

Nottinghamshire County **LINK**

Dentistry Provision for People with a
Learning Disability Task & Finish Group

March 2010



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Issue Origination

The issue of waiting time for dentist appointments for people with a Learning Disability who require general anaesthetic was fed into the LINK by Newark Mencap as a result of planned engagement activity. There was particular concern around the impact of long waiting times on individuals with learning disabilities and their carers. Newark Mencap had been made aware of this issue by service users and carers at the centre.

All issues raised to the Nottinghamshire County LINK are analysed by the Issues Panel (a panel of LINK participants) using a set of questions which help to score or prioritise the issues. The same questions are used for every issue, as approved by the Nottinghamshire County LINK Executive Board in April 2009.

Participants and partners involved in the group:

Participant Name / Role	Organisation (If applicable)
Tom Turner (Chair)	LINK Executive Board Member
Glen Swanwick	LINK Executive Board Member
Julie Hartley	Carer, LINK Participant
Adrian Hartley	Carer, LINK Participant
Lesley Booth	Carer, LINK Participant
Marie McGahey	Learning Disability Health Facilitator - Nottinghamshire Community Health, , LINK Participant
Helen Horsfield	PALS Officer – NHS Nottinghamshire County, LINK Participant
Kim Kirk	Carers Co-ordinator – NHS Nottinghamshire County
Richard McCallum	Head of Oral Health – NHS Nottinghamshire County/NHS Nottingham City/Bassetlaw PCT
Lorraine Gallacher	Nottinghamshire Healthcare Trust

Participant Name / Role	Organisation (If applicable)
Ruth Martin	Learning Disability Health Facilitator – Nottinghamshire Community Health
Laura Thomas	LINK Support Team
Katy Jeffery	LINK Support Team

Activities

At the Task and Finish Group meeting held on 8th October 2009, group members established the following focus for the piece of work:

The length of time that patients with a learning disability who require general anaesthetic for dental work have to wait before receiving treatment – associated concerns regarding service users and their carers.

This focus was chosen taking into account the following:

- The original referral made to the LINK.
- The information provided in response to the Statutory 20 Day Letters highlighted an issue with waiting times but the impact of this on individuals with a learning disability had not been ascertained.
- The Special Care Dentistry Review was not covering this aspect of the issue.
- High level of interest from stakeholders in this particular topic.

The patients using this service do not necessarily require complex dental treatment however, complications can arise from the use of general anaesthetic. The service involves behaviour management, and in some cases, it is necessary to administer a general anaesthetic at the assessment stage, before the treatment required is ascertained.

“Since December 2008, the longest you should wait after being referred by your GP until you start your treatment is 18 weeks - that is, unless you

choose to delay treatment or there is a clinical reason why you should wait longer. Wherever possible, you will wait less than this, with the average wait being around eight weeks. This means that any hospital appointments, tests, scans or other procedures that you may need before being treated will all happen within this maximum time limit."

(<http://www.chooseandbook.nhs.uk/patients/wait>)

The following policies have been identified by the group as relevant to the study:

- The British Dental Association Oral Health Inequalities Policy (2009)
- Delivering Better Oral Health: An evidence-based toolkit for prevention (Department of Health 2nd ed, 2009)
- Survey of Dental Services to People with Learning Disabilities in Northern Ireland (Department of Health, Social Services and Public Safety, 2005)

In order to obtain evidence to show the impact of long waiting times, it was decided that a questionnaire would be designed by the group in partnership with Nottinghamshire Healthcare Trust who would provide an audit service to ensure that the questionnaire is written appropriately. The group also decided to use its partners to arrange distribution of the survey in Day Centres and Supported Living Centres.

The purpose of this questionnaire was to build on a previous survey undertaken by Nottinghamshire Healthcare Trust which gathered people's experiences of special care dentistry in the Newark and Sherwood district. The benefit of conducting an additional questionnaire would be to focus particularly on experiences of dental treatment with a general anaesthetic and to capture experiences across the whole of Nottinghamshire, rather than in Newark and Sherwood alone. (Please contact Nottinghamshire Healthcare NHS Trust Clinical Audit for a copy of their Dental Audit report.)

Activities continued: Statutory 20 Day Letter Correspondence

Nottinghamshire County LINK sent the following requests for information using its authority which is set out in the LINKs Legislation: The Local Government and Public Involvement in Health Act, 2007 (available at www.dh.gov.uk/links).

Responses from these requests provided statistical information to justify the work of the Task and Finish Group. Please see Appendix Two, page 43 for full copies of all Statutory 20 Day correspondence.

Date Sent	Organisation	Brief Summary of Request	Date Response Received	Brief Summary of Response
28/05/09	Sherwood Forest Hospitals Foundation Trust (SFHFT) – Executive Director	<ul style="list-style-type: none"> ➤ Where can people with a Learning Disability access dentistry with a General Anaesthetic? ➤ What are the catchment areas? ➤ What is the average waiting time for this treatment? ➤ Any current / pending reviews of service? 	25/06/09	Responses provided for all requests
28/05/09	Bassetlaw Primary Care Trust – Chief Executive	As above		
28/05/09	NHS Nottinghamshire County – Chief Executive	As above	1/07/09 10/08/09	Responses provided for all requests Further information provided regarding waiting times
28/05/09	NHS Nottinghamshire County, Bassetlaw PCT – Head of Oral Health	As above	11/06/09	Information via telephone and email regarding review of service
28/05/09	Nottinghamshire Healthcare NHS Trust	As above		

Date Sent	Organisation	Brief Summary of Request	Date Response Received	Brief Summary of Response
28/05/09	Nottingham University Hospitals Trust (NUH) – Chief Executive	As above		
02/12/09	NHS Nottinghamshire County – Chief Executive	<ul style="list-style-type: none"> ➤ How many people per year require dental treatment under general anaesthetic? ➤ When are the results due from the Special Care Dentistry Review? 	18/12/09	Signposted to Head of Oral Health
02/12/09	Sherwood Forest Hospitals Foundation Trust (SFHFT) – Executive Director	<ul style="list-style-type: none"> ➤ Why is there such a high rate of cancellations of appointments? ➤ Why does the waiting time vary so much from month to month? 	04/01/10	Responses provided for all requests

Activities continued: Statutory 20 Day Letter Correspondence Analysis

Summary of responses from NHS Nottinghamshire County

Please see Appendix Two, page 43 for full copies of all Statutory 20 Day correspondence.

Table showing locations of General Anaesthetic (GA) Dental Services in Nottinghamshire, catchment areas and waiting times

Location	Catchment Area	Time between referral and first outpatient appointment	Time between referral and GA service
Nottingham University Hospital – Queens Medical Centre Site	Nottingham City Rushcliffe Broxtowe and Hucknall Gedling	6 weeks	23 weeks (average)
Sherwood Forest Hospitals Foundation Trust – Kings Mill Hospital	Mansfield Ashfield Newark and Sherwood	6 weeks	17 – 33 weeks (variation over 1 year)

Tables showing current activities based at Nottingham Salaried Service (Queens Medical Centre)

Data provided by NHS Nottinghamshire County, Special Care Dentistry Report
(2010)

April – September 2008

Session Type	No. of Sessions	Patients Seen	DNAs	Nottingham City	Nottinghamshire County
Day case – Adults	26	53	0	15*	13*
Day case – Child	27	72	2	22*	15*
Exodontia – Child	52	249	4	174	108
Assessments	26	131	14	41*	25*
In-patients	10	29	2	8*	8*

* July – September only

April 08 - March 09

Session Type	No. of Sessions	Patients Seen	DNAs	Nottingham City	Nottinghamshire County
Day case – Adults		98	1	48*	25*
Day case – Child		139	6	78*	26*
Exodontia – Child	99	476	45	338	253
Assessments		255	51	132*	63*
In-patients		39	3	17*	10*

* July – March only

April 09 - December 09

Session Type	No. of Sessions	Patients Seen	DNAs	Nottingham City	Nottinghamshire County
Day case – Adults		53	1	31	22
Day case – Child		108	8	57	46
Exodontia – Child	76	369	55	295	177
Assessments		147	38	90	57
In-patients		25	2	17	8

Summary of responses from Sherwood Forest Hospitals Foundation Trust

Kings Mill currently has capacity to undertake two cases per week under general anaesthetic, providing the dentist or anaesthetist is not on annual leave. A local dentist delivers the service.

Table providing a breakdown of referral sources to Kings Mill for the last two years, 2007 – 2008 and 2008 – 2009 (April to April)

Source of Referral to Kings Mill	07/08	08/09	Grand Total
Community Dental Service (School Dentist)	50	43	93
Consultant Transfer (Consultant to Consultant)	2	3	5
Dentist	9	13	22
GP	4	2	6
Other Provider (Millbrook)	1	0	1
Practice Based (Community GP)	8	4	12
Grand Total	74	65	139

Table providing breakdown of new referrals to Kings Mill by geographical area (based on residential address)

Geographical Area	07/08	08/09	Grand Total
Mansfield	24	21	45
Newark	12	13	25
Sutton in Ashfield	7	12	19
Bilsthorpe	11	5	16
Worksop	5	6	11
Kirkby in Ashfield	5	2	7
Rainworth	2	3	5
Nottingham	3	1	4

Retford	2	1	3
Southwell	2	1	3
Doncaster	1	0	1
Grand Total	74	65	139

Reasons offered by Sherwood Forest Hospitals Foundation Trust for length and variation in waiting times:

- Variation in waiting times is due to the service being so small
- Five weeks of operating time were lost in 2008 - 2009 as the service was moved into the Kings Treatment Centre at Kings Mill Hospital
- Due to often complex needs of the patient group, there is an increased chance of difficulty with transporting patients to hospital, or that another of the patient's needs supersedes the dentistry need
- If cancellations are made within 24 hours of the appointment, there is no time to fill the appointment
- If there is a high level of referrals at the same time as the dentist takes annual leave, this impacts further on the waiting time

Table providing rates of cancellations and did not attends (DNAs) combined at Kings Mill

Year	% Cancelled Appointments or DNAs	Number of Cancelled Appointments or DNAs
April 2008 – April 2009	12.6%	20 out of 159 appointments
April 2009 – Nov 2010	14.7%	20 out of 136 appointments

Results of the Nottinghamshire County LINK Dental Questionnaire

For a full copy of the Nottinghamshire County LINK Dental Questionnaire, please see Appendix One, page 39.

