed gender of significant other came up when we were discussing this with the user reference group. Staff should be trained to use language which doesn't assume the gender of the for example the person they may want with them when talking about their condition or treatment.

8. Assessing the Impact – Ear Nose and Throat Services and Oral Maxillo Facial Services

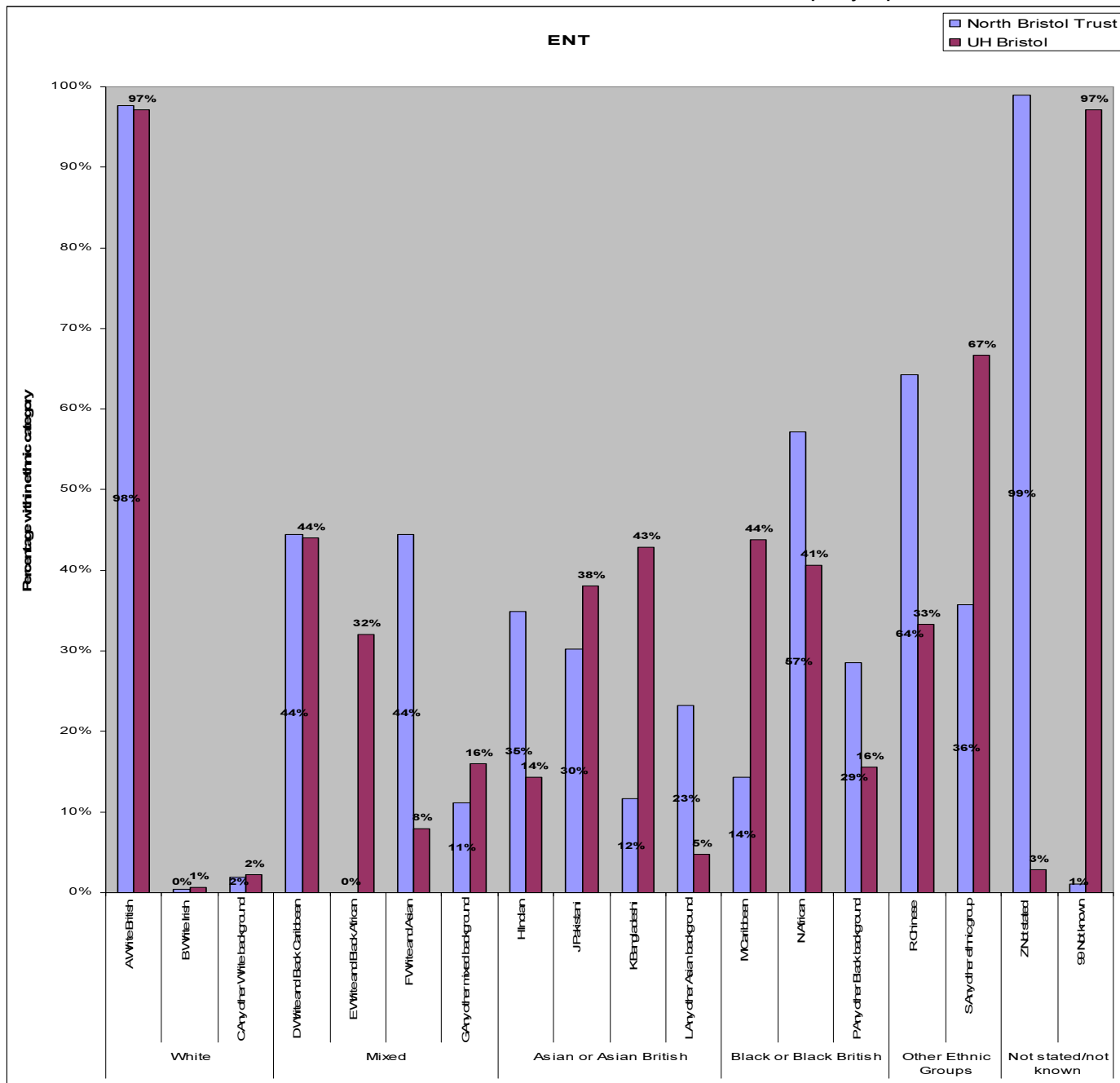
Many of the issues identified through engaging with patients accessing Head and Neck Cancer Services will be common to patients accessing both ENT and OMFS services. The following information is in addition to the issues already identified in the Head and Neck section of this Equality Impact Assessment. The review covers those patients who are accessing ENT and OMF services currently delivered by NBT or UHB. For those patients who live in the Avon, Somerset and Wiltshire Cancer network but who are accessing services outside of Bristol there will be no change in the existing service delivery and therefore this section of the document primarily focuses on Bristol.

