Neurology Hot Topic Report

Healthwatch Shropshire

14 December 2017

Hot Topics

Healthwatch Shropshire (HWS), through its Intelligence Committee, will choose a particular service or area of Health and Social Care on which to focus for a 2 month period. HWS will then concentrate publicity and engagement efforts around that service and its users.

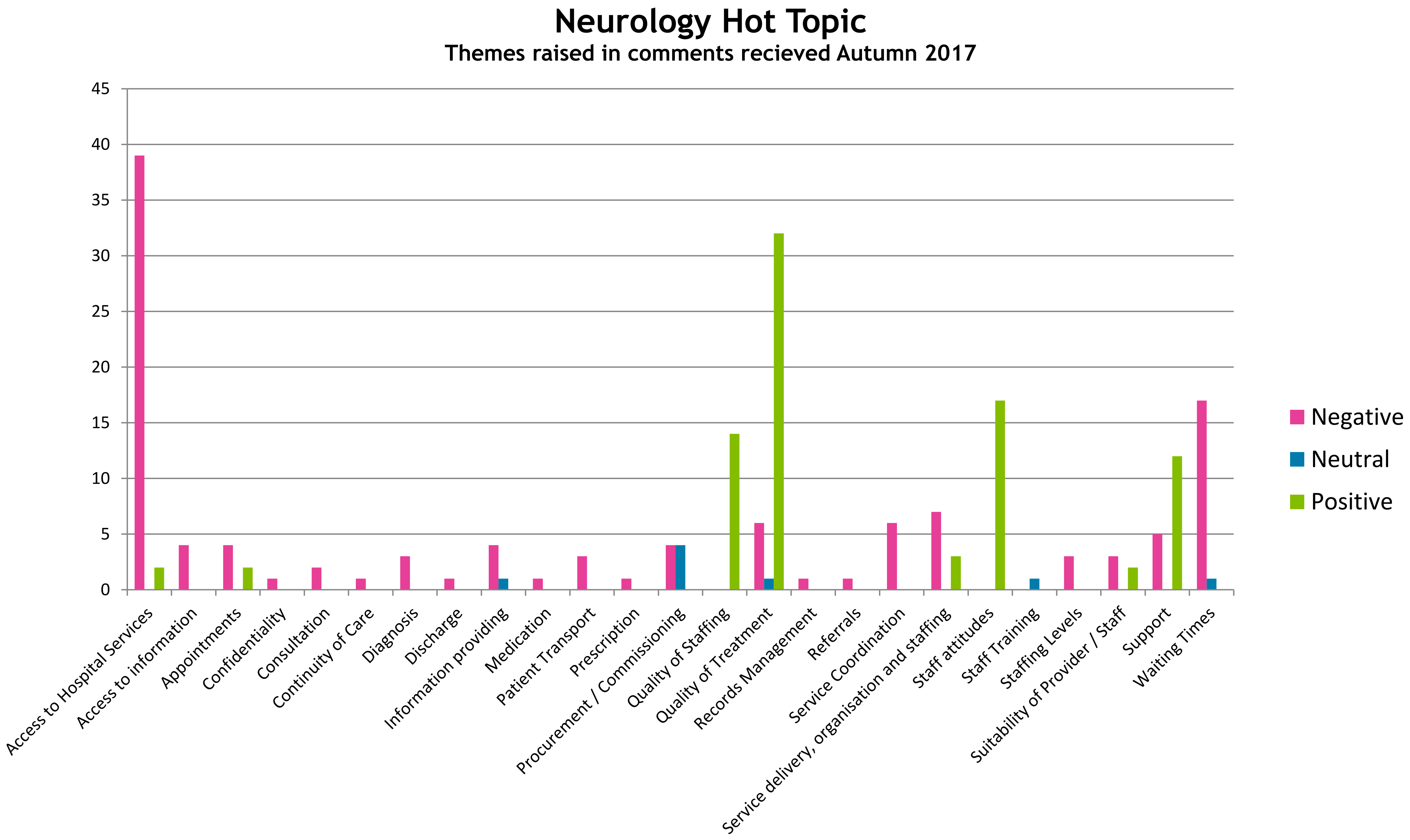
The committee felt that Neurological Services would be an appropriate subject for a Hot Topic for September and October 2017. This was for several reasons. Over the years there had been very little feedback about the Neurology Services in Shropshire; we were unsure why this was and were keen to understand the patient experience. The fragility of neurological services in Shropshire had been recognised and the service had been temporarily closed to new referrals with out of county hospitals providing alternative capacity. We wanted to understand how this was affecting the patient experience so that the patient voice could be fed into the discussion around the future of service provision in Shropshire and wider through the Shropshire and Staffordshire Neurology Workshops being organised by NHS England to coordinate neurological services provision.

