

NEUROSCIENCES DIRECTORATE

BRAMS (Bristol and Avon Multiple Sclerosis) Unit

**Out- Patient Satisfaction Survey
November 2010-December 2010**

REPORTED MARCH 2011

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ID – 1062**



Background

The BRAMS (Bristol and Avon Multiple Sclerosis) Unit opened in December 2008 as a regional centre of excellence for MS patients throughout the South West. The BRAMS charity established by Prof Scolding Dr Cottrell and Dr Wilkins has largely funded the creation of this unit and allowed the expansion of the MS services provided. The BRAMS team are a multi disciplinary team providing specialist MS out-patient services, physiotherapy, MS nursing input, a day case unit for IV drug infusions, access to numerous international clinical trials, urgent relapse clinics as well as Urology clinics.

The team have worked hard to provide these extensive services. We feel these expanded services are an improvement however we needed to know what our patients perception of the unit is .Are there aspects that are particularly good or bad and how can we improve upon what we do? Is the service provision better or worse than previous? What do our patients want from the service (in line with NICE guidance)?

Evidence:

NICE guideline no.8 - management of MS in primary and secondary care
NSF for Long Term Conditions

Aim

To ensure that all patients have equal access to services and that those services meet their expectations and conform to NICE guidance/NSF recommendations

Objectives

- ❖ To identify what we do well currently
- ❖ To identify what patients want from the service
- ❖ To identify gaps in the service

Methodology

Our Out Patient survey was compiled in conjunction with the Clinical Audit department at North Bristol Trust. We compiled a list of potential questions with the aid of other NBT approved and NHS approved Picker Institute Out- Patient satisfaction questionnaires. Reference was also made throughout to the NICE guidelines for MS and the NSF for Long Term Conditions.

Specimen questions were submitted to the NBT Questionnaire Review Group and their responses were used to edit the questionnaire.

The final draft was reviewed by NBT Clinical Audit department once again and the questionnaire was tested on a small number of BRAMS patients .Their comments were used to further amend the survey. 100 patient satisfaction surveys were given out from 15th November 2010 until 22nd December2010. Patients were asked to complete the surveys whilst they were in attendance in the unit however prepaid envelopes were provided to patients who wanted to complete the survey at home.

We had 76 responses from the 100 surveys (76%) handed out. The results are as follows.

Results

There were 76 forms returned from the out-patient clinics.

The following charts represent the answers given by the respondents.

Demographics

Chart 1 Who is completing the form on behalf of the patient?

N = 76

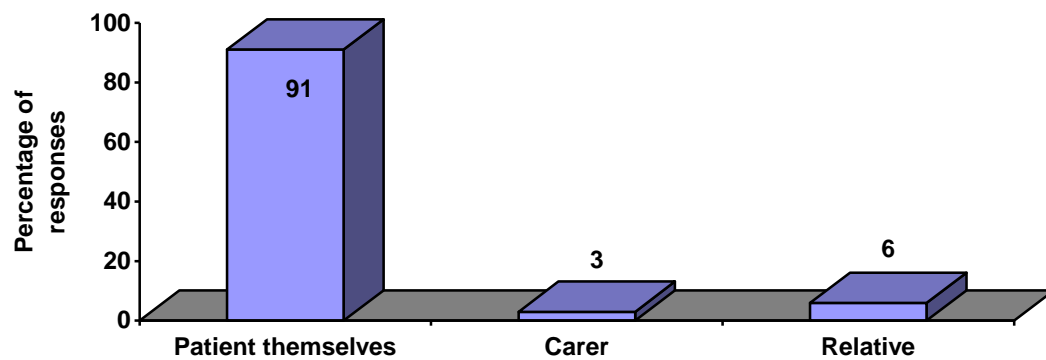


Chart 2 Patients age

N = 76

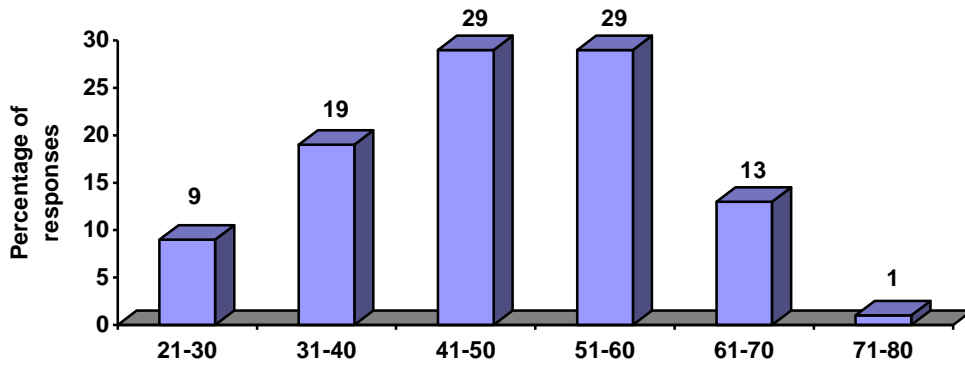
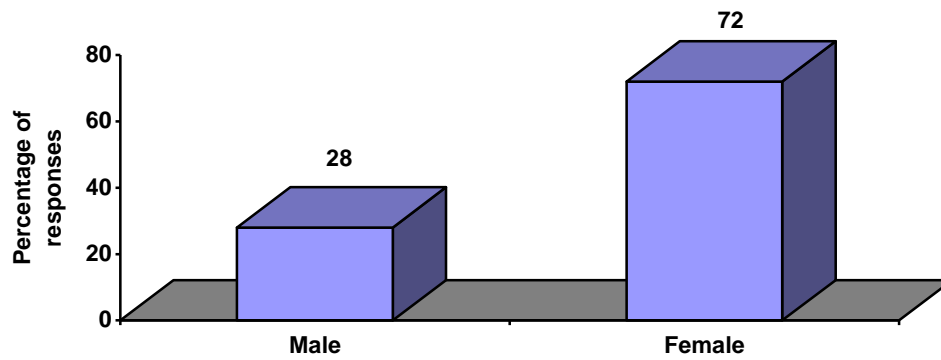