The questionnaire was distributed with the support of the following Day Centres:

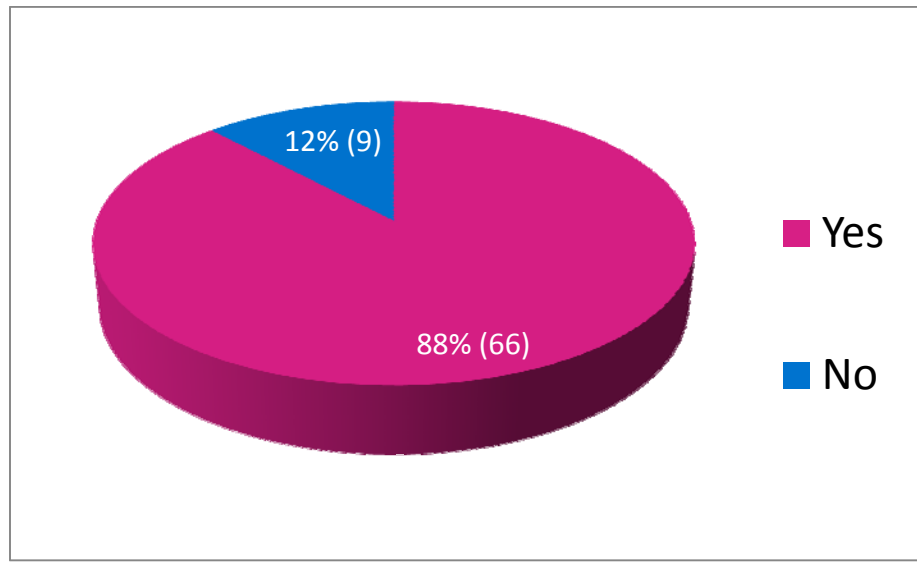
- Newark Mencap
- Ernehale Lea Day Centre
- Barncroft Day Centre
- Whitewater Day Centre
- Red Oaks Day Centre
- Greenacre Day Centre
- Rushcliffe Day Services (Thera)

A total of 530 copies of the questionnaire were distributed to the Day Centres, for people who have had experience of the dental general anaesthetic service to complete. 75 people completed and returned the questionnaire.

As the general anaesthetic service is relatively small, and due to the target audience, we feel that 75 completed questionnaires is a good result and will provide valid qualitative and quantitative data.

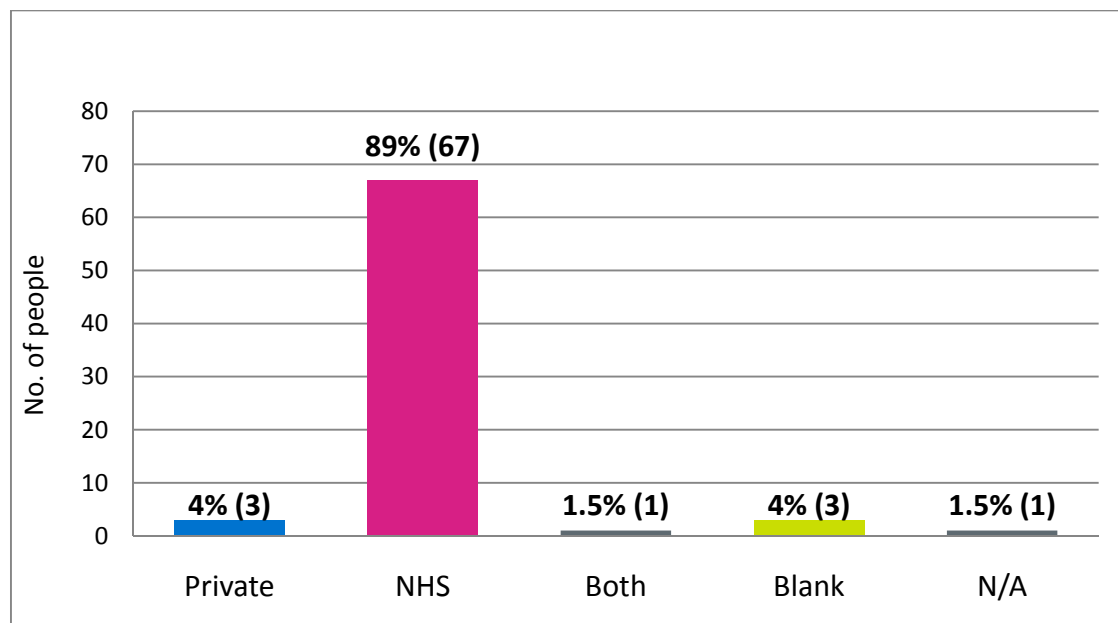
In the following analysis and for the purposes of this report, any names have been removed and spelling has been corrected. There are some slight variations between responses with branching questions.

Question 1
Do you go to the Dentist?



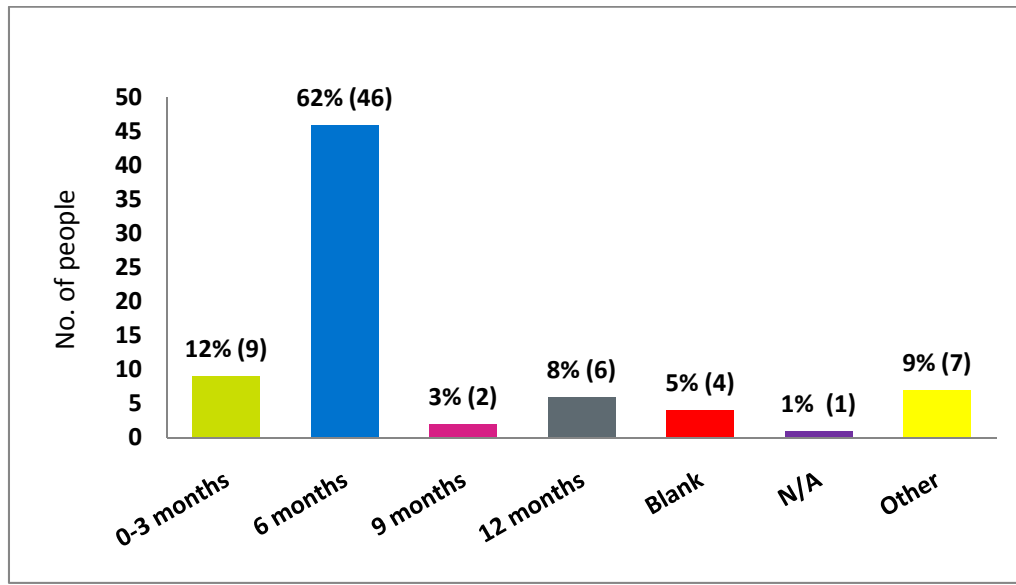
The above question was completed by 75 people, and shows that 66 (88%) of those that responded go to a dentist.

Question 2
Is your Dentist NHS or Private?



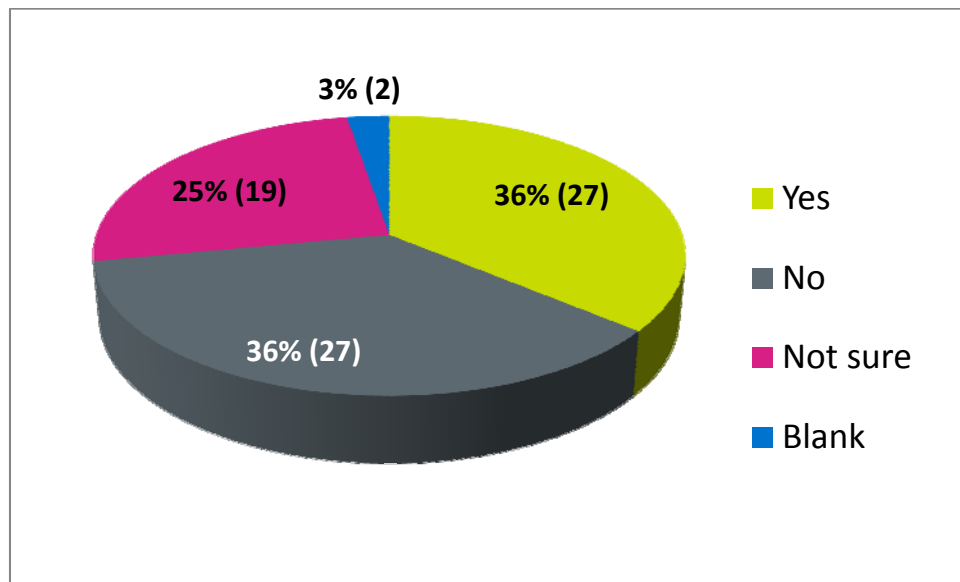
The above question was completed by 75 people, and shows that 89% of those that responded go to an NHS dentist.

Question 3
How often do you go to the Dentist?



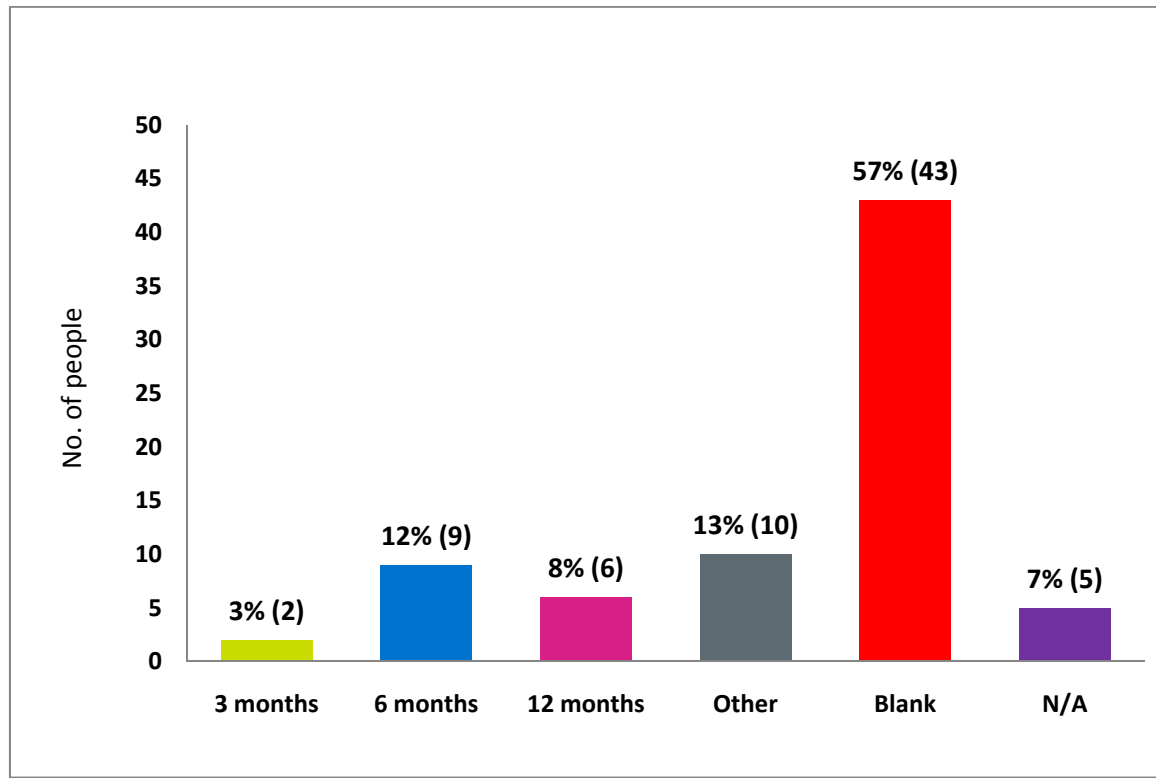
A majority of 46 people who responded to the above question visit the dentist every six months.