8.1 Race

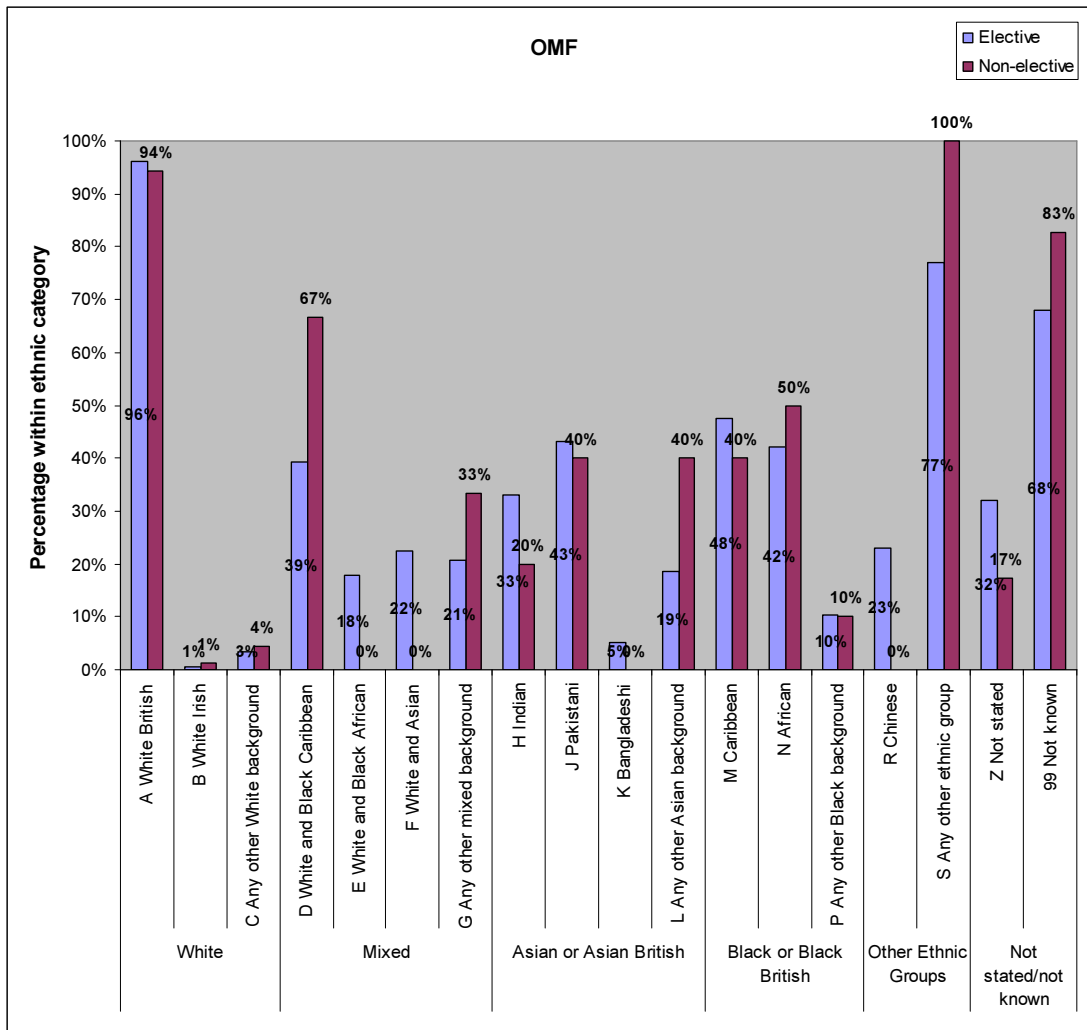
As the chart below shows, Bristol is an area of increasing ethnic diversity. There are more people from Asian, Chinese and mixed ethnicities living within Bristol compared to the South West and the neighbouring areas. South Gloucestershire also has a larger population of people of Asian ethnicities. In line with population projections the numbers of people from non White British ethnic backgrounds will increase. Therefore consideration needs to be given in the planning of services to ensure that any new services are accessible to all ethnic groups.

The Joint Strategic Needs Assessment identified that there are a number of information gaps, particularly around carers and people with learning difficulties, physical impairments, mental health and ethnicity recording. This will need to be improved in order to properly consider the needs of people from different ethnic groups and vulnerable groups and who as a result may be suffering health inequalities.

In ENT services there are a higher number of cases where ethnicity is not recorded at UHBristol, therefore there may be even higher numbers of patients from non white backgrounds presenting at UHBristol. Across both trusts there is a much higher proportion of unknown ethnicity in non elective cases than in elective cases. This highlights the need to improve ethnic monitoring at both trusts.



There is greater ethnic diversity within the patient population presenting at UHBristol than at NBT, with a higher proportion of mixed race and black patients and a smaller proportion of white patients. There is no significant variation in ethnicities between elective and non elective patients.



For patients accessing OMFS services there is a much higher proportion of unknown ethnicity in elective patients compared to non-elective patients and there are no significant differences between the ethnicity profile of elective and non-elective patients.

There is however greater ethnic diversity amongst OMFS patients at UHBristol compared to NBT and a higher proportion of all non-white groups.