Chart 3 Gender

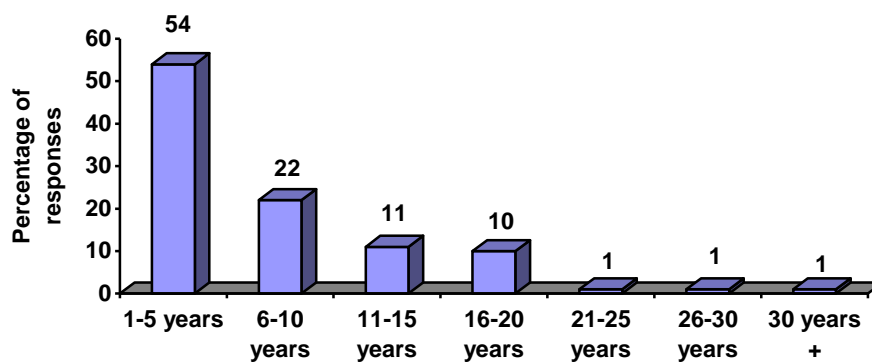
N = 72



4 blank responses

Chart 4 How long have you attended the Neurology Out-Patient as an Multiple Sclerosis patient?

N = 74



2 blank response

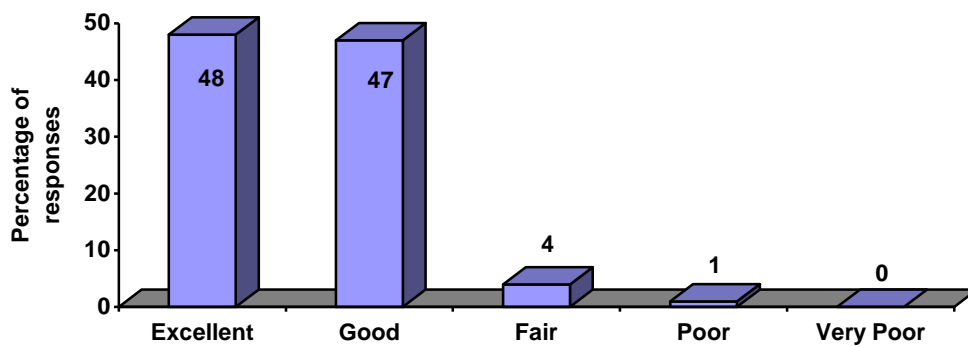
On Arrival

Were you made to feel welcome by the receptionist today?

- In all cases the respondents felt welcome.

Chart 5 Is the disabled access into and around the unit adequate?

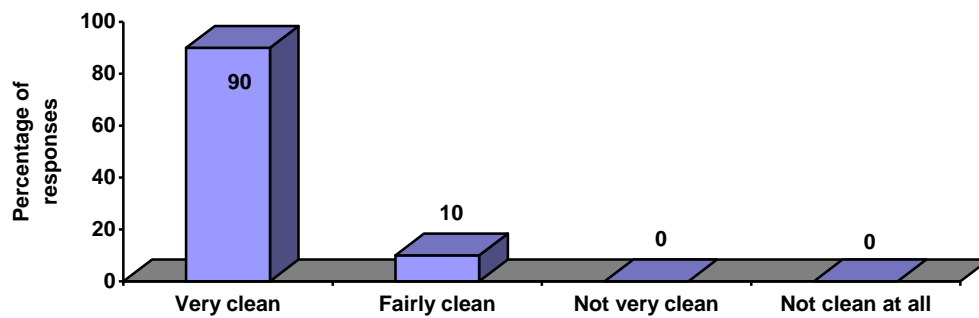
N = 73



3 blank responses

Chart 6 In your opinion was the unit clean today?

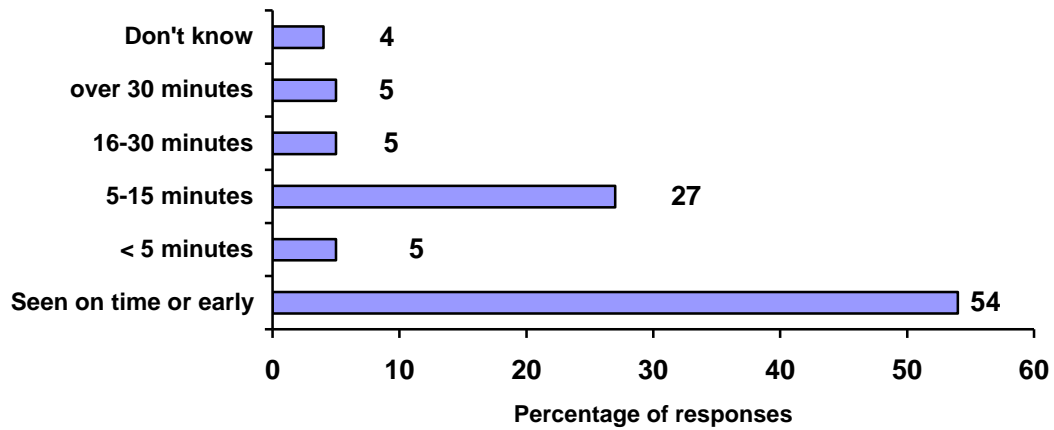
N = 72



4 blank responses

Chart 7 How long today after the stated appointment time did your appointment start?

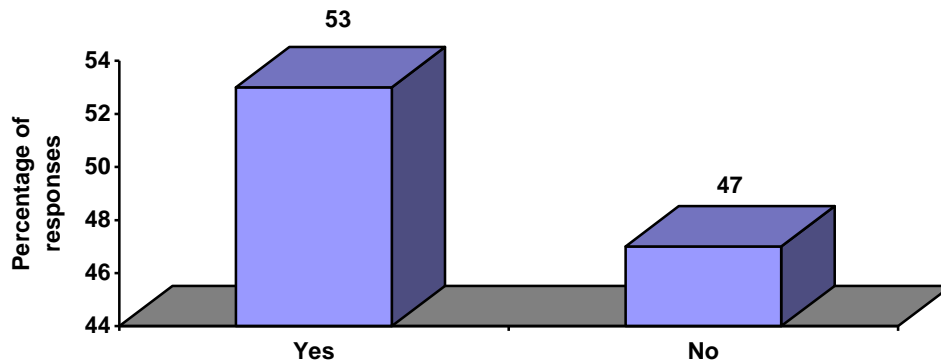
N = 74



2 blank responses

Chart 8 Were you informed of any delay?

