Buckinghamshire Neurology Rehabilitation Services

Patient feedback from neurology clinics

June 2023

What we did

Working with Buckinghamshire Healthcare Trust, we engaged with patients at neurology clinics to gather feedback on:

- Communication between staff and patients
- Service delivery and information sharing
- Making informed choices about treatment and care
- Patient-centred support

Healthwatch Bucks spoke to 62 patients in total. We attended neurology clinics at Amersham Hospital, High Wycombe Hospital and Rayner's Hedge Rehabilitation Unit. We completed eight on-site visits during May and June 2023.

Key findings

+ There were no significant differences in user experience between patients with different neurological conditions

+ We received more positive responses to questions from patients at the neurology clinic in Rayner's Hedge than Amersham and Wycombe Hospitals

+ Most people said that GP referrals to neurology services should be faster

+ Some patients at clinics in Amersham and Wycombe Hospitals were frustrated that their MRI test results were not available to discuss with the neurology specialist during their appointments

+ Poor communication between healthcare providers was highlighted as a problem by a few patients, one suggested that the hospitals should 'talk to each other'

+ 52% of patients told us that they were given helpful information about their condition. However, some people told us that there is a lack of specialist knowledge about neurological conditions, in particular Multiple Sclerosis

+ While most patients felt that they were involved in making choices about their treatment and care, some felt that the choice was out of their hands

+ Overall patients told us that they got the help and support that mattered to them but a significant proportion of responses were 'neutral' where the patient felt that had no choice but to follow medical opinion

Our recommendations

Based on what we heard from patients at neurology clinics, we recommend that the following improvements are taken into consideration by neurological services in Buckinghamshire.

Referrals:

☑ Recommendation to improve primary care aspect of pathway - speed up GP referral pathways by ensuring that all Buckinghamshire medical practices are fully informed about *NHS England Guidelines Offering Advice & Guidance: Supplementary Guidance for CQUIN (2017)*. Such guidelines include information about; Appropriate Referral, Inappropriate Referral, Referral Details and Additional Information.

Appointments:

☑ Schedule appointments around test results

☑ Quick rescheduling of postponed appointments to improve patient satisfaction

Joined-up working:

☑ Joined up rehabilitation services with a shared database of patient records for direct patient care and best practice to be fed through the Neurology Transformation Group to ensure single point of access

Support:

☑ More support and advice for carers looking after an adult with a long-term neurological condition

Information Sharing:

☑ Keep patients updated individually about new developments and treatments for neurological conditions. Better links with the research team will help to identify any new studies for entry into the services

Personalised care package:

☑ Integrated care plans for physical and mental health needs – communication between different services i.e. social prescribers

What was the project about?

A neurological condition is any condition that affects the brain, spinal cord, or nervous system. Some neurological conditions can begin suddenly, such as brain injury. Some you are born with, such as epilepsy. Others, like multiple sclerosis, can develop over time.

Buckinghamshire Healthcare NHS Trust neurology services sit across multiple divisions with the Specialist Neuro Nurses sitting within Integrated Medicine division. Neurology consists of several services, with specialist nurses supporting only some of these. Services currently with specialist nurse support include multiple sclerosis (MS), motor neurone disease (MND), clinically isolated syndrome (CIS), Parkinson's disease (PD) and epilepsy.

The aim of this project is to collect patient feedback about their experiences to inform a redesign of neurological services.

Who completed our survey

We collected **29** responses from the neurology clinic at Amersham Hospital, **28** from High Wycombe Hospital and **five** at Rayner's Hedge Rehabilitation Unit. Eight out of 62 people from a small snapshot research sample that we spoke to were attending the neurology clinic for their first time. These clinics covered a variety of general neurological conditions.

Just over half of the people that we spoke to (34/62) told us they have a disability.

Definition of disability under the Equality Act 2010

You're disabled under the Equality Act 2010 if you have a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities.

We spoke to people with a variety of neurological and other long-term conditions. We asked if people experience a range of conditions. Not all conditions are related to their attendance at the clinic.

Table 1 - Which of the following long-term conditions do you live with?

Response	Count
Multiple Sclerosis	37
Cardiovascular condition (including stroke)	7
Diabetes	6
Asthma, COPD or respiratory condition	5
Epilepsy	5
Hypertension (high blood pressure)	3
Blindness or severe visual impairment	2
Cancer	1
Mental health condition	1

Amongst those who said they had a MSK condition, 24 said they had Multiple Sclerosis (MS) and eight said they had Parkinson's disease.

More information about who we spoke to can be found in **Appendix 2**.