The proportion of unknown ethnicity is twice as high in OMF as in ENT (20% compared with 10%); this is particularly noticeable at NBT (22% compared with 4%). There are a higher proportion of non-whites accessing OMF services than ENT (10% compared with 6%) and this is spread across all of the non-white ethnic groups. However there is no specific evidence that indicates ethnic minority Maxillo Facial patients are at any greater risk.

As previously discussed, certain ethnic groups have been identified as having higher risk of oral cavity cancers. There is growing evidence of intracountry ethnic differences, mostly reported in the UK and USA.

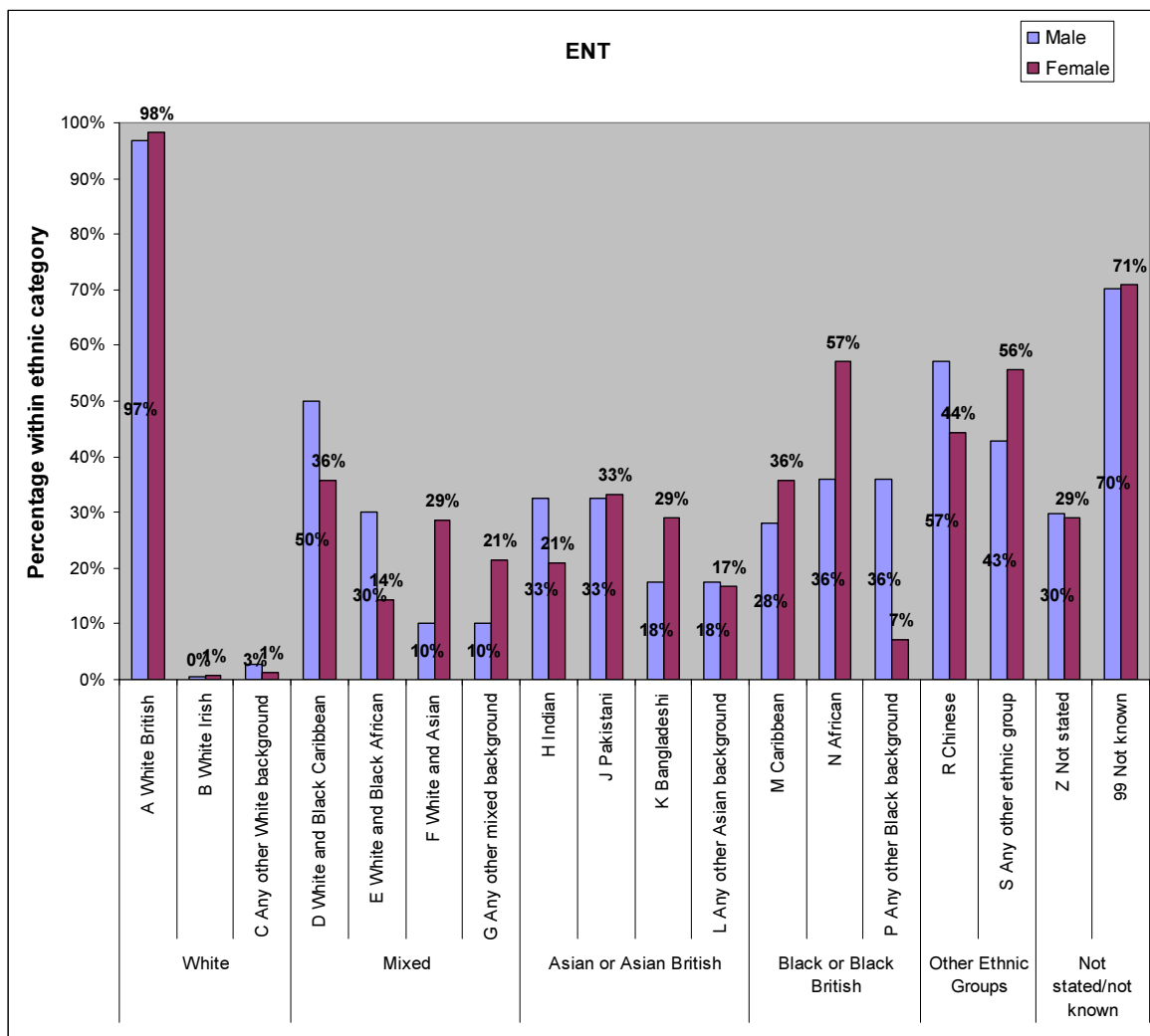
These variations among ethnic groups have been attributed mainly to specific risk factors, such as alcohol and tobacco (smoking and smokeless), but dietary factors and the existence of genetic predispositions may also play a part. Variations in access to care services are also an apparent factor (Scully C, Bedi R (2000) Ethnicity and Oral Cancer, Lancet Oncology Sep; 1(1):37-42)

No specific equality issues were highlighted during patient interviews concerning access or quality of service. Issues relating to communication were highlighted by head and neck cancer patients especially concerning verbal impairment due to a procedure or condition and these principles should extend to ENT or OMFS patients with similar communication difficulties either due to deficiency in English language skills or impairment due to a condition or disorder. One ENT outpatient who described himself as Indian commented on a “communication break down” in explaining to him his condition, treatment and outcomes post operatively. The patient was given the opportunity to speak with a clinician who could converse in Hindi and the patient highlighted the ease in further understanding his condition in a language he was more skilled in.