N = 34



42 blank responses – in the majority of these cases patients were seen on time or waiting 5-15 minutes

In 16 cases (47%) it was stated that patients had not been kept informed. Table 1 below shows how long after the stated appointment time did your appointment start?

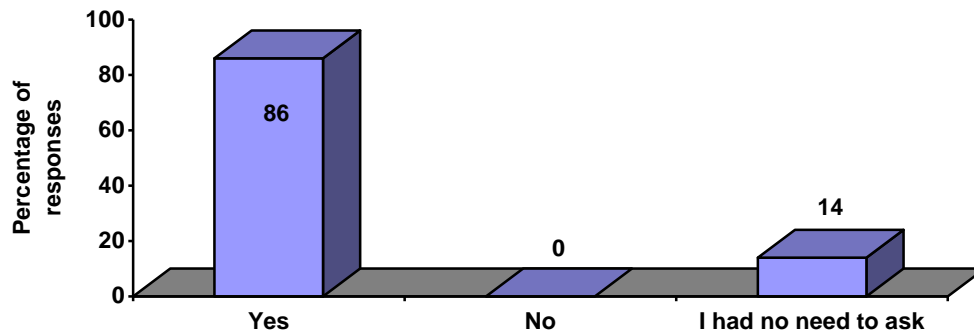
Table 1

Number of patients	Delay
Seen on time/early	1
<5 minutes	8
5-15 minutes	2
16-30 minutes	2
>30 minutes	2

Don't know	1
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Consultation/treatment/procedure

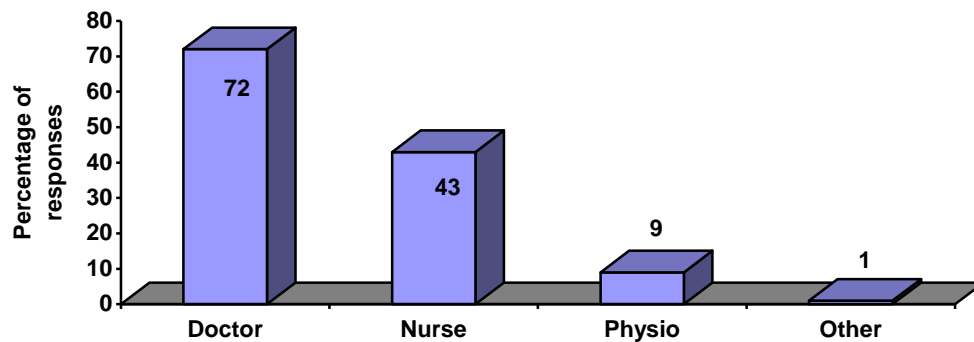
Chart 9 Did you have the opportunity today to ask questions about your care?
N = 70



6 blank responses

Chart 10 Which one of our members of staff did you consult with today?
(More than one response was given as respondents were asked to state all staff they saw)

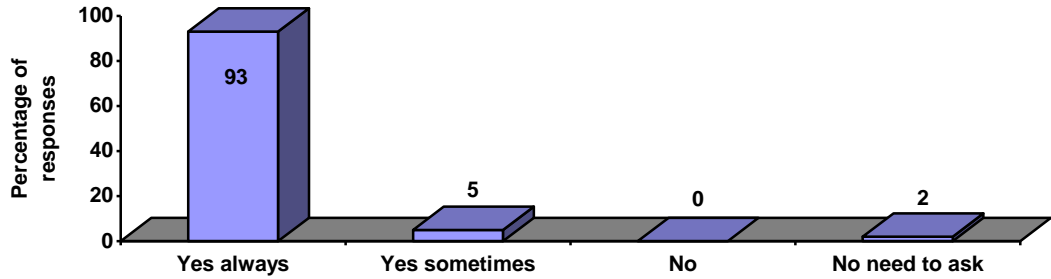
N = 76



Other = 1 - Professor

Chart 11 When you had important questions to ask the doctor today, did you get the answers you could understand? (n=55 (72% from graph 10))

N = 55



2 blank responses

If you saw a doctor today did you feel you were listened to?

- 52/55 replied 'yes' to this question. In the remaining 3 cases the form was blank.

If you saw a nurse today did you find the nurse helpful?

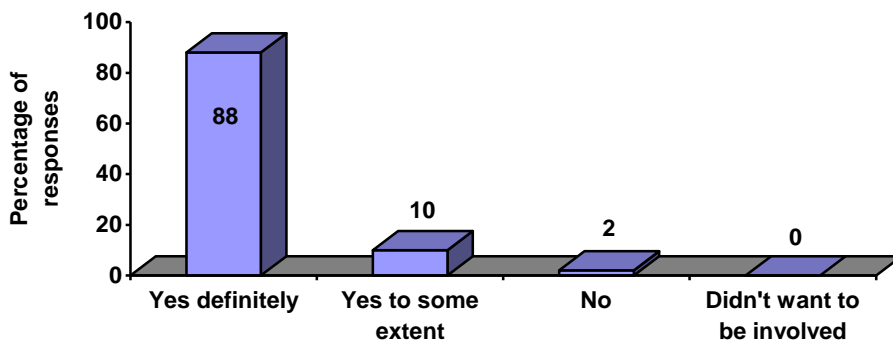
- 32/33 replied 'yes' to this question in the remaining case the form was blank.

If you saw a physiotherapist today did you have your questions answered in a way you could understand?

- 6/7 replied 'yes always' to this question and in the remaining case 'yes sometimes' was answered

Chart 12 Overall do you feel you have been involved in the decisions made about your treatment and care?