Question 4
Do you see the Dental Hygienist?



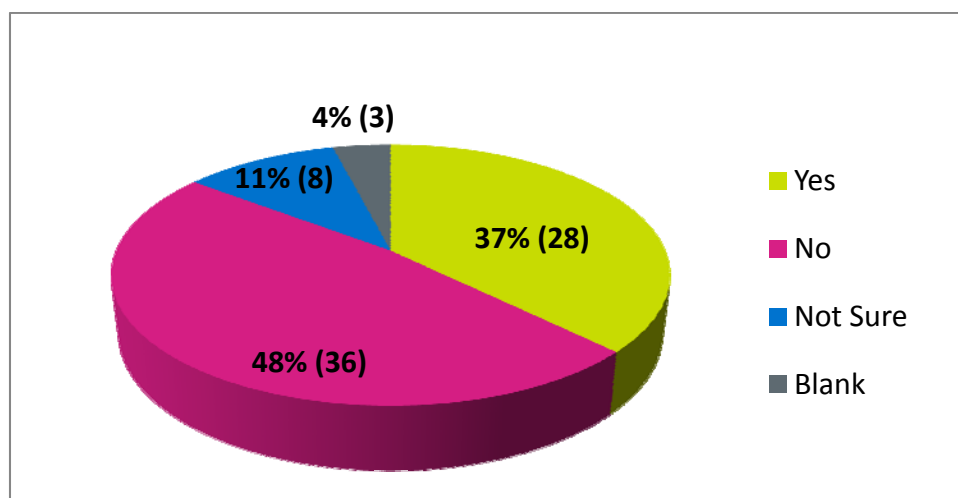
There is an equal number of respondents (36%) that said they do or don't visit a Dental Hygienist.

Question 5
How often do you see the Dental Hygienist?



Although 36% of respondents visit a Dental Hygienist (Q4), there was a varied response to this question, with the majority of respondents not making an indication.

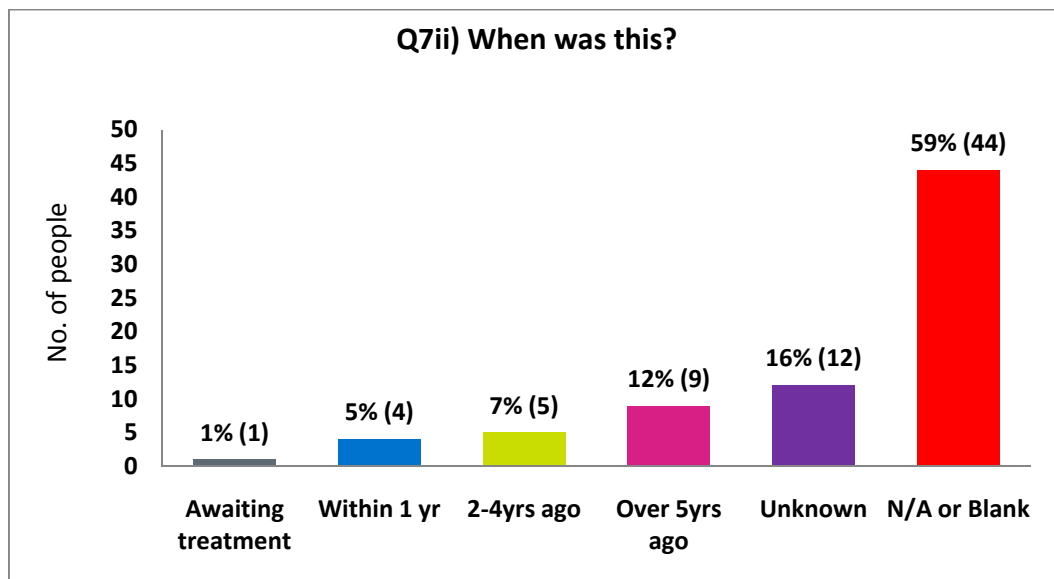
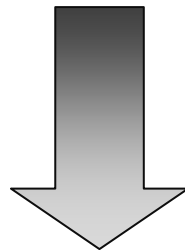
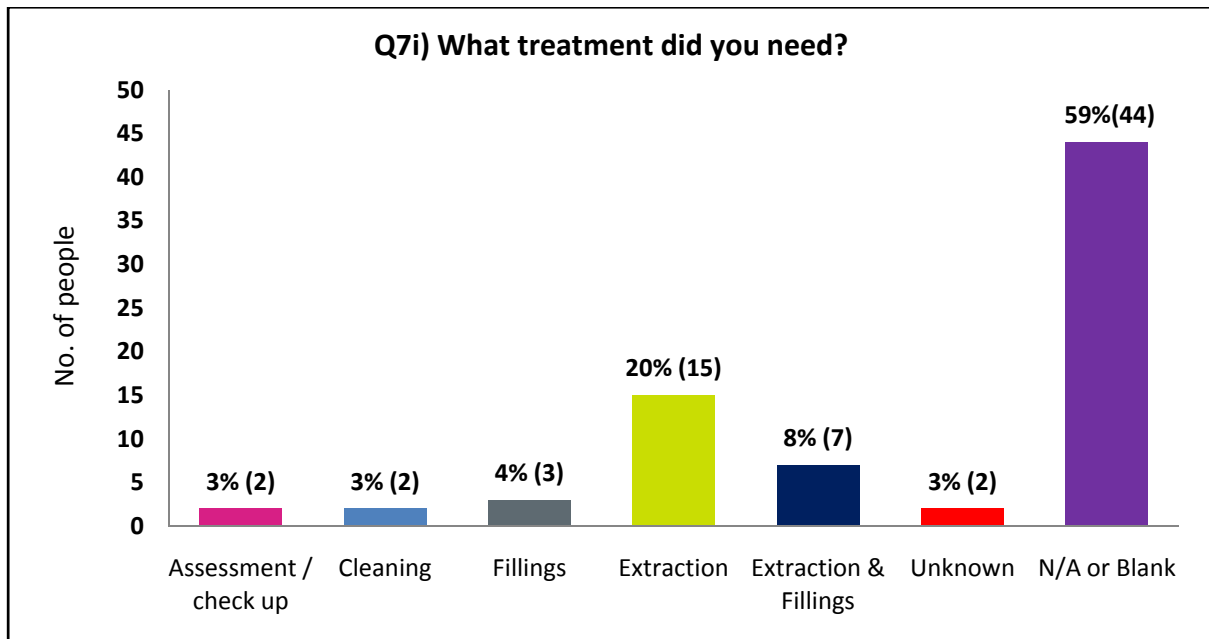
Question 6
Have you ever needed a general anaesthetic for dental treatment?



A total of 28 people who completed the questionnaire have received a general anaesthetic for dental treatment at some point in the past.

Question 7

What treatment did you need (i) and when was this (ii)?