The call for feedback was sent out in a press release to local papers, magazines and media organisations. It was advertised with posters and fliers distributed to hospitals, General Practice surgeries and pharmacies. Local neurological condition support groups were contacted and HWS staff offered to meet with groups across the county.

This resulted in the collection of 97 experiences. The majority of the feedback came from patients with long term conditions: Parkinson’s, Multiple Sclerosis and Motor Neurone Disease.

The number of comments received around about specific conditions (where specified):

Condition	Comments
Acquired Brain Injury	1
Epilepsy	2
Motor Neurone Disease	24
Multiple Sclerosis	10
Parkinson’s	38
Not Specified	22
Total	97


Neurology Hot Topic
Themes raised in comments recieved Autumn 2017
45
40
35
30
25
20
15
10
5
0
Access to Hospital Services
Access to information
Appointments
Confidentiality
Consultation
Continuity of Care
Diagnosis
Discharge
Information providing
Medication
Patient Transport
Prescription
Procurement / Commissioning
Quality of Staffing
Quality of Treatment
Records Management
Referrals
Service Coordination
Service delivery, organisation and staffing
Staff attitudes
Staff Training
Staffing Levels
Suitability of Provider / Staff
Support
Waiting Times
Negative
Neutral
Positive

Themes raised most frequently in overall feedback

Each piece of feedback was coded against a standard set of themes defined by Healthwatch England. A piece of feedback may raise multiple negative or positive themes. The following is a short overview of the themes raised most frequently.

Access to hospital services

This was a theme in many negative comments, especially those who were new to the service. The comments about MND and MS services came from almost exclusively patients who had started treatment before the current closure to new referrals was put in place at SaTH and consequently do not reflect this theme to such a large extent.

Examples include:

Patients with long term diseases receiving an initial diagnosis through Royal Wolverhampton Hospital Service are not put in contact with the relevant nursing support in Shropshire. It was reported that even when directed to the relevant nursing support by disease support associations the patients are unable to access the service. Patients were also unable to access nursing support through the normal RWH channels. Patients being treated at Robert Jones & Agnes Hunt were not offered nursing support through RJAH and were unable to access the nursing support provided by SaTH. Voluntary organisations are a valuable source of information which can help support patients with generic information but not always with individual concerns where patients rely on local specialised staff. Parkinson’s UK reported that they were attempting to address the problem in accessing nursing support for the newly diagnosed by providing remote access to the Parkinson’s UK national nursing staff but this could only be a temporary measure due to the capacity of the nurses.

Some patients felt that they should have access to specialist hospital staff but were left to deal with their condition with only the support of their GP which they valued and were pleased with but had concerns as their GP would not be an expert.

Distances to acute hospital based services were raised by many of those who provided feedback. In particular patients with Parkinson’s can find it challenging to attend hospital appointments due to the time limited effects of their medication. This is exacerbated if they have to spend time travelling extra distances. Many neurology patients are unable to drive because of their conditions and public transport is not always an option. Patients are concerned that this will be exacerbated if services remain outside the county.

Quality of staffing

The feedback about the overall quality of the staff involved in the service was positive. This was particularly marked in those with MND. Those with MS were very positive about the nursing staff previously in post.

Quality of treatment

Generally patients were very positive both about the treatment they received form the doctors and the nursing staff, in particular the management of medications was highlighted.

Continuity of care with specialist staff who know the patient's history is seen by many patients as being essential to the quality of their treatment. The perceived lack of succession planning for staff turnover was raised.

Staff attitudes

The feedback was very positive about the attitude of the staff and the person centred approach they take to patient care. The SaTH nursing staff dealing with Parkinson's and the Occupational Therapist supporting MND were generally seen as going above and beyond what the patients would expect.

Support

Across all of the conditions patients valued and relied on the medical and general support they received from the nursing staff and were concerned about how this might be impacted if staff members were to change in the future given the perceived difficulty in finding specialised staff. MND patients were concerned that their Occupational Therapist who provides a lot of general support is crucial to their support and treatment and would be very difficult to replace.

The change in MS nursing staff with the loss of 2 very experienced and highly valued nurses and the appointment of 2 less experienced staff, one of whom subsequently left, and the subsequent changes in how quickly patients were able to access their services caused some concerns.