Several others reported unlisted conditions including:

Table 2 - Other long-term conditions

Response	Count
Head Injury	4
Spinal Injury	2
Cerebral palsy	1

What we heard

Buckinghamshire Healthcare NHS Trust, together with neurology service users, designed the questionnaire. It consisted of four open-ended questions.

We reviewed the responses to these questions and identified key themes. We used the themes from Healthwatch England's taxonomy as a guideline. We also identified a sentiment for each theme: positive, negative or neutral.

1. Did staff listen to you and treat any questions or concerns seriously?

As shown in the table below, the most common theme in response to this question across all clinics was *Communication between staff and patients*. This

includes ongoing patient support when questions or concerns have been raised.
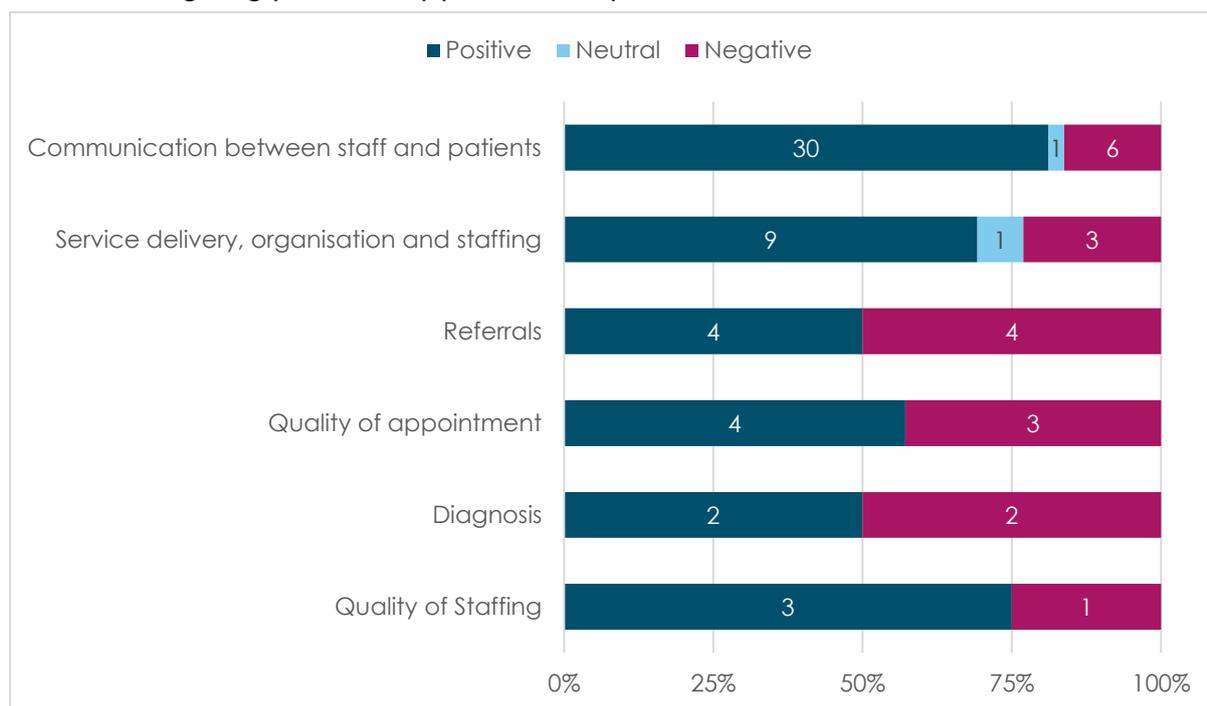
Figure 1 – Top themes and sentiments from Question 1

Overall patients believed that their questions were taken seriously. They spoke positively about neurology consultants and specialist nurses across all three clinics. They said:

> I'm given all the information needed. Not made to feel stupid when I've got stupid questions.

> What I was hoping to get actioned did today. MS nurse is brilliant, I feel like we got somewhere today.

> I brought a list of questions which they answered, didn't feel rushed.

> The MRI scan only tells so much. Dr X answered my questions.

> I had a list of questions about my Parkinson's. I think they were addressed OK.

On the other hand, some patients were not happy with the quality of appointments and thought that their visit to the neurology clinic was a waste of time.

> Initial support staff are very nice and personable. The consultant didn't listen. Regimented. Wasn't receptive to feedback. Felt like a wasted trip.

> I'm not very ill so they're not very interested. They could talk about new treatments, but they don't bother. I feel like it's sometimes a waste of time coming here.

> Not sure, asking all the questions. There are less options. Was meant to have an MRI scan before this appointment so not sure what they can tell me. Seems like a waste of time really.