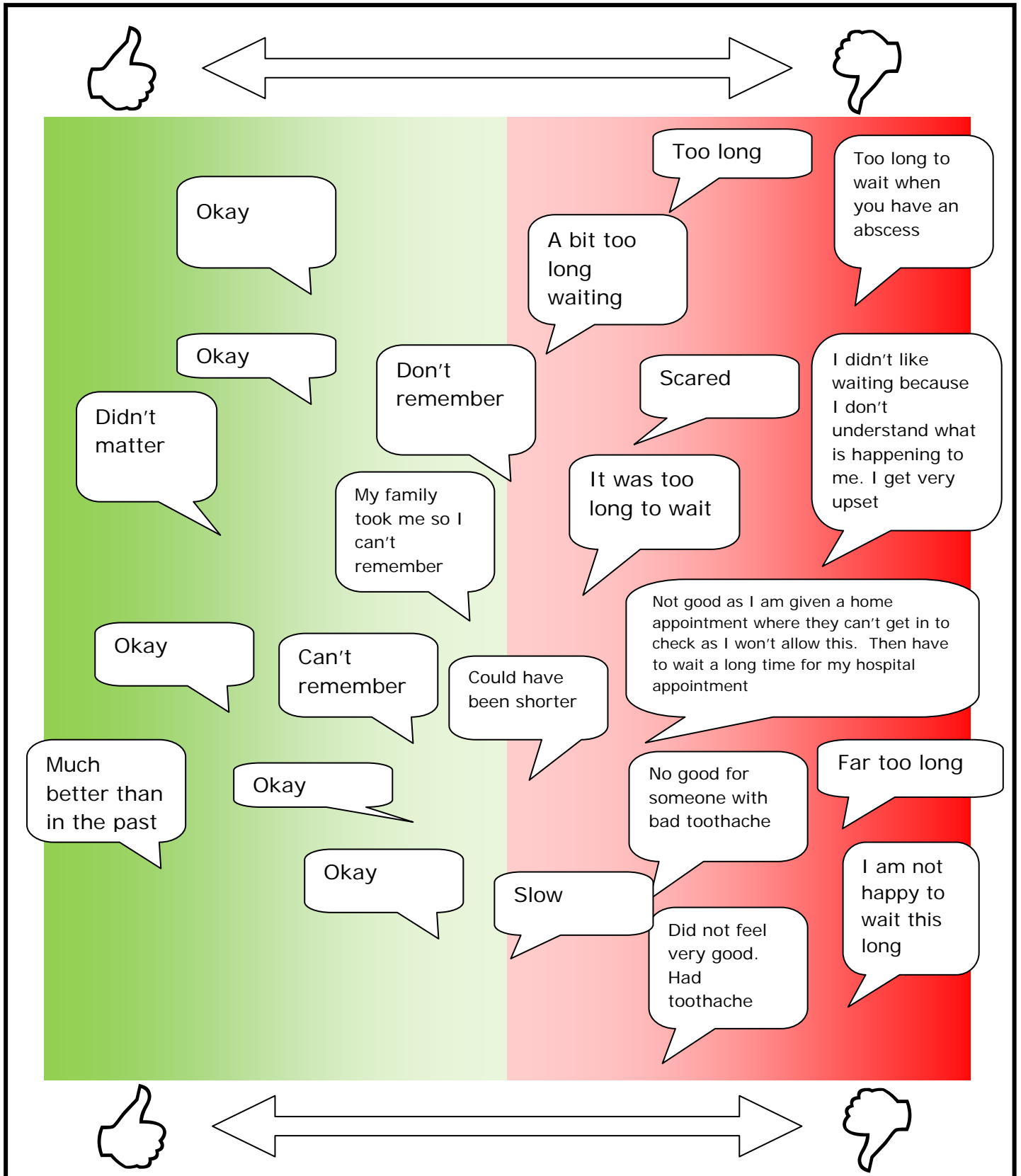
Question 8

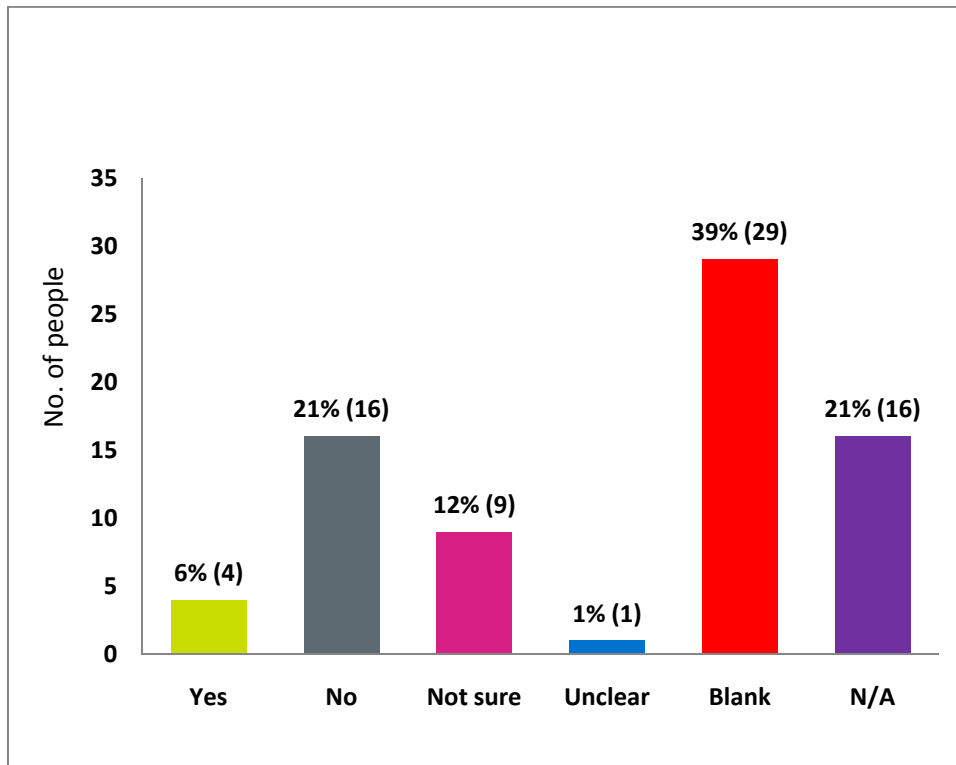
How long did you wait between seeing your dentist and going to the hospital for dental treatment?

Length of Time	Number of People	%
Less than 1 month	2	3%
1 – 2 months	4	5%
3 – 4 months	4	5%
5 – 6 months	2	3%
7 – 12 months	0	0%
Over 12 months	1	1%
Currently awaiting treatment	1	1%
Unknown	10	14%
N/A or Blank	51	68%

Question 9
How did you feel about the waiting time?

A total of 22 respondents provided comments about how they felt. These comments have been quoted on the scale below.



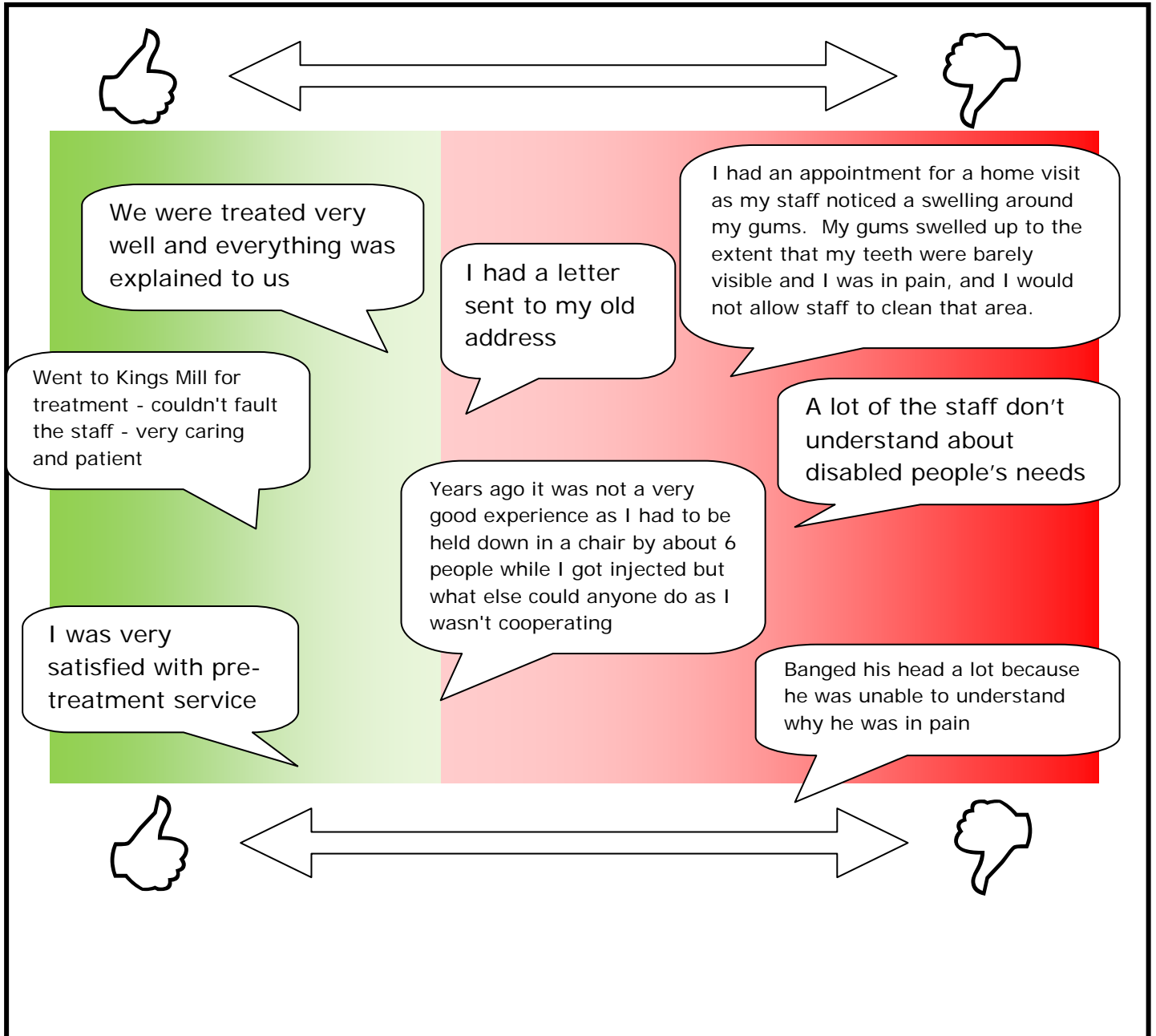
Question 10**Did you have a choice of appointments at the hospital?**

The chart above shows that only four respondents (6%) were able to choose their appointment.

Question 11

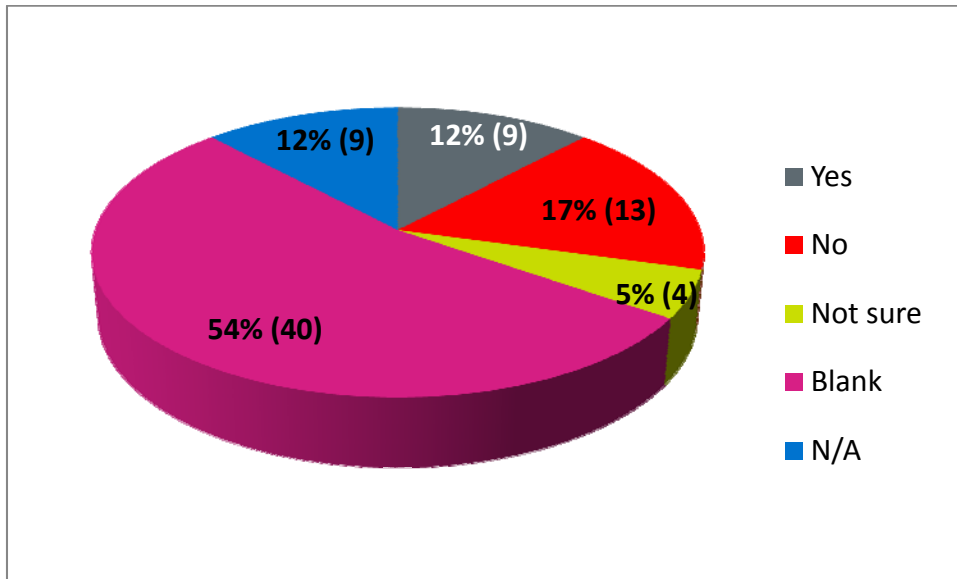
Did anything good or bad happen while you were waiting for treatment at the hospital? If good or bad please describe?

A total of 8 respondents provided comments about how they felt. These comments have been quoted on the scale below.



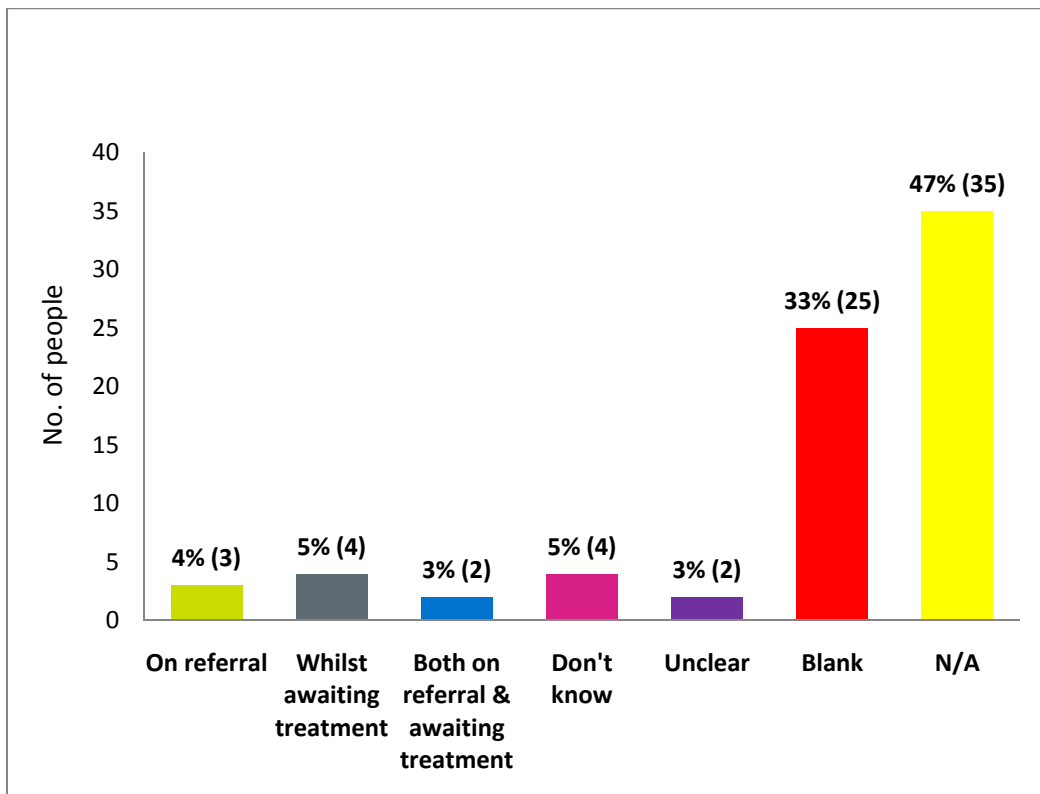
Question 12

Did you try to get treatment earlier because you were in pain?