N = 61

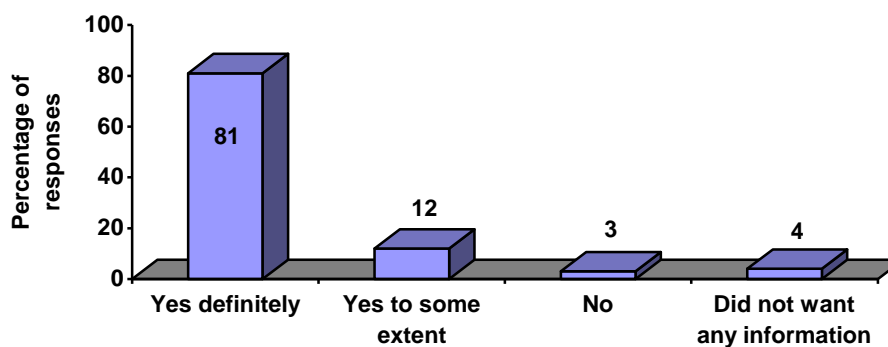


15 blank responses

The 2% of patients (1 patient) answering 'no' to the above question replied 'yes sometimes' to the question 'When you had important questions to ask the doctor today, did you get the answers you could understand?' (chart 11)

Chart 13 If you have received information have you been given information which describes/explains your condition in an appropriate way for you?

N = 67



9 blank responses

If no what information would you have liked

- ❖ Maybe to use the literature on MS available in foyer to further explain
- ❖ More to understand what was happening to me

Cross-referencing Graph 11,12, & 13

- Of the 8 patients (12%) in Graph 13 who felt that they had 'yes to some extent', been given information which describes/explains their condition to them in an appropriate way, when cross-referenced with Graph 11& 12 shows:

4 (50%) had felt they had 'yes definitely' been involved in the decisions made about their treatment & care.

4 (50%) had felt they had 'yes to some extent' been involved in the decisions made about their treatment & care. Only 2 of these patients had seen the doctor (today), but both replied 'yes always' to receiving answers they could understand to important questions asked.

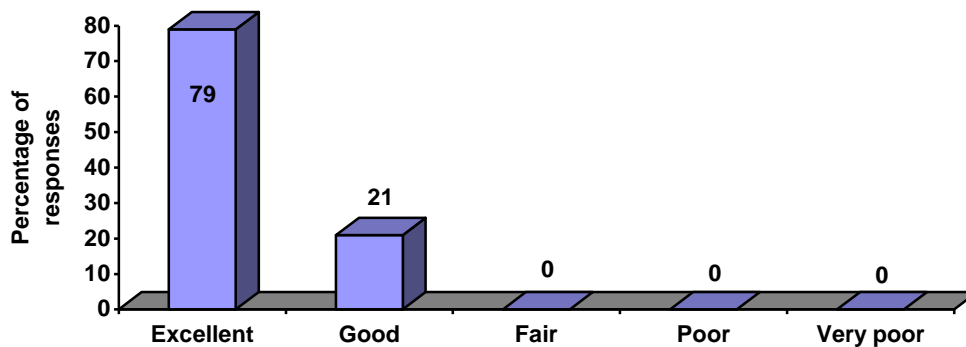
- Of the 2 patients (3%) in Graph 13 who felt that they had not been given information which describes/explains their condition to them in an appropriate way, when cross-referenced with Graph 11 & 12 shows:

1 (50%) had felt they had 'yes to some extent' been involved in the decisions made about their treatment & care (graph 12). This patient had seen the doctor (today), and answered 'yes always' (graph 11) to receiving answers they could understand to important questions asked.

1 (50%) had felt they had not been involved in the decisions made about their treatment & care (graph 12). This patient had seen the doctor (today), and answered 'yes sometimes' (graph 11) to receiving answers they could understand to important questions asked.

Chart 14 Please rate the overall communication you have received from the staff managing your condition

N = 75



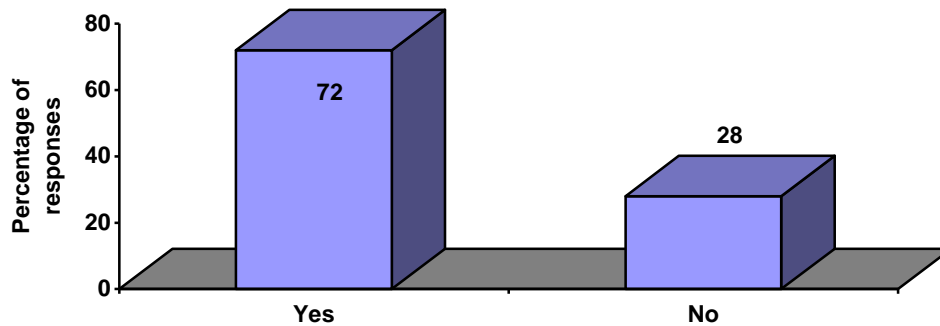
1 blank response

Comments

- ❖ Always friendly, clear, patient and helpful
- ❖ Dr explained clearly everything I asked. Response to telephone calls was slow
- ❖ Everyone I have seen has always been able to answer all my questions and been very helpful
- ❖ Good information on trial
- ❖ I feel all staff involved are doing a great job. Long may it continue.
- ❖ I have always been happy with communication at BRAMS; the unit is friendly and welcoming
- ❖ I was always aware you could see a nurse through a friend even though I had had MS for 12 years - no info through DR or neuro out patient given
- ❖ Listened and answered all my questions
- ❖ Nothing is ever too much trouble. I know I could speak to/see NV neuro or MS nurse whenever needed; everyone is incredibly friendly from receptionist to neuro
- ❖ Staff are always very kind & thoughtful
- ❖ Very prompt and informal and great care and advice

Chart 15 Did you have Multiple Sclerosis treated at Frenchay prior to the opening on the BRAMS unit in December 2008?

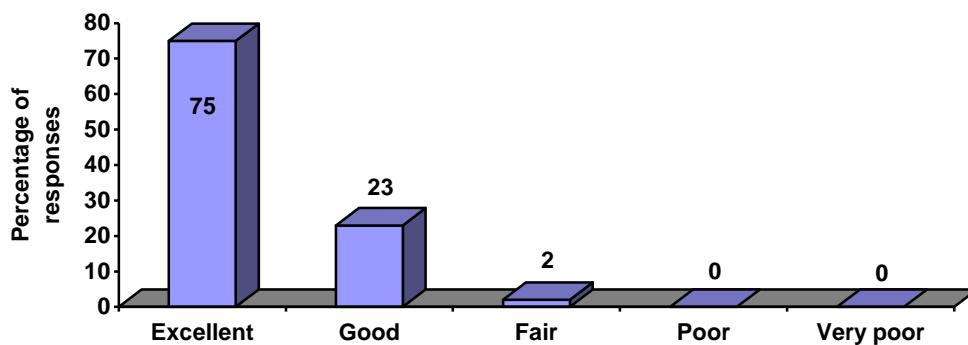
N = 74



2 blank responses

Chart 16 If yes how would you rate your experience since the opening of the BRAMS unit?