Whilst others told us that their questions were not addressed.

> Questions asked but not answered all of the time, then there's different doctors which mixes things up.

> Questionable. They could be more forthcoming with information. Not a lot is known about MS.

> Felt very alone [when first diagnosed], no support. The consultant said you've got Parkinson's and that's it.

Four patients told us that they paid for private healthcare to get a referral to neurology services. Another person said that they were 'thinking about going private' due to the stress of being treated with the wrong medicine.

Key summary: Question 1

While most people were happy that their questions and concerns were taken seriously, we heard that:

- Treatments for less serious conditions were not given enough consideration

- There is not enough information about treatment for certain conditions i.e. MS

- Appointments did not coincide with the timing test results including MRI scans and blood tests

- The GP referral process is drawn-out with some people resorting to private healthcare

2. Do you feel that the service has helped you to better understand and address your difficulties?

The most common theme to this question was *Information providing.* Over half of the responses (38/62) slotted into this theme.
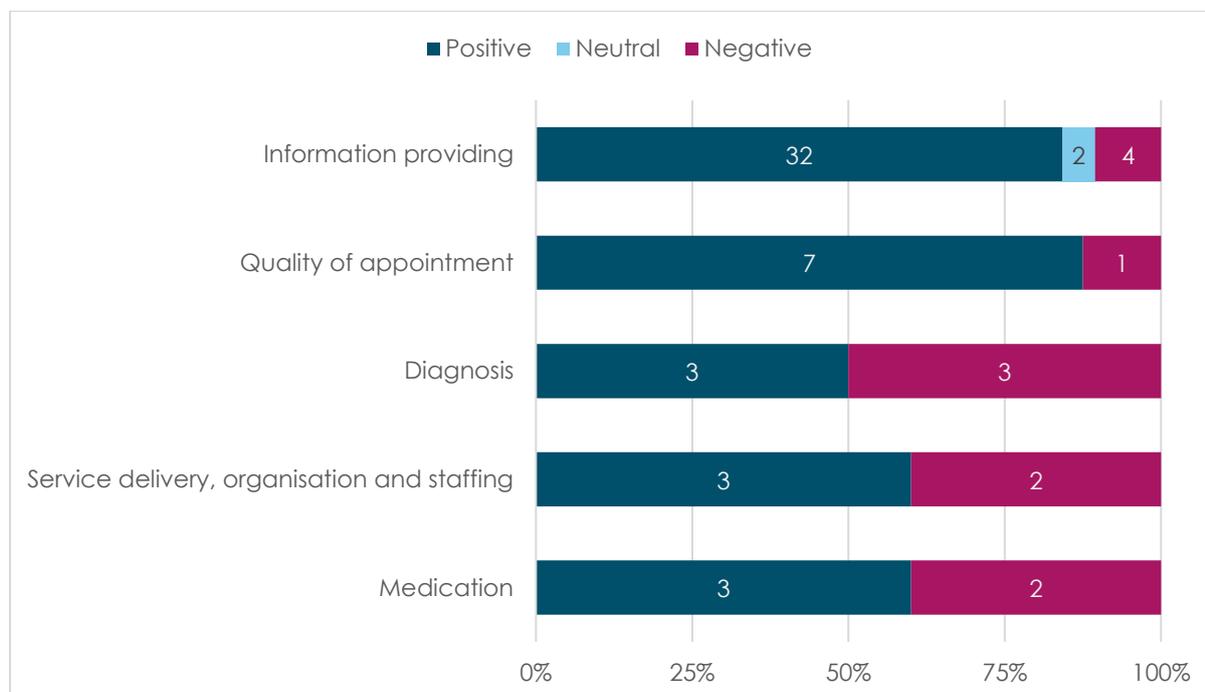

Figure 2 - Top themes and sentiments from Question 2

While most patients said that they were given information to help them to understand their conditions, they also did their own research for further knowledge. They told us:

> I had to ask lots of questions after lots of research. Other people might not be able to do that.

> Doctors themselves are trying to understand Parkinson's. Thank God for the internet.

However, there were mixed opinions in relation to medical support, diagnosis, and treatment.

> Actual treatment is good. It doesn't help waiting for medication.

> Nurse X is at the end of the phone. I had an issue with medication and changed it after talking about it. They've [staff] been good.

> I've been given loads of different exercise [to do]. Helped in some ways but still don't know what's wrong.

> Still don't know what the issue is after having ongoing tests for 5 years.