Question 13

If you were in pain: did you have this pain on referral or did the pain start while you were waiting for treatment?



Question 14

On a scale of 1 to 10 please rate how much pain or discomfort you felt during this time. (1 being low and 10 high)

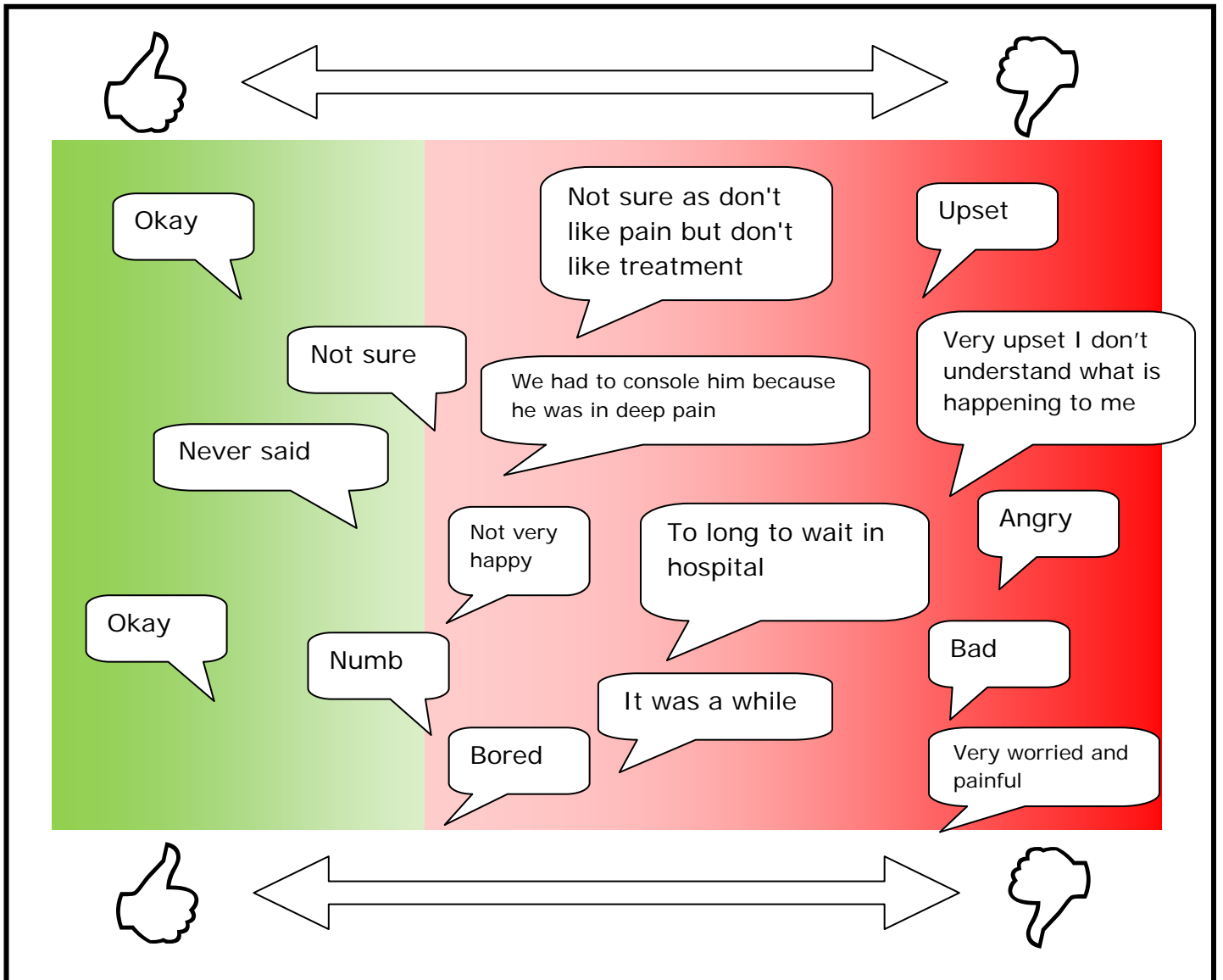
Level on scale	Number of People	%
Level 1 (Low)	2	3%
Level 2	1	1%
Level 3	1	1%
Level 4	1	1%
Level 5	1	1%
Level 6	1	1%
Level 7	2	3%
Level 8	1	1%
Level 9	1	1%
Level 10 (High)	1	1%
N/A	11	15%
Blank	48	65%
Unclear	2	3%
Don't know	2	3%

Question 15

How did you cope with the pain during the time that you were waiting for treatment at the hospital?

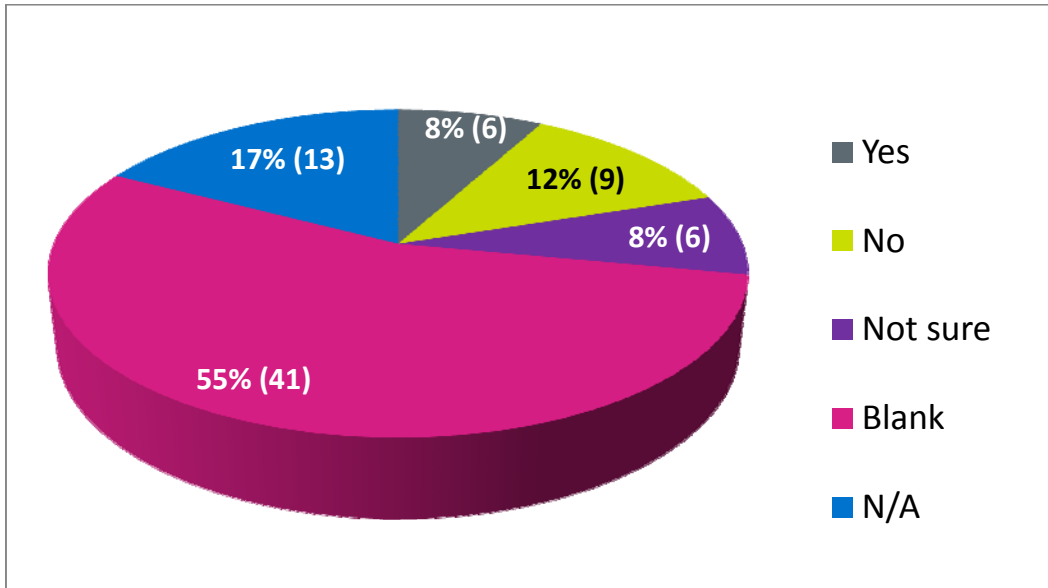
How did you cope?	Number of People	%
Okay	2	3%
Painkillers	7	9%
Prescribed medication	2	3%
Family support	1	1%
Unknown	2	3%
Not sure	1	1%
N/A	36	48%
Blank	24	32%

Question 16
How did waiting for treatment make you feel?



Question 17

Were you given any help to cope with any pain or discomfort while waiting for hospital treatment?



Question 18

If so, who helped you?

Who?	Number of People	%
GP	2	3%
Dentist	1	1%
Specialist Dentist	1	1%
Nurse	1	1%
Prescribed medication	1	1%
Family	2	3%
Blank	36	48%
N/A	31	42%

Question 19

What would make getting dental care easier for you?

In general, not to having to wait if in pain. People without learning disabilities should not have to wait so long

More checkups

To have a yearly appointment with the hospital directly, as I will always have to wait a long time between home visit

Not having to wait too long for my appointment

Everything is okay at present

My local dentist is good

It would be very good I could get six monthly check ups

Easier access to NHS dentists - no stairs

As I use a wheelchair and rely on support staff, to support me. Getting in/out of the dental chair is difficult for me.

Now we've got the dentist at clinic on Lombard St Newark, excellent service

I like my dentist and have no problems

Quicker admission to hospital

Quick and accurate correspondence

Finding a dentist who will be able to deal with my son requirements

Easier to see dentist and quicker treatment at hospital

Prompter treatment

Don't know, anything

Bassetlaw Hospital available for theatre session once a month - we have the qualified dentist but require an anaesthetist and theatre time

Finding a dentist who will a) see and treat without having to sit in a dentist's chair as the patient, can neither sit or stand and is prone on a 6ft long wheel chair

I'm happy at moment

To be able to have treatment straight away

Treatment at my day centre. I don't understand about going to the dentist

If dentists would listen to my parents and act on their information

Everything is okay at present

Very regular chance to see an NHS specialist dentist which is now happening I am pleased to report

Question 20

Is there anything else you would like to tell us about while you were waiting for dental treatment at the hospital?

Thumbs up icon ← → Thumbs down icon

I speak for my son who does not speak. It is a source of great concern that he will not be able to tell me the pain! Things are much improved now. I had very bad experiences in the past

Difficulty of travelling out of area with someone with severe learning and physical disabilities

Cannot write for himself as he has learning difficulties and it is very hard to determine if he is in pain

We were seen as quick as possible and everything went ok

Dental services are a complete let down, and have not got an inclusive service in this county

Activities continued: Additional Background from the British Dental Association Oral Health Inequalities Policy

British Dental Association, 2009

The following background information has been gathered based on the British Dental Association Oral Health Inequalities Policy. The Policy identified that an unacceptable and growing chasm exists in the UK between those with good and poor dental health. The 1998 Adult Dental Health Survey showed that many conditions in dental health are related to deprivation. Despite improvements in oral health over the past thirty years, inequalities still exist and are widely documented. Action to address this public health concern requires collaborative strategic input from all health and social care professionals. Improving oral health should be part of the government's wider public health strategy in all four UK countries, as many of the key factors that lead to poor oral health are risk factors for other diseases. The dental team has a vital role to play in maintaining the general and oral health of the nation, ideally placed to provide prevention and promotion messages to patients. Commissioners of dental services need to access appropriate dental public health advice to ensure support of strategies that address inequalities in oral health and ensure that oral health is included in health-related initiatives.

Dental services must be fully integrated within primary care to help develop local solutions for local needs, thus helping to tackle local oral health inequalities. However, there is agreement that dentistry should be more integrated in health services to improve holistic patient care. The need to engage people in their health and to shift the emphasis from cure to prevention of illness has been identified by the Wanless reports. (Wanless, D., *Securing our Future Health: Taking a Long-term View*, HM Treasury, 2002; Wanless, D., *Securing Good Health for the Whole Population*, HM Treasury, 2004) However, more emphasis is needed on health promotion and preventive approaches in conjunction with treatment of the damage caused by dental disease. Patients should be provided with the appropriate information in order to make informed decisions about their oral health, and information on dental services must be made available in an accessible format to the public, especially the "hard to reach" segments of the population.