N = 52



1 blank response

In what ways, if any, do you feel the opening of the BRAMS unit and expansion of the MS team has been improved or worsened your care/experience when attending hospital?

- ❖ Improved x 2
- ❖ It's improved I get to see somebody who knows what there talking about and they are only a phone call away
- ❖ Because the unit just deals with MS everything is just in one place now which is much better
- ❖ It has improved care because unit is exclusively for people with MS as opposed to being in a unit for people with a variety of conditions

- ❖ Good to know that specialist care is available generally or as an emergency
- ❖ BRAMS unit is very accommodating for appointments if needed urgently & nurses are very prompt in returning calls
- ❖ Easier access, individual attention
- ❖ Better more targeted care, more appropriate and understanding care from all staff in unit
- ❖ Easier to get in contact
- ❖ Nicer place to visit, easier to get hold of staff on telephone
- ❖ The old treatment attached to the ward was quite depressing and the new building is a significant improvement
- ❖ More user friendly more family atmosphere, better disabled access + parking
- ❖ Information easier to access, visit more comfortable able to meet more people with MS. Friendlier atmosphere, more open
- ❖ Better understanding of the condition felt more supported & not isolated as before
- ❖ Everything is orientated to MS which is better than being a general neurology environment
- ❖ It is much easier to access I have built positive relationships with all
- ❖ Improved direct phone line
- ❖ Not sure since my contact with the unit is so intermittent, the staff clearly like the new building
- ❖ Better facilities more welcoming, and make you feel special. Easier to get to appointments and care when necessary
- ❖ The new unit is much better. Staff know your name when you arrive and vice versa. More of a friendly atmosphere. All the patients have the same health problem
- ❖ There is more information given + available & I feel it is one of the places that I can talk freely + in comfort
- ❖ I think waiting times seems less now that centre is devoted to MS. I prefer the office/building facility also more inviting less clinical
- ❖ Enables specialism in one place everything related to MS is in one place. Increased number of MS specialist nurses available, easier to contact people as necessary
- ❖ Good waiting area
- ❖ I now don't have to wait up to 3 hours to be seen
- ❖ Knowing it's here helps
- ❖ More organised and efficient
- ❖ The environment has improved markedly. I don't always see a consultant now, but I can appreciate some other cases need the experienced consultation/urgent relapse appointment
- ❖ Improved sense of a specialist rather than general team dedicated to MS. Sense of a team that are working both in clinical practice and research with good quality up to date evidence
- ❖ Improved care and more personal
- ❖ I like the specialist unit - just MS
- ❖ Closer to parking, medical staff friendlier, more thorough examination
- ❖ Specialist knowledge essential and good to know that there is a specialist team
- ❖ When attending neurology it dealt with many people with different conditions now it can concentrate on individuals with me
- ❖ BRAMS had already opened when I was diagnosed but I feel very lucky to have this unit so close, particularly after speaking to other MS sufferers who struggle to contact their MS nurse in other counties
- ❖ I am now able to see a MS specialist whereas before I saw a consultant neurologist. The experience feels more personal than it did in the neurology department

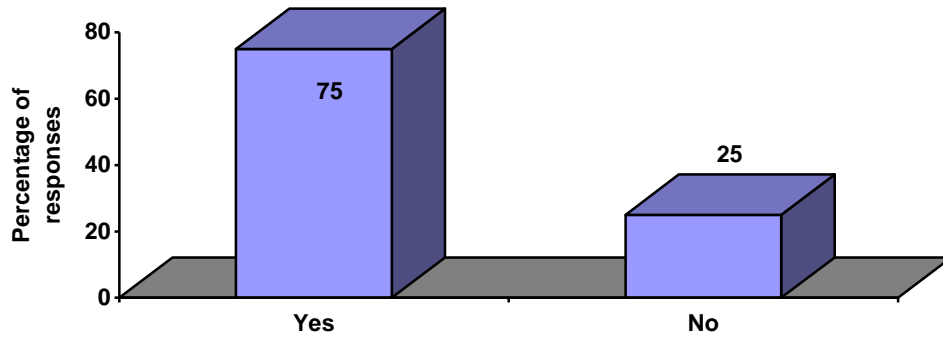
- ❖ Before coming to BRAMS I was at Bath, I can't praise the team at BRAMS enough. They are friendly, helpful knowledgeable, great at what they do
- ❖ It feels more personal
- ❖ Generally improved although we were unable to get a response from the unit during a crisis despite leaving answer phone messages & emails
- ❖ Parking not very good

In what ways do you feel, if any, the unit/services we provide could be improved?

- ❖ Nothing needs improving
- ❖ None I can think of
- ❖ I don't think it could be improved
- ❖ No services need to be improved on, just maintained
- ❖ The disabled parking needs more spaces because if you get there after 9am you'll be very lucky to get a space
- ❖ Better parking and close to the unit
- ❖ A few more disabled parking spaces outside the units would be nice
- ❖ More disabled car parking for clients
- ❖ More parking
- ❖ Exercise classes
- ❖ Better parking. Private place to undertake the walk till you drop test!
- ❖ Occasionally it seems difficult to have privacy if you do have a problem when coming in for Tysabri
- ❖ Phone lines often can't get any answer
- ❖ Time keeping (**waited over 30 minutes**)
- ❖ Response to messages. A drop in service
- ❖ Drinks facilities - coffee machine/water machine, larger reception area
- ❖ Perhaps BRAMS could possibly be re positioned, I think being so near accident unit can make access difficult
- ❖ I'm not sure it can - except more physio would be good **-(the patient did not see the physio today)**
- ❖ Allocated parking
- ❖ When using the patients toilet there was little space because of large bin beside it. Is there any possibility a Slimline bin could be positioned behind the door so room could be increased. It is difficult to give urine sample in this restricted space
- ❖ Telephone attendance reception frequently not manned. No reply after leaving message on relapse mobile phone. 36 hours from initial enquiry to contact with anyone. **(Although patient stated that overall communication was good – Chart 14).**

Chart 17 Are you aware of the role of the BRAMS charity in setting up and helping the unit and the services it provides?