Key summary: Question 2

Patients were happy with the information that they are given to help them to understand their conditions. The main concerns raised were:

- Not getting a diagnosis

- Waiting for medication

- Appointments getting postponed

- Lack of specialist knowledge to understand certain neurological conditions

3. Did you feel involved in making choices about your treatment and care?

The theme *consent to care and treatment* in the following table refers to patients making informed choices about their personal treatment and care. Most of the responses to this question (49/62) came under this theme. There were 10 neutral responses. This is when people have told us that they are not given many choices due to the nature of their condition. Their involvement in making choices about their treatment and care was neither positive nor negative.
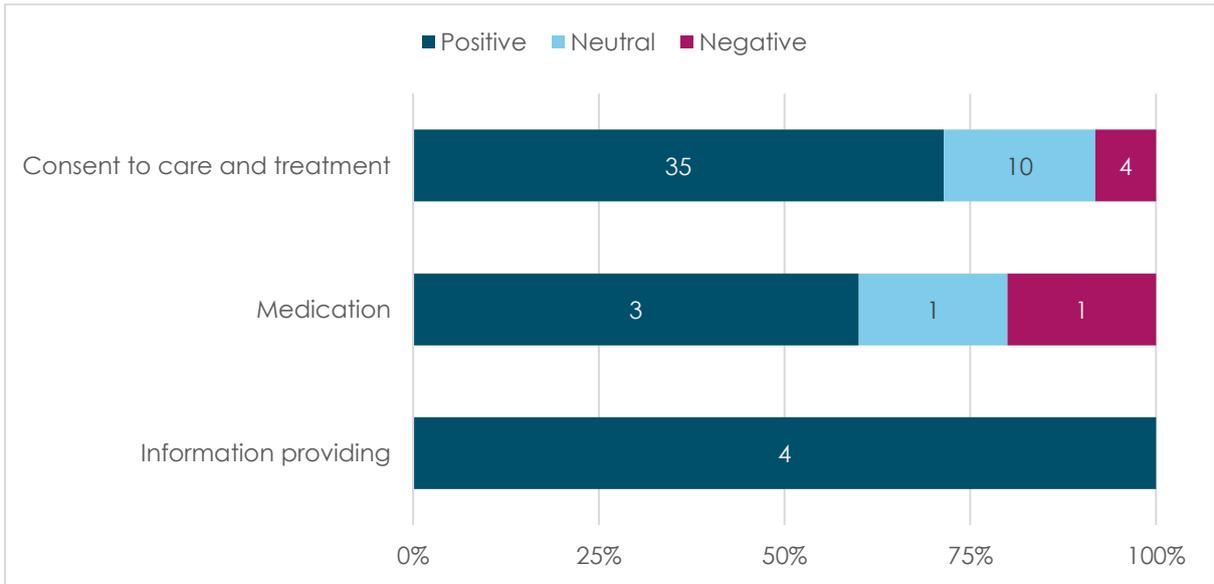
**Figure 3 – Top themes and sentiments from Question 3**

Most people (35/49) felt involved in making informed decisions.

> They ask you what your goals are and how you can achieve them. It's very reassuring.

Informed decisions were discussed around medication and treatments. Most responses were positive. This included options for choosing different medications and changing medications that were not effective.

> Always involved in making the final decision. There were risks involved in one medication, so I came off it.

For others, their involvement in decision making has only been effective in recent years.

> Not 100% supported to start with but then it got better. I raised concerns with Nurse X, it's been good for the last three/four years.

There was a high number of neutral responses to this question. Patients felt comfortable with decisions made by their neurology specialist. They were happy to accept whatever treatments were recommended at the clinic.

> I'm quite happy for a specialist to know the best course of action.

> Whatever treatment is offered will be accepted.

Key summary: Question 3

Many people that we spoke to across all three neurology clinics felt that they were involved in making informed decisions about their care and treatment. It should be noted that:

- 11 people were on the fence when making decisions about their care, treatment and medication