Dental health is an important part of general health and should not be considered in isolation. More multi-agency working should promote

collaboration between health, local authority and voluntary organisations to tackle health inequalities.

Dental public health functions such as screening, epidemiological surveys, the identification of oral health inequalities and the evaluation of health improvement interventions designed to tackle these inequalities are all essential to service planning. These functions must be safeguarded and developed. In addition, dental public health advice must be available to commissioners of dental services.

PCTs have a responsibility to improve oral health in addition to carrying out dental public health functions. Oral health improvement can only happen if primary care organisations (PCOs) have the capacity within their structures to carry out the activities.

Oral health is an important aspect of overall health and the benefits of good oral health should not be underestimated. Good oral health empowers adults and children with disabilities, and can give them the confidence to enable them to reach their full potential in participating in all aspects of society. (Department of Health, Valuing People's Oral Health: A good practice guide for improving the oral health of disabled children and adults, 2007)

Enabling provision of responsive oral health services to these groups can require additional action and support. The 2007 Department of Health document Valuing People's Oral Health suggests that competence in provision of oral health care to these groups can be developed through research, consistent advice, professional training and provision of specialist care. The recommendations given in this report include assessing need through local surveys, and ensuring children and adults with a disability receive the necessary information, advice and support to give them the best opportunity to achieve and maintain optimal oral health. This can include ensuring multilingual information is provided for people whose first language is not English. The report also recommends including oral health in every care plan. However, guarantees should be implemented to ensure that local authorities and social service providers effectively act in accordance with these recommendations. It should be also considered that children and adults with learning disabilities may have difficulty using the health information available to them. (Department of Health, Choosing Health: Making healthy choices easier, 2004)

Primary care organisations (PCOs) need to acknowledge that dentists will need additional time when dealing with patients with more specific needs, such as disabled children and adults as well as elderly or complex mental health patients. Valuing People's Oral Health alluded to this - one of the messages contained within was that disabled children and adults have an equal right to access dental care at their general dental practitioner (GDP) along with the rest of their family, rather than being sent off to the salaried services or dental hospital. The British Dental Association (BDA) recognises a spectrum of complexity from patients with mild to moderate disability, most of whom should have access to care in general dental practice, through moderate to severe cases requiring a service with facilities specific to particular needs, to extreme cases needing specialist services. Salaried services should focus on those for whom a general dental practice environment is unsuitable, with an option of shared care where appropriate, and encourage others to attend general dental practitioners (GDPs).

Diet is also an important contributing factor to oral health. There is strong evidence to link frequency of sugar consumption and dental decay. Other measures such as reducing the use of medicines that contain sugar and promoting alternative delivery methods of medicines e.g. tablets, or if liquid medicine is the only method of delivery, ensuring that this is sugar-free wherever possible, should be encouraged.

Uniform dietary messages that go beyond oral health education should be promoted by the dental team as this would provide an opportunity to mention links to general health (e.g. obesity, diabetes, etc.) thus contributing to a consistent and holistic public health approach. (Department of Health and the British Association for the Study of Community Dentistry, Delivering Better Oral Health: An evidence-based toolkit for prevention, 2007)

Commissioners of services need appropriate dental public health advice to ensure support of strategies that address health inequalities and ensure that oral health is included in the wider agenda. In addition, the focus should be on the most vulnerable groups in society, such as children and adults with disabilities.

Activities continued: Additional background from the Survey of Dental Services for People with Learning Disabilities in Northern Ireland

Health, Social Services and Public Safety, December 2005

This study highlighted the need to prioritise the dental services to reduce inequalities in oral health and improve access to general dental services and general anaesthesia services.

Initiatives for prevention of oral disease are essential including the implementation of a policy on water fluoridation, training of carers, oral health protocols in residential units and a skill-mix balance of staff to implement oral health programmes. Training of dental staff in special care dentistry is also essential.

Trusts should co-ordinate dental initiatives and share oral health programmes. During the planning of dental services and the training of staff, a multidisciplinary approach should be taken with the aim of creating a supportive environment for good oral health. When planning dental care it is important to recognise the role of the carer and the person with the learning disability and in consultation, to encourage person centred planning of services.

Finally, it must be remembered that people with learning disabilities are not a homogenous group, they have many different needs and aspirations; but most of all it should be remembered that oral health and dental aesthetics are important to everyone and services should be planned and adapted to promote this.

Previous studies investigating the dental health of people with learning disabilities revealed a high level of untreated dental decay, with the main treatment experience being extractions instead of restorations. Oral hygiene was poor amongst people with learning disabilities and gum disease more prevalent than in the general population. (Crowley et al., 2005, Cumella et al., 2000, Shapira et al., 1998)

A report by Mencap highlighted that people with a learning disability have a lower uptake of dental services than the general population (Mencap 2004). Health information has been shown to be largely inaccessible to people with a learning disability, resulting in an inequality of knowledge about health services and health promotion (D'Eath et al. 2005).

Studies have demonstrated the lack of knowledge, support and training about oral health that is available for parents and carers of people with learning disabilities (Taylor-Dillon et al., 2003).

A challenge to the dental services is the policy of deinstitutionalisation and integration into community settings. Research highlights that as individuals move from institutions to communities their dental attendance is less regular and there is a necessity to expand and develop community-based services (Stanfield et al., 2003).

If dental services are to respond in a local community setting, it is important that teams are trained and confident in care (Wilson 1991). A study with the community dental service in Northern Ireland in 1993 claimed that lack of experience and knowledge were the main barriers for dentists providing care for people with disabilities (Russell and Kinirons, 1993).

Concerns

1. Prevention of Oral Disease

- A greater emphasis should be placed on prevention of Oral Disease including involving health visitors and social workers in oral health education and increasing targeted screening programmes. (See Recommendation 1.1 and 1.3)
- Increased oral health training for carers, carer staff in residential units, nursing and people with learning disabilities. (See Recommendation 1.2)
- Primary Care Trusts have a responsibility to improve oral health in addition to carrying out dental public health functions. Oral health improvement can only happen if primary care organisations (PCOs) have the capacity within their structures to carry out the activities. (See Recommendation 4.6)
- Non-compliance with the Disability Discrimination Act in dentist surgeries is detrimental to the treatment of patients with more complex needs, increasing the likelihood of general anaesthetic services. (See Recommendation 1.3, 1.4, 4.1)

2. Training of Dental Teams

- Increased disability awareness education and training in communication and behaviour management. (See Recommendation 2.1, 2.2, 2.3)

3. The Status of Oral Health and Disease

- The prevalence of oral disease was higher, and the treatment provision lower, in the population of people with learning disabilities compared with the general population. (See Recommendation 3.1, 3.2)
- The valuable contribution of dental hygienists has been highlighted (See Recommendation 1.4)

4. General Anaesthetic

- General concerns around the sustainability of the current service provision and evidence of succession planning.

- At present, the general anaesthetic services required to perform dentistry on a patient with a learning disability have long waiting lists, this has a negative impact to patients, families and carers. (See Recommendation 4.1, 4.5, 4.6, 4.7, 4.8)
- The number of available sessions should be increased and the pool of dentists and anaesthetists trained and willing to work in General Anaesthetic clinics should be increased. (See Recommendation 4.1, 4.5, 4.6, 4.7, 4.8)
- In addition, that facilities, support and care for people with learning disabilities staying overnight in hospital should be improved. (See Recommendation 4.1)
- The process of general anaesthetic administration should be made less traumatic for the patient, and that medical and dental staff have better communication about the procedure. (See Recommendation 4.3)
- Improved pain management should be available for those patients on long General Anaesthetic waiting lists. (See Recommendation 4.4)

5. Access to Dental Services

- Better communication from the dental team, and a more creative approach to conveying information such as on the appointment cards. Family carers and care unit managers also suggested the use of visual aids in explaining dental disease and treatment.
- The inequity of accessing 'out-of-hours' dental care for people with learning disabilities. (See Recommendation 5.2)
- Accessing regular dental care for all is a priority, yet it is often difficult for carers to prioritise dental appointments. Screening in day centres and residential units is positive and should be continued. A targeted recall appointment system would facilitate better access. This would also better support people with learning disabilities living in the community. (See Recommendation 5.3, 5.4)

Recommendations for Action

As a result of the work of the Task and Finish Group for Dentistry Provision for People with a Learning Disability, the following recommendations for action are made in the interest of improving services. Red flags indicate those recommendations considered to be of highest priority.

1. Prevention of Oral Disease

1.1. The community dental service should focus the priority of care of people with learning disabilities, by increasing targeted screening programmes.

Outcome: Implementing this will allow earlier diagnosis of disease and help to reduce the need for treatment and develop a personal plan.

1.2. Oral health promotion should be evidence-based, shared, and adapted throughout the dental service.

Outcome: The positive outcome of this recommendation would be sustainable services meeting the future needs of the population.



1.3. All carers and people with learning disability should be offered a personalised oral health disease prevention and treatment plan.

Outcome: Better planning will reduce the waiting time for assessment and treatment for patients.

1.4. Increased dental hygienists to work specifically with people with disabilities as part of a multidisciplinary approach.

Outcome: This will increase staff awareness and help reduce the need for dental treatment.

2. Training of Dental Teams

2.1. All staff should have disability awareness and communication skills training.

Outcome: Promotion of equality and diversity.

2.2. Training programmes in Special Care Dentistry for dentists and dental care professionals should be developed.

Outcome: This would ensure a sustainable service.

2.3. Training in the provision of dental care to people with learning disability should be included in the undergraduate curriculum.

Outcome: This would ensure a sustainable service.

3. The Status of Oral Health and Disease

3.1. Treatment of untreated dental disease should be a priority within the Community Dental Service.

Outcome: Implementing this will allow earlier diagnosis of disease and help to reduce the need for treatment or extractions.

3.2. The aim of dental care should be to reduce the number of extractions experienced by people with learning disabilities, coupled with evidence based preventive practices.

Outcome: Reducing the amount of patients who require avoidable extractions.

4. General Anaesthetic



4.1. Across NHS Trusts, there should be equitable access to dental care for all patient groups, including treatment provided under general anaesthetic to those with a learning disability.

Outcome: Promoting standards of equality and diversity



4.2. Trusts should work towards a standard referral pathway and implement more extensive planning for patients who are known to require a general anaesthetic for dental treatment.

Outcome: Planning would ensure that the service meets the needs of patients and is sustainable in the future. This would also ensure that the service is more efficient, for example, assessment and treatment in one stage if a patient requires general anaesthetic for assessment.



4.3. The patient experience of general anaesthetic could be improved with better planning and communication.

Outcome: This would have a positive impact on the patient's experience.

4.4. An effective care and pain relief service is required for those patients on long general anaesthetic waiting lists.

Outcome: This would have a positive impact on the patient and carer's quality of life whilst waiting for treatment.



4.5. Work should be undertaken in all Trusts to contribute to the reduction in waiting lists by reviewing the way that the waiting list is managed.