However both trusts have access to translation and interpretation services for speakers of other languages both face to face and via a telephone interpretation service. All patients must be given the opportunity to access this service and this would be facilitated by the collection of data around language spoken and read but also the asking of the question would you like to use translation and interpretation services.

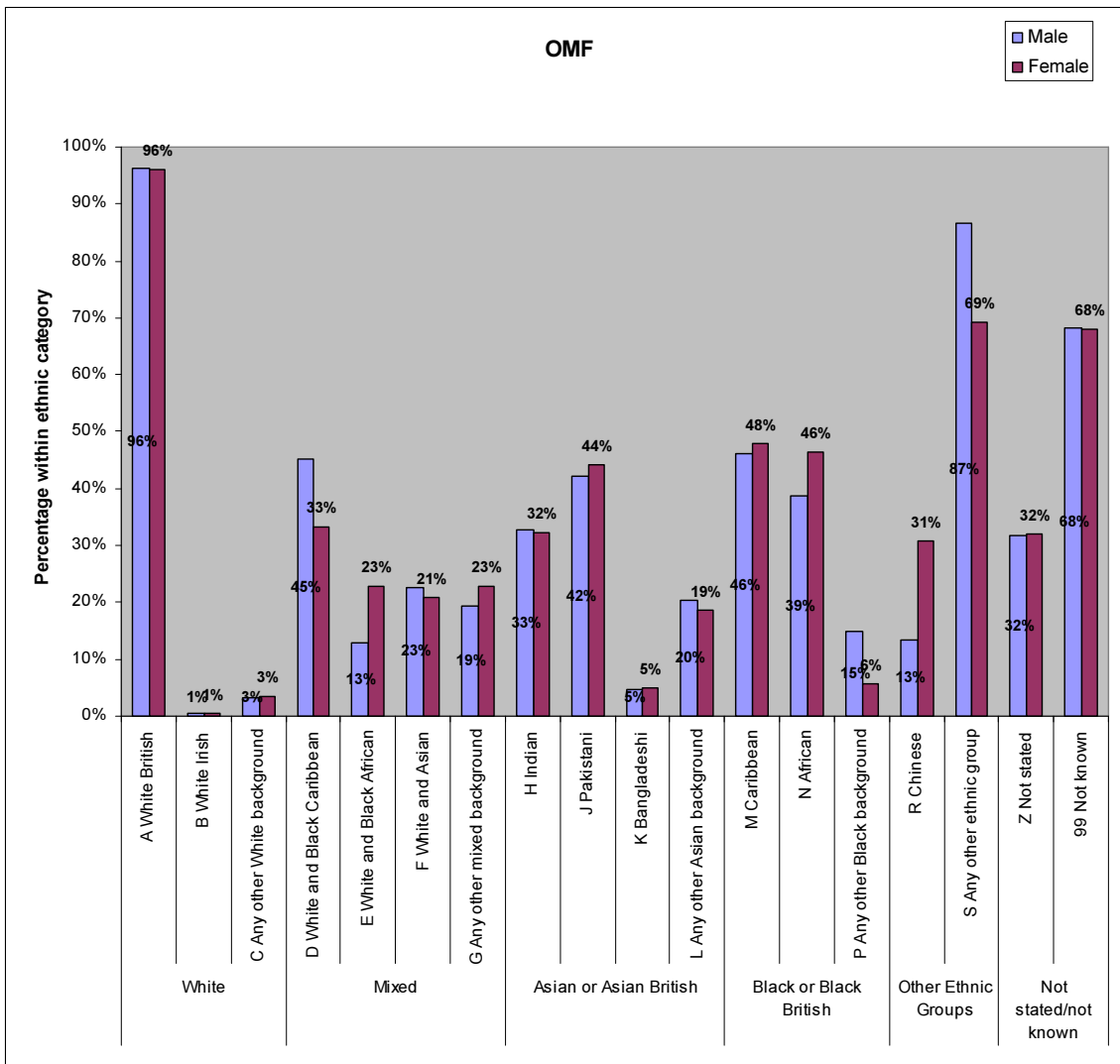
As with all NHS services, Oral & Maxillofacial Surgery Services and ENT services are to be designed around core standards of care and delivery and apply to all patients irrespective of ethnic backgrounds or other personal criteria.

8.1 Gender



The numbers of males and females accessing ENT from the White British population are almost equal. Within other populations there are variances between males and females accessing ENT services. Within the patients recorded as North African there is a greater percentage of females in ENT services. There is no known evidence to suggest that females of Black African descent are at a higher risk of ENT conditions.