- Four out of 49 people had negative responses to making informed decisions

- In some cases, involvement in decision making did not happen straight away

4. On reflection, did you get the help that mattered to you?
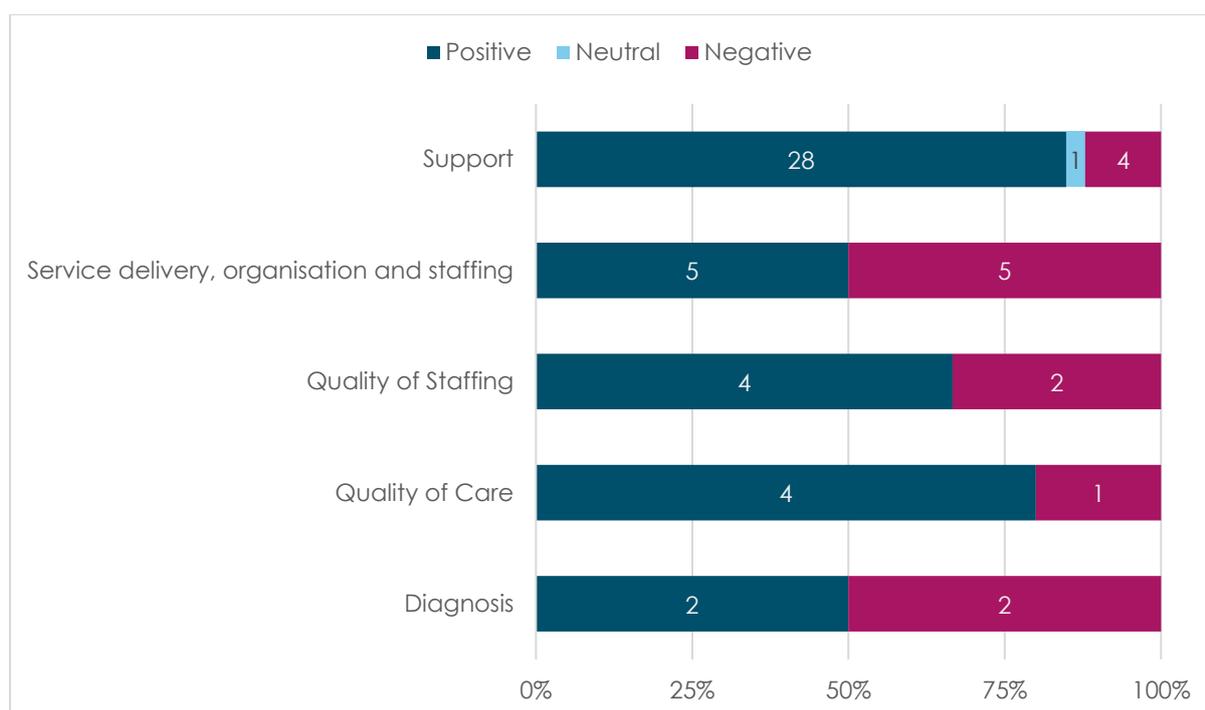
Figure 4 - Top themes and sentiments from Question 4

This final open-ended question related to patient-centre support. Overall patients felt well supported and got the help that mattered to them. However, two patients only felt supported after requesting to see a different neurologist. One told us:

> The original [neurology] consultant was a joker. I saw them once and refused to see them again. The new consultant sat down and explained everything.

Other themes were more divided. Service delivery, organisation and staffing was an equally divided theme (5 positive/5 negative). One patient spoke to us about their frustration with communication between hospitals:

> It [information] should go on one database so everyone can see it. I had MS blood tests in two different hospitals. It's frustrating doing the same things twice. The hospitals should talk to each other.

Whilst another patient felt supported, it was a long journey through the referral pathway.

> It took nearly a year to get an appointment. GP was a poor referral. I went through charities to get help. I got more help from the chemist than the doctor. My GP was not interested.

One patient pointed out that a long referral means a delayed diagnosis.

> Shame it took so long. Realistically you want to be seen [straight away]. It took so long for a diagnosis.

Once referred to neurology services, most patients responded positively to two themes: quality of staffing and quality of care.

Key summary: Question 4

Most people told us that they got the help and support that mattered to them.

We also heard that:

- Patient information including test results should be stored on a central database to avoid repeated tests for the same outcome
- GP referrals should be faster for a prompt diagnosis