N = 73



3 blank responses

Do you think it is appropriate for us to advertise the BRAMS charity in the reception area?

- In 72 cases respondents felt it was appropriate and in the remaining 4 cases there was no response

When NHS resources are limited, do you think it is appropriate for a charity to help fund this sort of project?

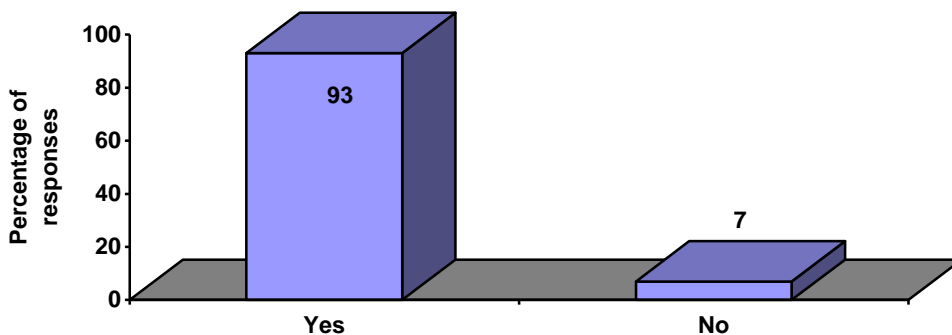
- 68/76 answered 'yes' 3/76 replied 'no' and in the remaining 5 cases the form was left blank

Would you recommend the unit to other patients?

- 70/76 answered 'yes' 2/76 replied 'no' and in the remaining 4 cases the form was left blank

Chart 18 Have you been given direct access telephone numbers to MS nursing staff and advice on how and when to contact if you need to.

N = 71

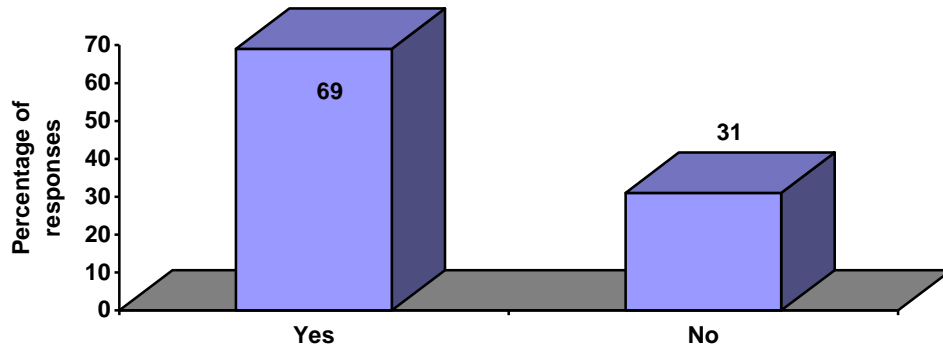


5 blank responses

Of the 5 patients (7%) answering no to the above questions, 3 stated that overall communication (graph 14) was 'excellent' and 2 stated 'good'.

Chart 18 Are you aware that since 2008 and the opening of the BRAMS unit that urgent relapse appointments have become available?

N = 71

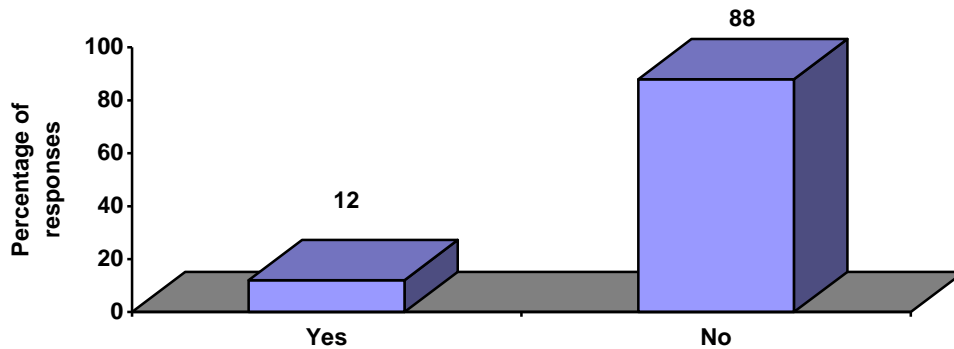


5 blank responses

All 22 (31%) of patients answering 'no' to the above questions, rated overall communication as 'excellent' or 'good'.

Chart 19 Have you attended an urgent relapse appointment today?

N = 74



2 blank responses

Chart 20 If yes how long did you wait for your appointment with the Doctor?

N = 9

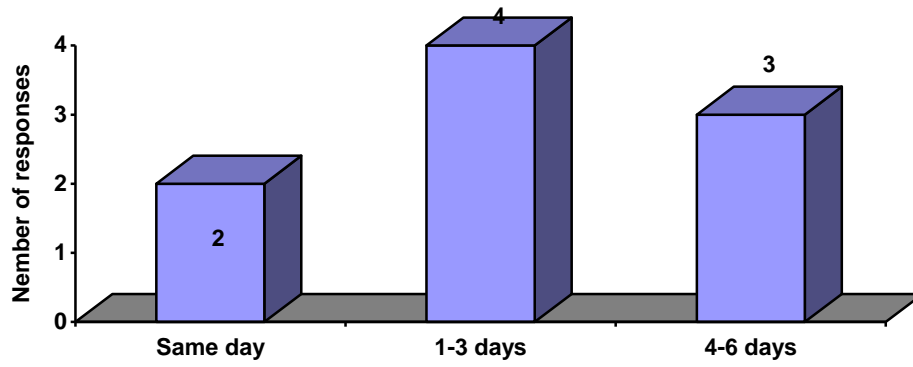


Chart 21 How useful did you find this urgent service?