There are a higher number of males of any other black background, accessing ENT services. This may be a result of the monitoring process with males identifying themselves as any other black background. This also highlights the need for the quality of ethnic monitoring to be improved.



For OMFS service patients from a white British background the gender split is equal. Similarly to ENT services a higher number of women from the Black African population are accessing OMF service compared to males of the same ethnicity but this difference is less than for ENT services. Males from any other ethnic groups are the second largest population accessing OMFS services.

No issues were raised during consultation with ENT and OMFS patients around access to or the appropriateness of service in relation to gender.

8.2 Religion and Belief

There is no available data on the self reported belief or religion of patients accessing ENT or OMFS services. During patient interviews no issues were raised regarding access to or the appropriateness of the service for patients with beliefs or who practised a religion. The issues raised during interviews with Head and Neck Cancer patients are also applicable to all patients accessing services.

8.3 Disability

There is no statistical evidence on the disabilities of people accessing ENT or OMFS services within Bristol. However certain disabilities will require treatment and diagnosis by ENT and OMFS. It can be assumed that a proportion of patients currently accessing ENT and OMFS services are being treated for an ENT or OMFS disorder relating directly to a disability. Two patients interviewed described themselves as disabled due to the conditions they were being treated for by ENT services.

There is evidence that disorders of the ear, nose and throat are high within people with Down syndrome and it is predicted that ENT specialists may treat these disorders in people with Down syndrome with increasing frequency as life expectancy for this population increases.