Conclusion

We did not find significant statistical differences in responses to our questions by neurological condition and demographic factors. However, we found variations in positive/negative responses by neurological clinic. The following graphs show sentiments to the four research questions by clinics held at – Amersham Hospital (AH), Rayner's Hedge rehabilitation unit (RH) and Wycombe Hospital (WH).
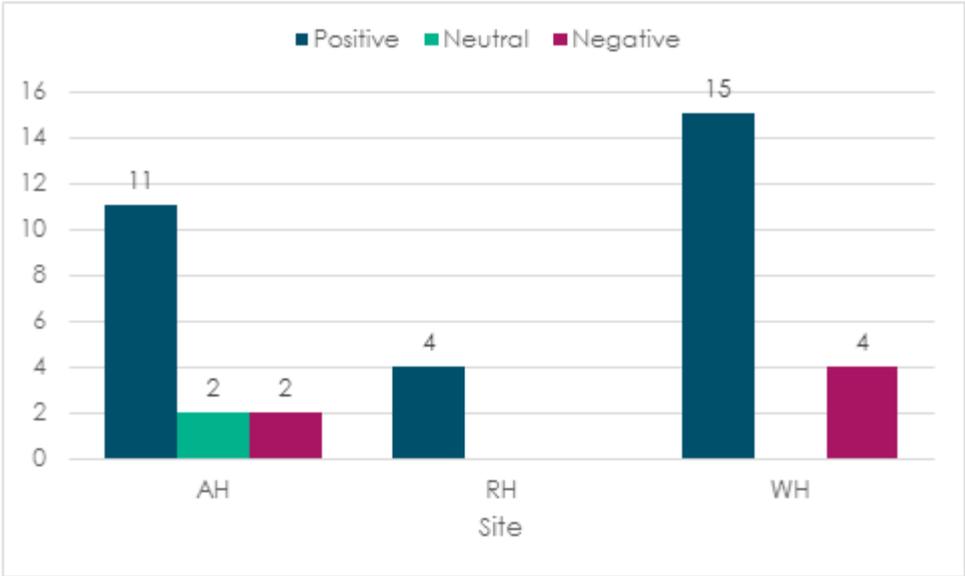
Figure 5 – Sentiments from Question 1
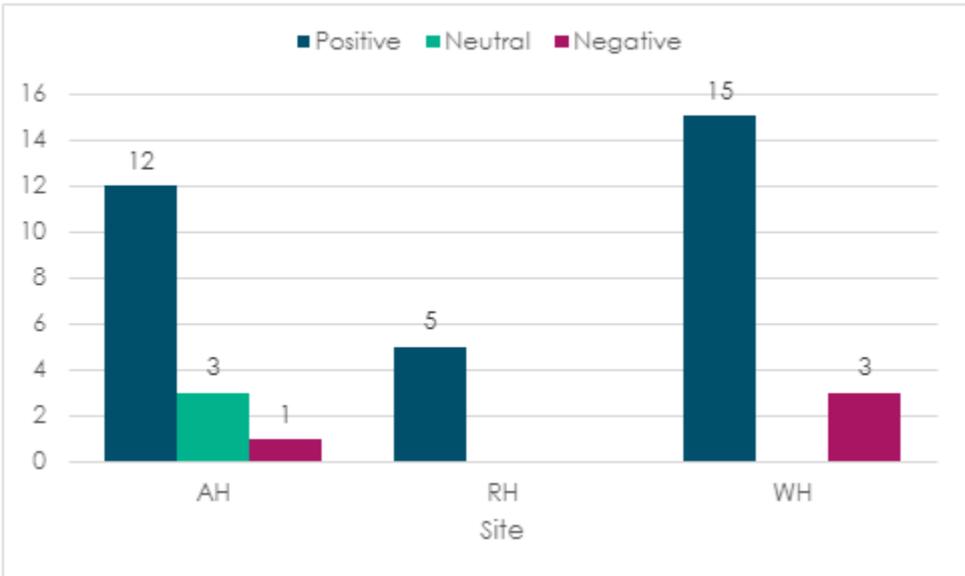
Figure 6 – Sentiments from Question 2
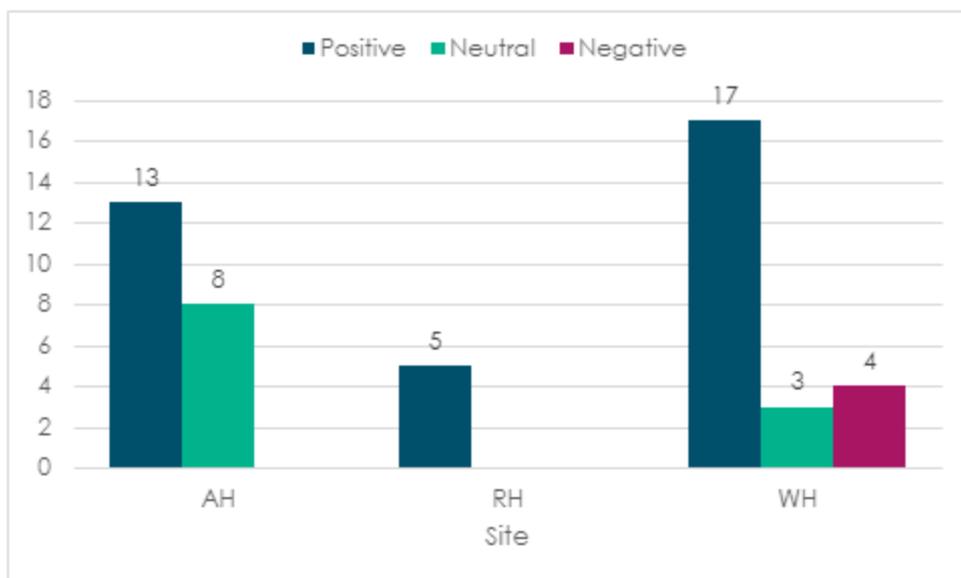
Figure 7 - Sentiments from Question 3
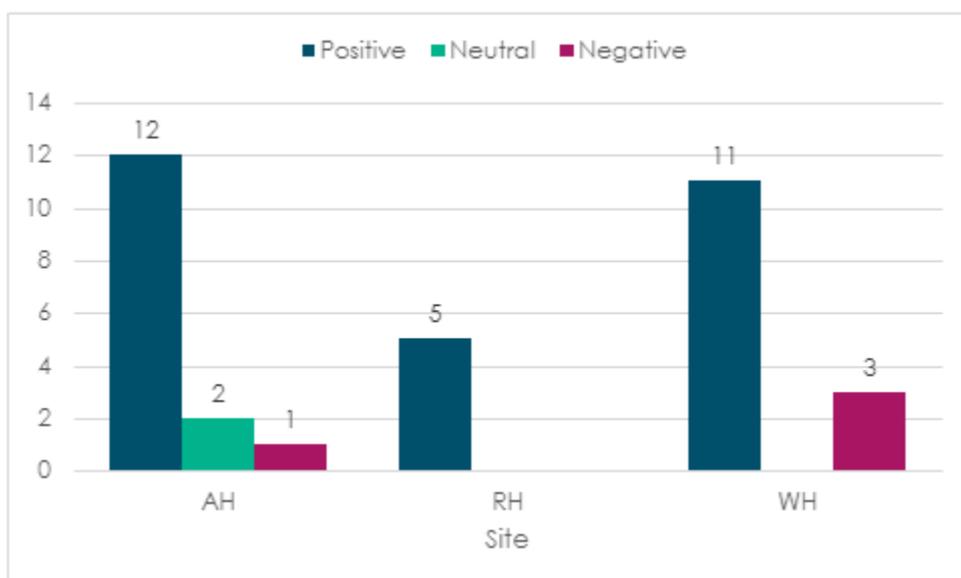
Figure 8 - Sentiments from Question 4