N = 9

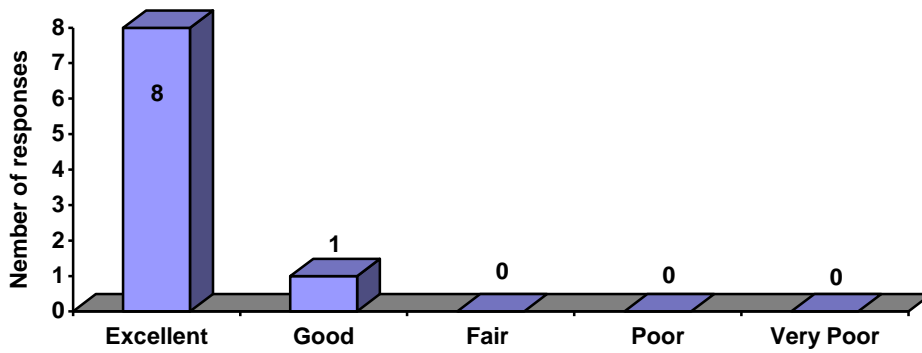
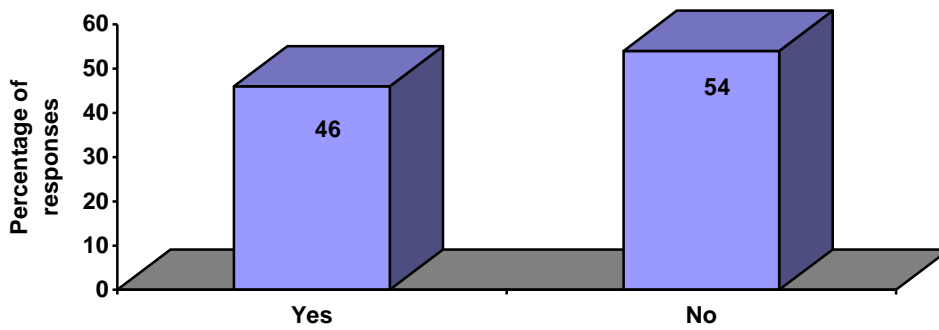


Chart 22 Have you been involved in any of our MS clinical trials?

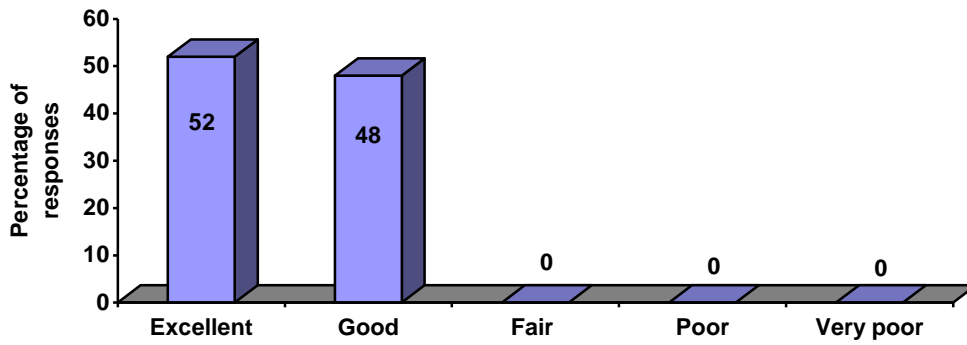
N = 69



7 blank responses

Chart 23 If yes how would you rate your experience?

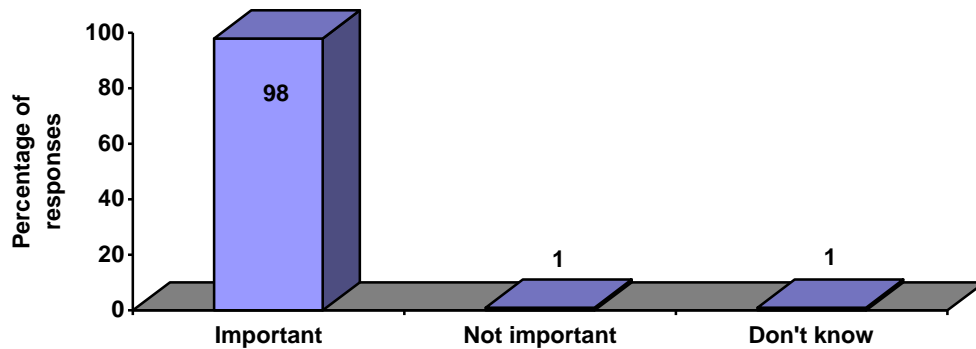
N = 31



1 blank response

Chart 24 How important do you think clinical trials and research are in Multiple Sclerosis?

N = 73

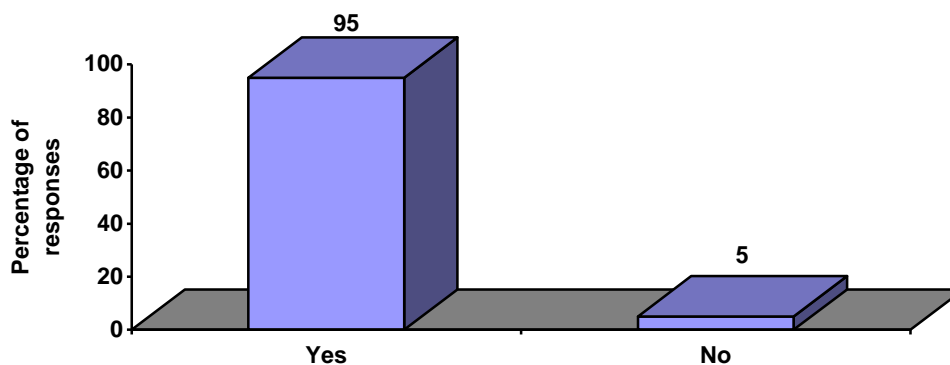


3 blank responses

The patients above answering 'not important' or 'don't know' had not been involved in any clinical trial.

Chart 25 If we had a suitable clinical trial for you, would you be interested in participating?