Patients should be offered a choice of hospital appointments, where possible, particularly if the waiting time at Queens Medical Centre continues to be shorter than at Kings Mill. Increased appointment choice could reduce appointment cancellations and pre-assessments could be done at an earlier stage to enable last minute appointment cancellations to be utilised.

Outcome: This would reduce the waiting time for treatment, increase the efficiency of the service, and increase patient choice.

4.6. Primary Care Trusts must identify a solution to how they intend to commission adequate general anaesthetic services that meet the standards for World Class Commissioning in line with the 18 week waiting time limit. The impact of transport for the patient group must be taken into consideration.

Outcome: This would ensure that the service is both adequate and sustainable in the future.



4.7. There should be better management of the waiting list including a prioritisation system to ensure that patients in severe pain are seen more quickly. This seems to be more of a concern for patients awaiting treatment at Kings Mill as the waiting time is longer.

Outcome: This would reduce the waiting time for treatment and increase the efficiency of the service.

5. Access to Dental Services

5.1. On-line access to dental records between community dental clinics and hospitals should be facilitated in future planning.

Outcome: This would improve the patient experience and increase the efficiency of the service.

5.2. Clear information on how to access 'out-of-hours' emergency dental care should be provided to all patients.

Outcome: The impact of this would be increased patient choice and awareness of services available.

5.3. Greater use of mobile units and more targeted screening should be considered.

Outcome: Mobile units would increase accessibility and reduce distress for patients by reducing travel.

5.4. Appropriate and effective follow-up screening procedures for learning disabled patients after leaving school need to be developed.

Outcome: This would contribute to promoting oral health and establishing a patient care pathway earlier.

Outcomes (March 2010)

Whilst the Task and Finish Group for Dentistry Provision for People with a Learning Disability has been in progress, NHS Nottinghamshire County have been conducting a Special Care Dentistry Review. Following this review, a service specification is being drawn up and the Task and Finish Group has been invited to contribute to the development of this service specification.

This opportunity will enable the Task and Finish Group to contribute to development of the Quality Requirements and Activity Performance Indicators within this service specification and to promote the inclusion of the Nottinghamshire County LINK's key recommendations.


Monitoring and Expected Outcomes








Nottinghamshire County LINK has undertaken this piece of work to highlight community concerns and existing good practice around Dentistry Provision for People with a Learning Disability.






We are keen to receive feedback from organisations on these recommendations, and would like to monitor positive outcomes from this work in September 2010. The results of this monitoring will be included in appropriate LINK publications and fed back to communities relevant organisations.

Thank You

Nottinghamshire County LINK would like to thank the following people and organisations for their support in this piece of work:

-  Everyone who completed a questionnaire

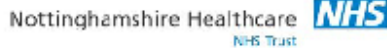
-  Newark Mencap
-  Ernehale Lea Day Centre
-  Barncroft Day Centre
-  Whitewater Day Centre
-  Red Oaks Day Centre
-  Greenacre Day Centre
-  Rushcliffe Day Services (Thera)

-  Nottinghamshire Healthcare NHS Trust
-  NHS Nottinghamshire County
-  Sherwood Forest Hospitals Foundation Trust
-  Nottinghamshire County Council
-  Nottingham University Hospitals NHS Trust

Appendices

- Nottinghamshire County LINK Dental Services Questionnaire
- Statutory 20 Day Correspondence

Appendix One: Nottinghamshire County LINK Dental Services Questionnaire



Dental Services Questionnaire

This questionnaire is for people with learning disabilities who have used hospital dentistry services.

Nottinghamshire County LINK is trying to make dental services for people with a learning disability better. We want to know what you think about any dental treatment you've had at the hospital.

If you like, you can ask someone you trust to help you fill in the questions – like a friend or someone in your family. You don't have to give your name but we will use your views to help make the service better. Please send the questionnaire back to us in the envelope provided by 26th February 2010. There is no need for a stamp.

Thank you for your help.

1	Do you go to the dentist?	Yes/No
2	Is your dentist NHS or private?	NHS / Private
3	How often do you go to the dentist? <input type="text"/>	
4	Do you see the dental hygienist?	Yes/No/Not Sure
5	If yes, how often? <input type="text"/>	
6	Have you ever needed a general anaesthetic for dental treatment?	Yes/No/Not Sure
7	What treatment did you need, and when was this? <input type="text"/>	

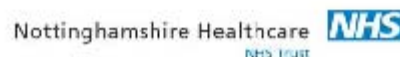
8	<p>How long did you wait between seeing your dentist and going to hospital for the dental treatment?</p> <div style="border: 1px solid black; height: 50px; width: 100%;"></div>	
9	<p>How did you feel about the waiting time?</p> <div style="border: 1px solid black; height: 150px; width: 100%;"></div>	
10	<p>Did you have a choice of appointments at the hospital?</p>	<p>Yes/No/Not Sure</p>
11	<p>Did anything good or bad happen while you were waiting for your treatment at the hospital?</p>	<p>Yes/No/Not Sure</p>
	<p>If good or bad, please describe.</p> <div style="border: 1px solid black; height: 150px; width: 100%;"></div>	
12	<p>Did you try to get treatment earlier because you were in pain?</p>	<p>Yes/No/Not Sure</p>

13	<p>If you were in pain: did you have this pain on referral or did the pain start while you were waiting for treatment?</p> <div style="border: 1px solid black; height: 120px; width: 100%;"></div>
14	<p>On a scale of 1 to 10 please rate how much pain or discomfort you felt during this time. (1 being low and 10 high)</p> <p style="text-align: center;"> 1 2 3 4 5 6 7 8 9 10 </p>
15	<p>How did you cope with pain during the time that you were waiting for treatment at the hospital?</p> <div style="border: 1px solid black; height: 150px; width: 100%;"></div>
16	<p>How did waiting for treatment make you feel?</p> <div style="border: 1px solid black; height: 150px; width: 100%;"></div>

17	Were you given any help to cope with any pain or discomfort while you were waiting for your treatment at the hospital?	Yes/No/Not Sure
18	If so who helped you? <div style="border: 1px solid black; height: 80px; width: 100%;"></div>	
19	What would make getting dental care easier for you? <div style="border: 1px solid black; height: 100px; width: 100%;"></div>	
20	Is there anything else you would like to tell us about while you were waiting for dental treatment at the hospital? <div style="border: 1px solid black; height: 150px; width: 100%;"></div>	

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Appendix Two: Statutory 20 Day Correspondence

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Ref: 20 day Statutory Letter

Date: 28/5/2009

Dear Sirs

Nottinghamshire County LINK

I am writing on behalf of the Nottinghamshire County LINK, an organisation of volunteers set up by the Government to promote their Duty To Involve agenda. It is the responsibility of the LINK and its participants to look at community issues in relation to health and social care, and to investigate and offer suggestions to service providers if the LINK is able to suggest any improvements.

A significant number of LINK participants have raised the same issue recently – namely, the fact that there is a shortage of provision for people with Learning Disabilities to access dental services. In particular, concern has been raised about the length of time that patients who require general anaesthetic for dental work have to wait before receiving treatment. We would like to look into this issue further and see if there are any solutions we can suggest to improve the current system.

Before we can begin any work, we have a number of questions that need to be answered:

- Please could you tell us at which locations people with learning disabilities can access dental services in conjunction with a general anaesthetic
- We would also like to know what the catchment areas are for the above type of treatment at each location. For example, where would a Newark resident have to go to receive treatment?
- How long do patients have to wait on average to receive such treatment in each location?
- Is there any review of this service pending?
- Is there any review of this service currently being undertaken?


We have several LINK participants and a number of local organisations interested in partnership working to look at this issue. If you are currently undertaking a review of this position, please let us know if there is anything we can do to assist you. We are hoping that we can use the powers given to us by government legislation (Local Government and Public Involvement in Health Act 2007) in order to assist our local community and yourselves to make sure that a very difficult situation can be dealt with as advantageously as possible.

We look forward to hearing from you in relation to this matter and, if possible, working alongside you in relation to this issue.

Yours faithfully



Shirley Inskip
Chair
On behalf of the Nottinghamshire County LINK



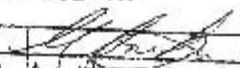
Nottinghamshire County

Nottinghamshire County Teaching Primary Care Trust
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 Ransom Wood Business Park
 Southwell Road West
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Tel: 01623 673133
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 Our Ref: 01623 673133
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 Email: wendy.sevicur@notnspct.nhs.uk
 Date: 24 June 2009

Mrs Shirley Inskip
 Chair
 Nottinghamshire County LINK
 Unit E2, Southglade Business Park
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Code Number	
Date Received	01 JUL 2009
Signature	
Print Name	IN SKIP

Dear Shirley,

Thank you for your letter dated 28 May 2009 enquiring about access to dental services requiring a general anesthetic for people with Learning Disabilities. Below I have tried to address the queries you raise in your letter.

1) GA dental services are available at:

Nottingham University Hospital – (Queens Medical Centre Site)
 Sherwood Forest Hospitals NHS Foundation Trust – (Kings Mill Site)

2) Catchment areas

In general:

Greater Nottingham (Nottingham City, Rushcliffe, Broxtowe & Hucknall, Gedling) is served by NUH

Central Nottinghamshire patients (Mansfield, Ashfield, Newark & Sherwood) are served by KMH

3) Waiting times

I am awaiting some information from the service providers on current waiting times and I will write to you again in two weeks with an update on this issue.

4) Service review (pending or underway)

A review of this specific service is not underway at present. A review looking at dental services on the whole for people with Learning Disabilities is due to commence in July 2009.

Preliminary work has commenced on reviewing Special Needs Dentistry with the initial scoping meeting on 10th June 2009. This will review the current provision of oral health services, preventive and treatment, against needs and propose future service models.

This is a joint piece of work and will cover NHS Nottingham City, NHS Nottinghamshire County and Bassetlaw PCT.

The specific aims are:

1. To identify the current provision of preventive, promotional and care services.
2. To compare, through a gap analysis, the current position with standards in the national Special care dentistry strategy (Valuing People's Oral health DH 2007) and Choosing Better Oral Health (DH 2005).
3. To develop an action plan with clearly stated priorities and timescales, in line with the Next Stage review (Darzi) and World Class Commissioning principles.
4. To develop standards for service provision based on evidence-based practice standards to ensure high quality. These should reflect the needs of people identified as having special dental needs. Consideration of Dentists with Special Interests (DwSI) in Special care Dentistry will be included.
5. To develop service models through a care pathway approach, incorporating preventive and treatment care services. These services should minimise barriers to care and improve boundary issues.

It is important that service users and their representatives are actively involved in this work and Richard McCallum as lead of the review would welcome ideas as to how this may be achieved. I will ask Richard to contact you to discuss this.

I also wanted to make you aware that this PCT has recently invested in two LD acute liaison posts. These nurses will assist in the patient pathway for people with LD accessing health services at acute hospital sites.

Thank you for your enquiry and offer of help in progressing these services. I will write to you again once I have the information regarding waiting times.

Best Wishes.