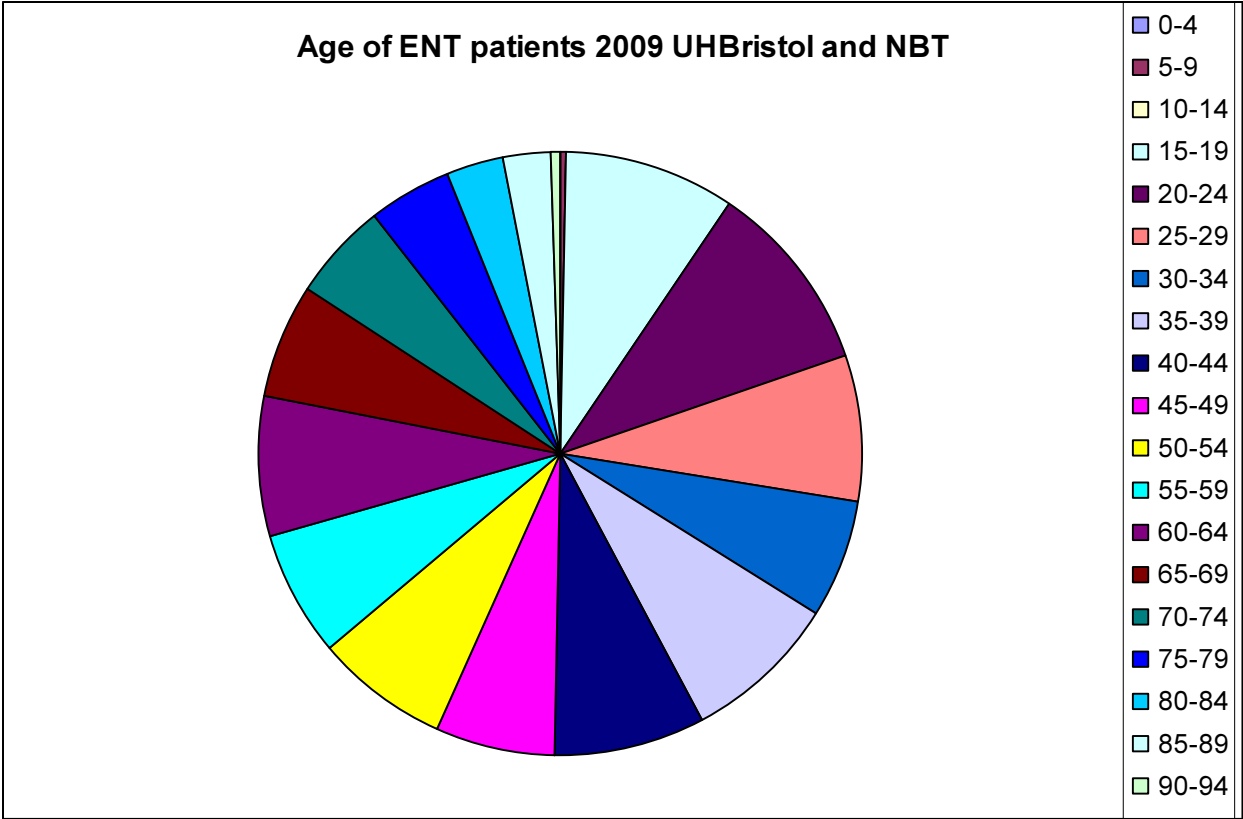
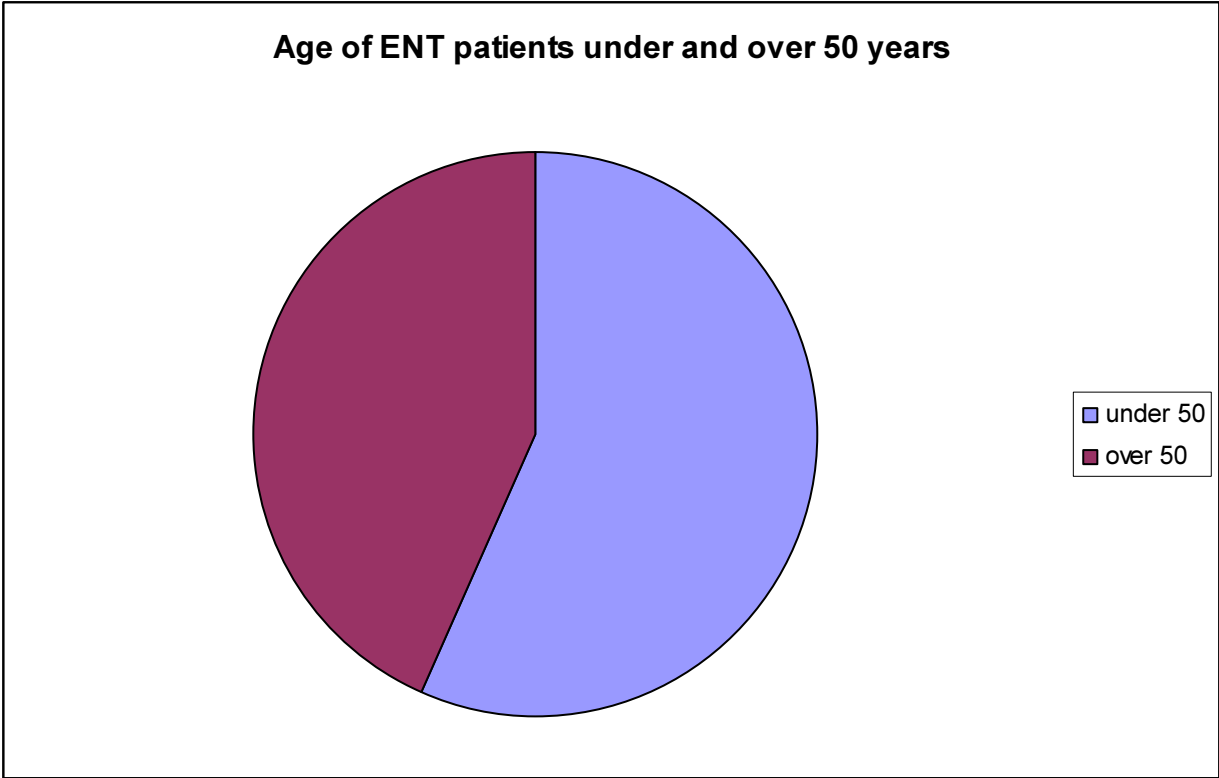
No issues relating to disability were raised during ENT and OMFS patient interviews. However as previously mentioned the standard equalities issues around accessing a service such as physical building access, leaflets available in accessible formats, longer appointments for patients with learning difficulties need to be considered when providing all services.

The communication needs of people accessing these services will need to be considered. A large proportion of patients accessing ENT and OMFS are likely to have hearing and/or speech impairments.

In 2008 a survey was carried out with 28 GP practices in Bristol looking at the health of people with learning difficulties in Bristol. Information was received concerning 1098 patients with LD. 11.7% of people with learning difficulties were identified as being hearing impaired. In addition, communication difficulties were present in 139 of the 1001 patients for whom information was available.