N = 62



14 blank responses

General comments received

- ❖ I always look forward to attending the BRAMS unit because it is always friendly and useful with the information books available to take home
- ❖ Been attending neurology O/P 2 months
- ❖ You do a wonderful job and are a credit to Frenchay hospital and the NHS. Thank you so much
- ❖ Wonderful team always friendly always helpful + supportive, very efficient. You make the whole experience a lot easier to handle
- ❖ Keep up the good work!
- ❖ The BRAMS centre is so much better than previously to its creation. The staff are so friendly and professional & always give you their time to make you feel that you are cared for and best practice is given at all times
- ❖ Very good unit, with lots of specialist MS care and information. I feel fortunate to be able to come to BRAMS and have my MS treated. I feel fortunate to be on a clinician's trial for an oral medication. BRAMS is a very valuable resource. BRAMS has almost outgrown this space now, and should be looking for larger accommodation.
- ❖ Perhaps to have a social event i.e. at carers centre in Gill Ave Fishponds where there are more parking places
- ❖ BRAMS team have become a necessity for various MS patients from counselling & treatment stages. Long may it continue to evolve the research side the staff are doing a great job in trying & different times
- ❖ I am happy with my experience here since my diagnosis and have felt a nice relationship develop with X + Y in particular as they are the nurses I have seen most frequently, they have always offered their direct phone line if I needed help with anything. In the early days of diagnosis and when I was not feeling well they were attentive
- ❖ I am willing to try any new drugs for MS. Thank you
- ❖ This service is excellent
- ❖ Think everyone here is really helpful
- ❖ Very happy with service received
- ❖ I think you have a great team and they make my treatment as pleasurable as it can be, more physio would good and hints and tips on things I can do at home would be good. Also any information on complimentary treatments (e.g. fish oil B12 injections)

- ❖ Thank you for your sensitive and informative care, it is rare to find such good interpersonal skills combined with excellent clinical expertise and everyone that I have met in this team seems to have both in abundance
- ❖ It gives me a positive feeling. I leave feeling better!
- ❖ The MRI unit appointments as part of the trial can be running late

- ❖ I understand that MS has no cure, and relapse events cannot be prevented, and for this reason advice is not always available. However sometimes some advice or treatment can alleviate particular symptoms or features of a particular relapse, however I sometimes sense an unwillingness to consider this apart from the medical staff from the patient point of view anything that helps control or mobility will help the patient with the event/relapse
- ❖ Car parking near BRAMS would be useful because walking is difficult
- ❖ Names/photos of all members of the team which helps clients put names to faces. Maybe satellite clinics
- ❖ Direct physiotherapy clinics on site with regular appointments (if not already provided)
- ❖ Generally good & supportive service not easy to get in touch when we needed more urgent help. A drop in would be useful.

Conclusions

76% patients asked to fill in our out-patient satisfaction survey responded.
 100% patients attending were made to feel welcome.
 95% patients thought our disabled access was either excellent or good.
 91% patients were seen within 30min and 86% patients were seen within 15 min. Our data shows we could do better at informing patients of delays.
 100% patients responded that overall communication from all staff was either excellent or good with 79% responding that communication was excellent.
 72% patients had had their MS treated at Frenchay prior to the opening of the BRAMS unit in December 2008.
 98% of these respondents said that their experience since the opening of the unit was either excellent or good with 75% patients responding that their experience was excellent.
 When asked in what ways the opening of the BRAMS unit and expansion of the team has improved or worsened your care there were a multitude of positive responses citing the fact that patients liked the specialist unit

dedicated only to MS, better access to appointments quickly, nicer place to visit, friendlier staff an chance to build relationships with the staff, better facilities, friendlier environment. Overall there were 38 positive responses commenting in different ways on how the unit has improved.
 21 patients commented on how the unit/service could be improved 7 respondents wanted better parking facilities and 3 patients wanted an improvement in the time taken to reply to telephone messages other suggestions included improved privacy when wanting to discuss an issue when attending the IV suite (this will be looked at more closely in the Day-case Patient Satisfaction Survey to see if it is a theme there), less clutter in the disabled toilet, more on-site physiotherapy as well as availability of drinks machines and a larger waiting room.

95% patients felt it was appropriate to advertise the BRAMS charity in reception.
89% patients felt it was appropriate for a charity to help fund this sort of project when NHS resources were limited.
92% patients would recommend the unit to friend.
93% patients knew how to contact the MS nurses.
Of the patients who attended an urgent relapse appointment 100% patients had been seen within 6 days 66% had been seen within 3 days and 33% within 4-6 days.

100% patients said that this service was either excellent or good with 88% saying that it was excellent.
46% respondents were involved in clinical trials and 100% said that their experience was either excellent or good with 58% saying that it had been excellent.
98% respondents thought that clinical trials in MS were important and 95% said that if there was an appropriate clinical trial for them that they would be interested in being involved.

Overall comments were fantastic and again there were a multitude of them. There were again some comments about parking, direct physiotherapy on-site, time taken to reply to telephone messages and a suggestion about providing a display in the unit with photographs to identify all of the members of staff.

We have had a fantastic response to this survey it has identified a few issues which will be addressed as follows.

We plan to audit the time taken for the MS nurses to answer telephone calls and messages and this will be carried forward by MS nurse Kate Golding.

We will endeavour to inform patients of delays in their appointment times.

We will contact the chief executive of NBT Ruth Brunt to relay patients comments about parking facilities.

We will compare the outcomes of the survey to other NBT Out- Patient Surveys.

We will publicise the results of the survey on the BRAMS website. A copy of the completed survey will be available within the reception area of the BRAMS unit. We will contact the PR department of the hospital to make the results of the survey widely available to the trust e.g. message of the day, Trust magazine "Insite"

The results of the survey will be presented at either or both of the following local neurology meetings South West Neurology Association and the weekly Frenchay Neurology Departmental meetings.

This audit will be repeated in 2-3 years time.

Action plan (to be completed when report finalised)

Recommendations	Actioned by	Target Date
Audit of time taken to reply to telephone messages from time patient left message to return call	Nurse Kate Golding	September 2011
To write a letter to Ruth Brunt (Chief Executive NBT) to relay patient comments re parking	Dr Kirsty Inglis	September 2011
To compare outcomes of survey with other NBT Trust Out Patient Satisfaction Surveys	Dr Kirsty Inglis	September 2011
To publicise the results of the survey on the BRAMS website.	Shaun McCarthy and website coordinator	September 2011
Copy of the completed survey to be placed in reception.	Dr Kirsty Inglis	September 2011
To contact NBT PR department and further advertise through this route.	Dr Kirsty Inglis	September 2011
To present the audit results to the South West Neurology Meeting	Dr David Cottrell	September 2011
To put up a display of BRAMS staff, their names and photos in the waiting area	BRAMS team	September 2011