Everyone at Rayners Hedge Rehabilitation Unit responded positively to our questions. However, it must be noted that this site only represents a small cohort of respondents (5/62).

Although most patients in neurology clinics at Amersham Hospital and Wycombe Hospital responded positively to all questions, it should be noted that patients at Amersham Hospital were more likely to sit on the fence and give neutral answers.

Acknowledgements

We are grateful to all the patients that spoke to us before/after their neurological appointments. We would also like to thank staff at Wycombe Hospital, Amersham Hospital and Rayner's Hedge for providing information about clinic days and times. Finally, thank you to our volunteers who helped us to gather responses from patients at neurology clinics.

Disclaimer

Please note this report summarises responses to our in-person questionnaire. It does not necessarily reflect the experiences of all patients using neurology rehabilitation services.

Appendix 1

More about our approach

Who we included

We included views from people across three neurological outpatient sites: Amersham Hospital, High Wycombe Hospital and Rayner's Hedge Rehabilitation Unit.

Entry to these sites for data collection was arranged by Buckinghamshire Healthcare Trust. They provided us with a named contact at each site so that we could attend clinics on scheduled days.

Full details about who completed our survey can be found in Appendix 2.

Who we will share our findings with

We will share our findings with Buckinghamshire Healthcare Trust. This report will also be shared with the Care Quality Commission (CQC) and Healthwatch England, the independent national champion for people who use health and social care services.

Qualitative analysis

We have summarised the comments and feedback according to the taxonomy (themes) used across the Healthwatch network. This ensures we can share our findings with Healthwatch England and the network.

We also decided whether the comment/feedback was positive, negative or neutral.

Some people commented on more than one service or gave feedback on more than one aspect of a service so the number of comments is greater than the number of people who made comments.

Appendix 2

Who did we hear from?

Two persons did not answer any of the demographic questions.