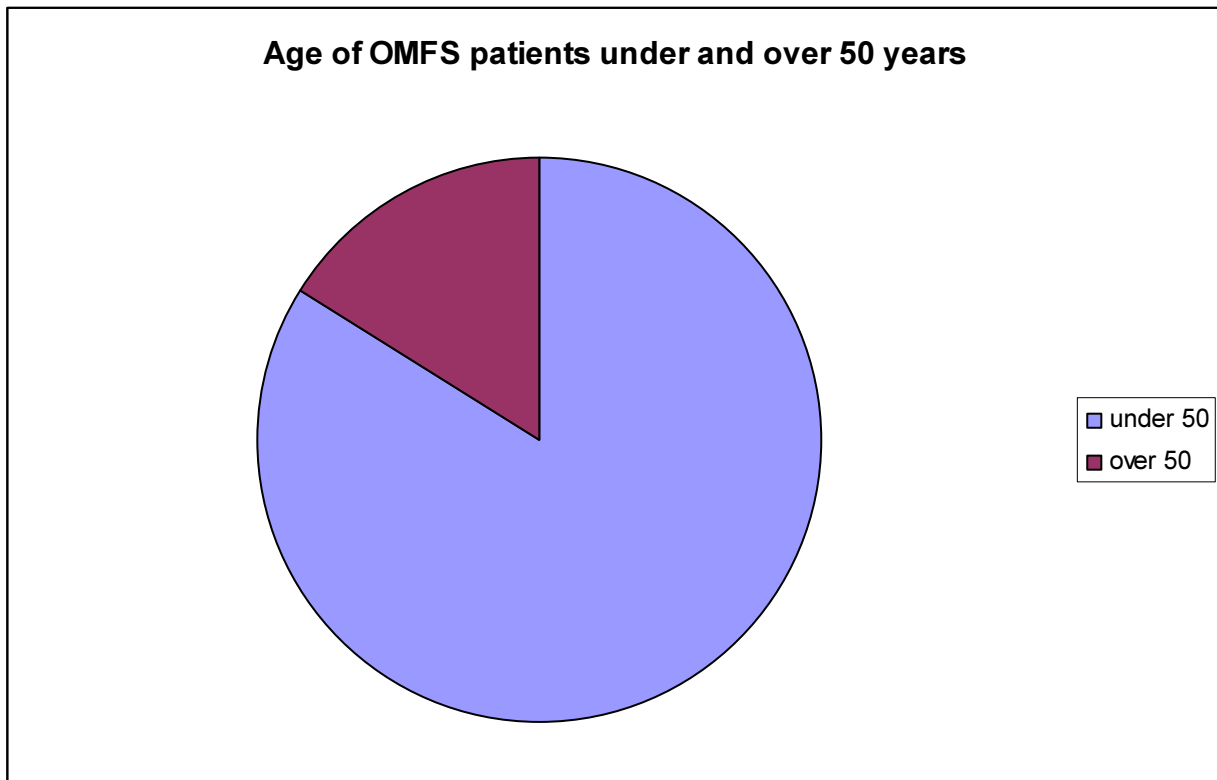
All health services should ensure that they are able to provide appropriate methods of communication for people with learning difficulties and to provide where possible extended appointments when needed. Literature should be made accessible and produced in large font with pictures to accompany text.