Yours sincerely



Wendy Saviour
Chief Executive
NHS Nottinghamshire County



Nottinghamshire County

Nottinghamshire County Teaching Primary Care Trust
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Mrs Shirley Inskip
Chair
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Dear Shirley

Re: Dental services requiring a general anaesthetic for people with Learning Disabilities

In my response on 24 June to your letter dated 28 May 2009, I promised to write to you again with further information regarding your original question on waiting times. I have now received the information which is outlined below.

Central Nottinghamshire – service run by Sherwood Forest Hospitals Trust from the Kings Mill Hospital site

From referral to first outpatient appointment = 6 weeks
The wait for the specific general anaesthetic service has varied in year between 17 – 33 weeks.

Greater Nottingham service – run by Nottinghamshire Community Health using Nottingham University Hospital facilities (QMC campus)

From referral to first outpatient appointment = 6 weeks
The wait for the specific general anaesthetic service is on average 23 weeks

It is worth pointing out at this point that once referred to the service patients enter the special needs dental service pathway and are assessed and treated in a variety of settings. Patients waiting for GA dental treatment will have received assessment and previous intervention on the pathway before being listed for General Anaesthetic.

Best wishes
Yours sincerely

Wendy Savicour
Chief Executive
NHS Nottinghamshire County

cc. Jane Warder, Sherwood Forest Hospitals NHS Foundation Trust

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Ref: 20 day Statutory Letter
 Date: 2nd December 2009

Dear Ms Saviour

Nottinghamshire County LINK

Thank you for your previous response to our 20 day Statutory letter dated 24th June 2009.

In support of the information you provided to our Task and Finish Working Group in this letter, we would like to request the following information;

1. How many people per year require dental treatment under General Anaesthetic?
2. When are the results due from the Special Care Dentistry Review Group?

We look forward to hearing from you in relation to this matter and, if possible, working alongside you in relation to this issue.

Yours faithfully

Jane Stubbings
 Vice Chair
 On behalf of the Nottinghamshire County LINK

cc: Jane Warder, Executive Director, Sherwood Forest Hospitals Foundation Trust



Nottinghamshire County

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Jane Stubblings
Vice Chair
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Dear Jane

Thank you for your request for further information for your Task and Finish Review Group on Dental Provision under General Anaesthesia for People with a Learning Disability.

Unfortunately I am unable to give you an answer to your request on the number of people within NHS Nottinghamshire County area requiring dental treatment under General Anaesthetic as we just do not have the information to hand. The Special Care Dentistry Review Group is collating this information and is due to report in February 2010. Once this has been completed, I will forward it to you.

I will ask Richard McCallum, Head of Oral Health, to continue to provide support to your Review.

Best wishes

Yours sincerely

Code Number:	1
Date Received:	18 Dec 2008
S:	
F:	

Wendy Saviour
Chief Executive
NHS Nottinghamshire County

Code Number	1
Date Received	04 JAN 2009
S:	
Print Name	

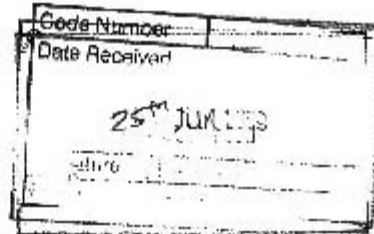
Sherwood Forest Hospitals

NHS Foundation Trust

Trust Headquarters

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 E Mail: jane.warder@sfh-tr.nhs.uk

King's Mill Hospital
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 Tel: 01623 822515



Our Ref: JW/KAG/Inskip090609

23rd June 2009

Ms S Inskip
 Chair
 Nottinghamshire County LINK
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 NG5 9RA

Dear Ms Inskip

Re: Dental service provision for people with learning disabilities

Thank you for your letter dated 28th May 2009. I have looked into your questions and can answer them on behalf of Sherwood Forest Hospitals NHS Foundation Trust.

I would note that to get a full picture of the whole Nottinghamshire position you would need to liaise with NHS Nottinghamshire County who commission the services and manage the Community Dental Service.

To take your questions individually.

1. Which locations can people with learning disabilities access dental services in conjunction with a general anaesthetic?

We provide this service in the King's Treatment Centre at King's Mill Hospital, Sutton in Ashfield. It is delivered by a local dentist, not one of our consultants. Referrals are received from a few sources, but come predominantly from the Community Dental Service. We currently have capacity to undertake 2 cases per week under a general anaesthetic, unless the dentist or the anaesthetist is on holiday.

Given the spectrum of learning disabilities, some patients with complex needs require a general anaesthetic prior to even a simple examination.

There is no emergency service offered at the hospital.

Patient Advice & Liaison
 01623 672222
 p.a.l.s.kmh@sfn-tr.nhs.uk



Chairman Tracy Drouel
 Chief Executive Jeffrey Worrall

Table 1 provides a breakdown of referral sources for the last two years, 2007-08 and 2008-09 (April to April).

Table 1

Referral source	07/08	08/09	Grand Total
Community Dental Service (School Dentist)	60	43	93
Consultant Transfer (cons to cons)	2	3	5
Dentist	9	13	22
GP	4	2	6
Other Provider (ref from Millbrook)	1		1
Practice-Based (Comm GP)	8	4	12
Grand Total	74	65	139

2. What catchment areas are for the above type of treatment?

We have provided this information based on the residential address of individual patients. As you can see, from Table 2 below, patients from Newark are seen at the King's Treatment Centre, but the catchment area is mainly central Nottinghamshire.

The service is there only for patients who can not be managed without a general anaesthetic. The Community Dental Service will be providing the majority of care. However, many patients need several visits, so the numbers of referrals does not reflect the case load.

Table 2

New Referral's received split by area (based on residential address)

Area Group	07/08	08/09	Grand Total
Mansfield	24	21	45
Newark	12	13	25
Sutton In Ashfield	7	12	19
Bilsthorpe	11	5	16
Worksop	5	6	11
Kirkby In Ashfield	5	2	7
Rein worth	2	3	5
Nottingham	3	1	4
Retford	2	1	3
Southwell	2	1	3
Doncaster	1		1
Grand Total	74	65	139

3. How long do patients wait to receive such treatment?

Currently new referrals into the service are waiting a maximum of 6 weeks for a first outpatient appointment.

As this is a small service, there is a lot of variation in the waiting times. The waiting time from referral for a dental procedure requiring a general anaesthetic to the treatment itself is showing a median average of 22 weeks, during 2008/09. In April 2009, the median waiting time was 17 weeks, but this was 33 weeks median in May 2009.

However, 5 weeks of operating time were lost as we moved into the King's Treatment Centre this year.

To note, there is also a high rate of cancellations and many patients do not attend on the day. This is again related to the nature of the patients and their complex care needs.

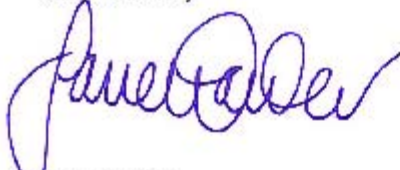
4. Is there any review of this service pending or currently being undertaken?

As I mentioned to Kate Jeffries, from the LINK, when she called – we have just started to review this service within the trust in order to begin discussions with our commissioners, NHS Nottinghamshire County. We wish to continue providing this service. The issue is that if the current dentist were to leave – we would struggle to replace him. There needs to be a plan for this.

In addition, we need to discuss the current payment structure. Currently we are paid a price (a tariff) for the patient being seen in clinic or for a minor procedure but this does not reflect the fact that each appointment slot needs to be at least an hour long in order to anaesthetise and recover these patients. We potentially need to negotiate an appropriate local price.

In raising these issues for review and discussion with NHS Nottinghamshire County, I would imagine this will require them to review the demand and capacity across their population, as well as the current performance and quality of services, and the views of service users and their carers. This will lead to a commissioning plan for the future.

Yours sincerely



Jane Warder
Executive Director of Strategy and Improvement

Copied to:

Wendy Saviour, Chief Executive, NHS Nottinghamshire County

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Ref: 20 day Statutory Letter
Date: 2nd December 2009

Dear Ms Warder

Nottinghamshire County LINK

Thank you for your previous response to our 20 day Statutory letter dated 23rd June 2009.


In support of the information you provided to our Task and Finish Working Group in this letter, we would like to request the following information:

1. Please can you provide further information to why there is such a high rate of cancellations for appointments/procedures?
2. Why does the length in waiting times for a procedure vary so much from month to month?

We look forward to hearing from you in relation to this matter and, if possible, working alongside you in relation to this issue.

Yours faithfully

Jane Stubbings
Vice Chair
On behalf of the Nottinghamshire County LINK

Hosted by  CAREERS FEDERATION
LWIPB
Registered Charity Number: 1029779



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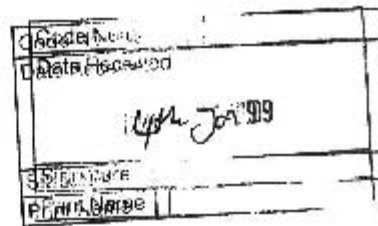
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Our Ref: JW/KAG/Stubbings211209

21st December 2009

Mrs J Stubbings
 Nottinghamshire County Link
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Dear Jane

Thank you for your letter of 2nd December 2009, in which you ask the following questions:

1. Please can you provide further information to why there is such a high rate of cancellations for appointments/procedures?
2. Why does the length in waiting times for a procedure vary so much from month to month?

In response to these questions I will expand more on the letter I sent on 23rd June 2009.

1. The patient appointment cancellations within 24 hours (so there is no time to fill the slot) and did not attend on the day (DNA) rates for this service combined are as follows:

08/09 – 12.6% (20 out of 159 booked appointments)
 April – November 2009 – 14.7% (20 out of 136 booked appointments)

As previously noted, some patients have very complex needs, some requiring a general anaesthetic for even a simple examination. There is therefore an increased chance that there can be difficulty getting the patient there, or for one of their other needs to supersede the dentistry one. For example we sometimes find that a patient could suffer something like an epileptic fit, or

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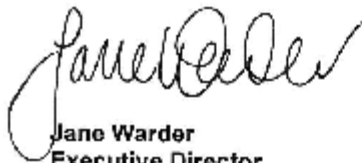
have another problem, on the day they are due to attend for the treatment, so their carers don't bring them on the day.

2. Where there is a small service, particularly where the service is provided by one practitioner, in this case a dentist, waiting times vary more. There is normal variation in how many referrals are received in a month (for example in May 2008 the Trust received two referrals but in March 2009 ten referrals were received). This can be compounded by things like annual leave. So if there is a spike in referrals at the same time as the dentist takes 2 weeks leave then the waiting time will be much longer than when there is a dip in referrals and the dentist does not have any leave.

I hope this gives further clarity in answer to your questions.

In my last response I suggested you liaise with our commissioners, NHS Nottinghamshire County, as I imagined, and suggested to them, that they needed to review the demand and capacity for this service across the county. I suggested this review included performance and quality aspects, as well as the views of service users and their carers, to inform commissioning.

Yours sincerely



Jane Warder
Executive Director
Strategy and Improvement