Age group

Responses	Count
18 to 25 years	2
26 to 35 years	6
36 to 45 years	10
46 to 55 years	9
56 to 65 years	14
66 to 75 years	14
76 to 85 years	1
86 and over	3
(blank)	3
Grand Total	62

Gender

Responses	Count
A man	21
A woman	38
(blank)	3
Grand Total	62

Ethnicity

Responses	Count
Asian / Asian British: Indian	1
Asian / Asian British: Pakistani	2

Black / Black British: African	1
Black / Black British: Caribbean	1
Mixed / Multiple ethnic groups: Any other Mixed / Multiple ethnic groups background (please tell us below)	3
Mixed / Multiple ethnic groups: Asian and White	2
White: Any other White background (please tell us below)	3
White: British / English / Northern Irish / Scottish / Welsh	47
(blank)	2
Grand Total	**62**

Sexuality

Responses	Count
Asexual	2
Bisexual	2
Heterosexual / Straight	52
Lesbian / Gay woman	2
Prefer not to say	1
(blank)	3
Grand Total	**62**

Religion/belief

Responses	Count
Christian	37
Muslim	2
No religion	18
Prefer not to say	2
(blank)	3
Grand Total	**62**

Disability

Responses	Count
No	22
Prefer not to say	4
Yes	34
(blank)	2
Grand Total	**62**

Disabilities

Which of the following disabilities apply to you?	Count
Physical or mobility impairment	22
Long term condition	16
Sensory impairment	4
Neurodevelopmental condition (ADHD, ASD, learning disability or difficulties)	1
Mental health condition	1
Prefer not to say	1

LTC

Responses	Count
No	6
Prefer not to say	7
Yes	47
(blank)	2
Grand Total	**62**

Long-term conditions

Which of the following long-term conditions?	Count
Musculoskeletal condition	37

Cardiovascular condition (including stroke)	7
Diabetes	6
Asthma, COPD or respiratory condition	5
Epilepsy	5
Hypertension (high blood pressure)	3
Blindness or severe visual impairment	2
Cancer	1
Mental health condition	1

Carer

Responses	Count
No	57
Yes	2
(blank)	3
Grand Total	**62**

Appendix 3 – Full Results

Themes from Question 1

Responses	Positive	Neutral	Negative	Grand Total
Communication between staff and patients	30	1	6	**37**
Service delivery, organisation and staffing	9	1	3	**13**
Referrals	4		4	**8**
Quality of appointment	4		3	**7**
Diagnosis	2		2	**4**
Quality of Staffing	3		1	**4**
Cancellation			2	**2**
Support			2	**2**
Information providing	2			**2**
Complaints procedure			1	**1**
Quality of Care	1			**1**
Staff attitudes			1	**1**
Waiting time to be seen once arrived at appointment	1			**1**

Responses	Positive	Neutral	Negative	Grand Total
Continuity of Care	1			1
Booking appointments			1	1
Quality of treatment			1	1
Grand Total	**57**	**2**	**27**	**86**

Themes from Question 2

Responses	Positive	Neutral	Negative	Grand Total
Information providing	32	2	4	38
Quality of appointment	7		1	8
Diagnosis	3		3	6
Medication	3		2	5
Service delivery, organisation and staffing	3		2	5
Communication between staff and patients	2		1	3
Cancellation			3	3
Quality of treatment	2			2
Continuity of Care	2			2
Booking appointments			2	2

Responses	Positive	Neutral	Negative	Grand Total
Referrals	2			**2**
Administration			1	**1**
Quality of Staffing	1			**1**
Engagement	1			**1**
Holistic Support	1			**1**
Grand Total	**59**	**2**	**19**	**80**

Themes from Question 3

Responses	Positive	Neutral	Negative	Grand Total
Consent to care and treatment	35	10	4	**49**
Medication	3	1	1	**5**
Information providing	4			**4**
Support	1		2	**3**
Service delivery, organisation and staffing	1		2	**3**
Quality of treatment	1		1	**2**
Quality of appointment	2			**2**
Referrals			1	**1**

Responses	Positive	Neutral	Negative	Grand Total
Cancellation			1	1
Communication between staff and patients	1			1
Grand Total	**48**	**11**	**12**	**71**

Themes from Question 4

Responses	Positive	Neutral	Negative	Grand Total
Support	28	1	4	33
Service delivery, organisation and staffing	5		5	10
Quality of Staffing	4		2	6
Quality of Care	4		1	5
Diagnosis	2		2	4
Communication between staff and patients	1		2	3
Quality of treatment	1		2	3
Referrals	1		2	3
Quality of appointment	2			2
Cancellation			2	2
Other			2	2

Responses	Positive	Neutral	Negative	Grand Total
Booking appointments			2	2
Information providing	1		1	2
Continuity of Care	1			1
Holistic Support	1			1
Car Parking Access			1	1
Medication			1	1
Grand Total	51	1	29	81