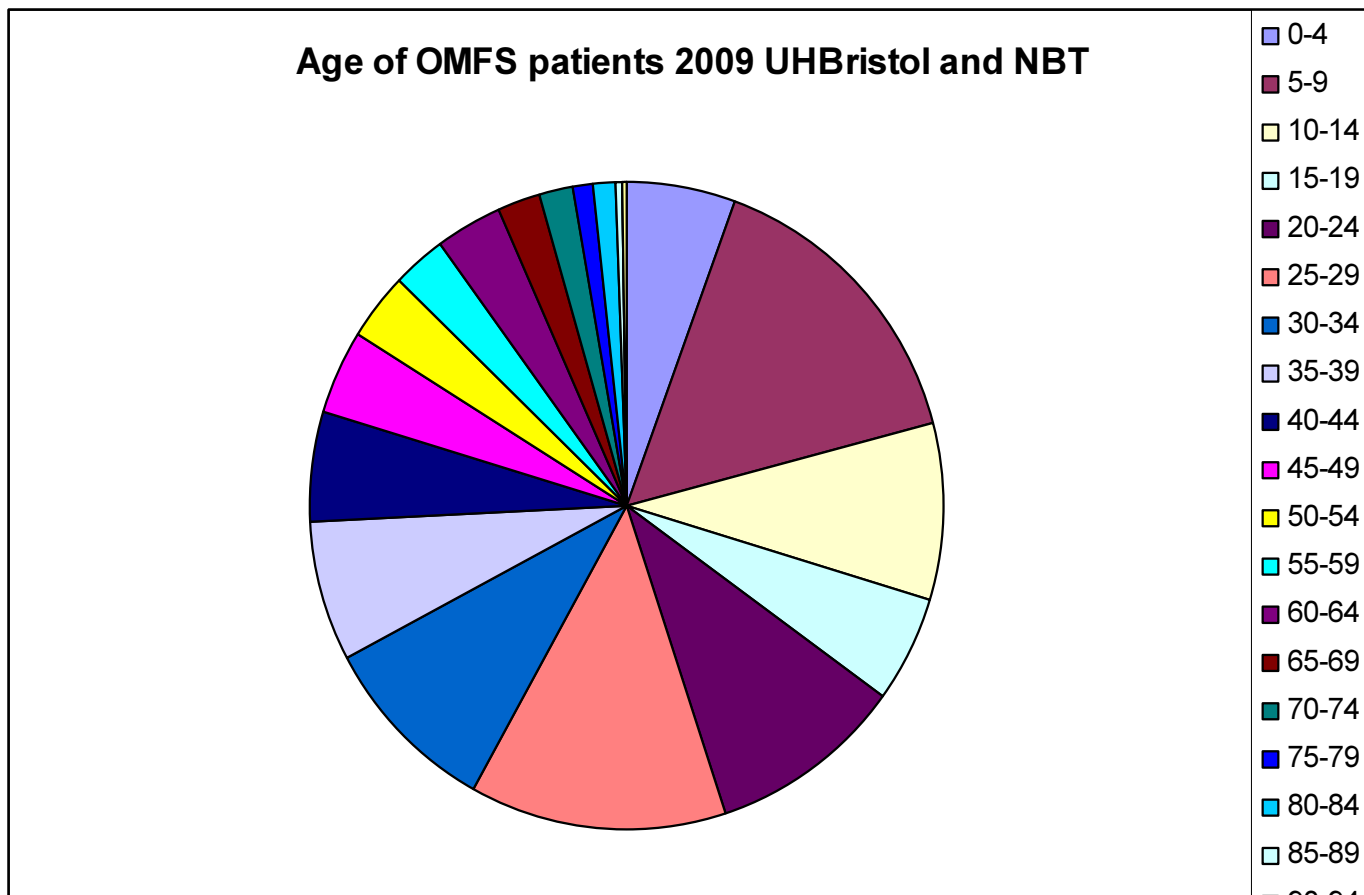
8.4 Age



ENT services are accessed across the lifespan but there appears to be a greater proportion of both elective and non elective cases under the age of 50. The most frequently seen age group at both NBT and UHBristol is the 20 – 24 year old age group.

This is very different picture to the cancer patients and services should be sensitive to ensuring the information provided in appealing this wide demographic.





No issues were raised during patient consultations regarding appropriateness or access to ENT and OMFS patients regarding age. It is worth noting that considerably more elective and non elective OMFS cases are aged under than fifty years of age.

8.5 Sexual Orientation

There is no recorded information on the sexual orientation of patients accessing ENT or OMF services. However all services should comply with equality policies and deliver services to the same quality irrespective of sexual orientation. It would be valuable for monitoring purposes for sexual orientation to be captured.

Action Plan

Recommendation	Key activity	Progress milestones	Officer Responsible	Progress made
It is vital that race, sexual orientation and language spoken and read is monitored, recorded and reported on in the new service to ensure that people from higher risk groups are engaging with the service.	This requirement should be built into the service specification and monitored via performance management		Ellen Rule	
The provider should consider as part of their response to the service specification how they support prevention activities and they develop partnerships with community groups, health trainers, faith communities etc,	Provider response template completed considering this action		Claire Thompson	
The provider should ensure that there is a clear link between the service and “Cancer Help for Minority Ethnic Communities” hosted by Bristol Community Health.	Provider response template completed considering this action		Claire Thompson	

<p>The provider should ensure there is a link between the service and the hospital chaplains</p>	<p>Provider response template completed considering this action</p>		<p>Claire Thompson</p>	
<p>For patients undergoing surgery, there needs to be a plan in place in advance which details their food choices for their time of temporary disability. A choice of food for oral or PEG feeding should be available for patients to choose from while in hospital</p>	<p>The service specification should detail the need for food choices to be made available in advance. The provider response template should consider the recommendation regarding patient choice for both oral and PEG feeding.</p>		<p>Ellen Rule Claire Thompson</p>	
<p>For patients undergoing surgery, there needs to be a plan in place in advance which details their communication needs during a time of temporary disability. Different communication methods should be offered for patients to choose from.</p>	<p>The service specification should detail the need for communication tools to be discussed during the preoperative stage. The provider response should consider how to make this available in practice.</p>		<p>Ellen Rule Claire Thompson</p>	

Follow up of the annual Learning Difficulties health check questions whereby patients who are identified as not being registered with a dentist are followed up.	Project Manager to inform Lesley Russ of this specific requirement		Ruth Hallett	
Ensure there are links between the Community Learning Disabilities Team and Dentists and GPs.	Project Manager to inform Lesley Russ of this specific requirement		Ruth Hallett	
A shuttle bus service using an accessible vehicle to be used between NBT and UHB sites is investigated.	This should be referred to the Healthy Futures Programme Board for consideration, as part of wider service planning		David Tappin	
A leaflet is produced which explains access to UHB sites including public transport and parking facilities nearby.	The provider should consider this as part of their response		Claire Thompson	
There needs to be communication and information about cancer and cancer treatments, ENT and OMFS procedures in an easy to understand format appropriate to the patient and family e.g. in a different language or accessible to people with Learning Difficulties	The service specification should detail this requirement. The provider should consider as part of the their response how they could enable this to happen		Claire Thompson	
A quiet place to be provided for patient and family	The provider should consider as part of the their response how they could enable this to happen		Claire Thompson	

Provision is made for family members to stay with the patient	The provider should consider as part of the their response how they could enable this to happen		Claire Thompson	
Providers should ensure that translation and interpretation services are offered to every patients for whom English is not a first language	The provider should consider as part of the their response how they could enable this to happen		Claire Thompson	