A theme running through the feedback was a lack of information about what support patients could expect, where they could access it and what the timescales might be. Examples being:

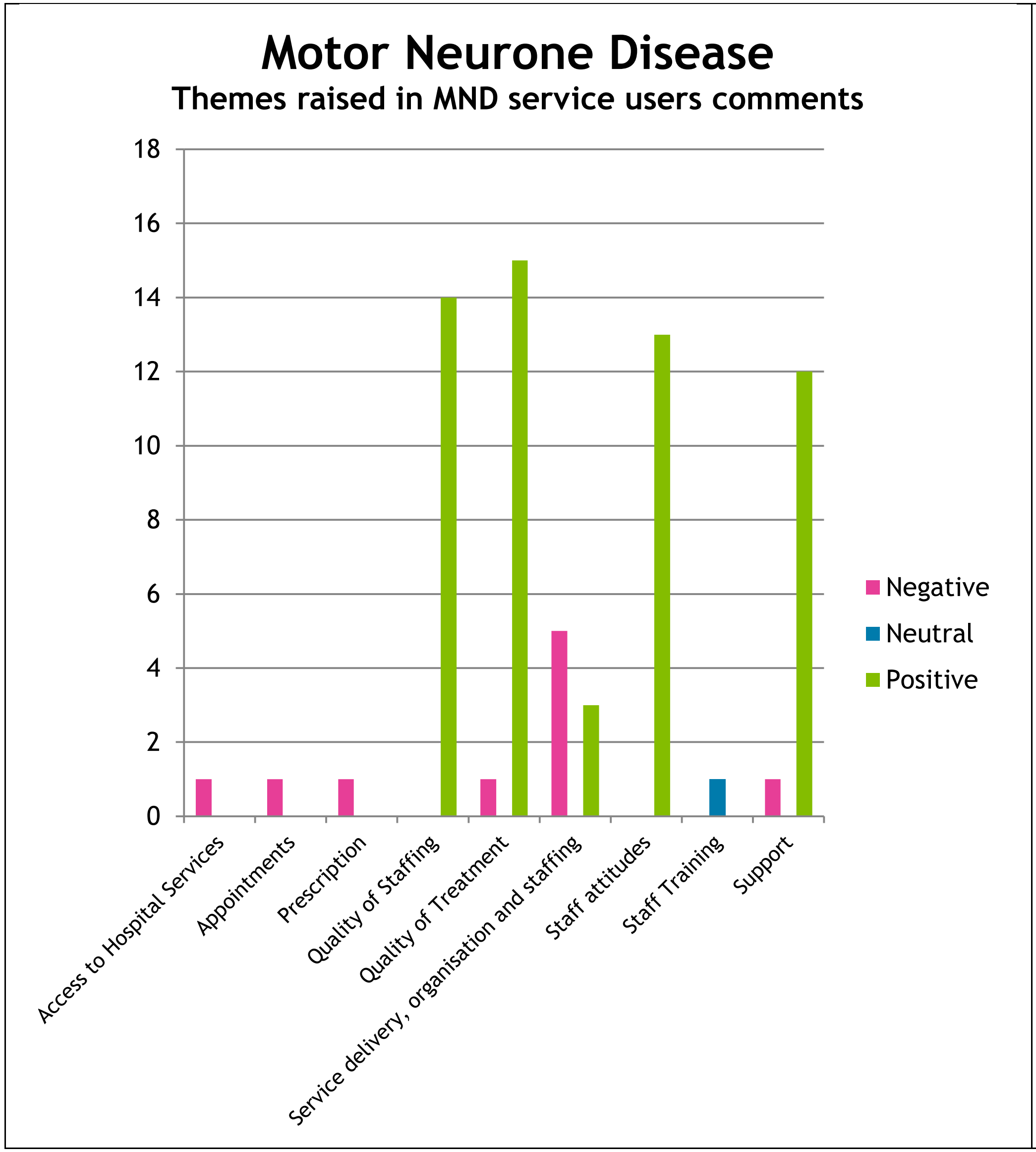
- Some MND patients on riluzol were told they needed, and were receiving, 3 month liver function tests while some patients had not been given this information and were not receiving the tests.
- One Parkinson's patient found through a chance conversation with a neighbour that there were support services available in the county and that other newly diagnosed patients saw the consultant much more frequently.
- Some Parkinson's patients report having been given no information about support at the time of their diagnosis.
- A patient reports being referred to a consultant and diagnosed with Parkinson's but since the initial diagnosis he has not seen a consultant for 3 years, 'not sure if this is usual'.

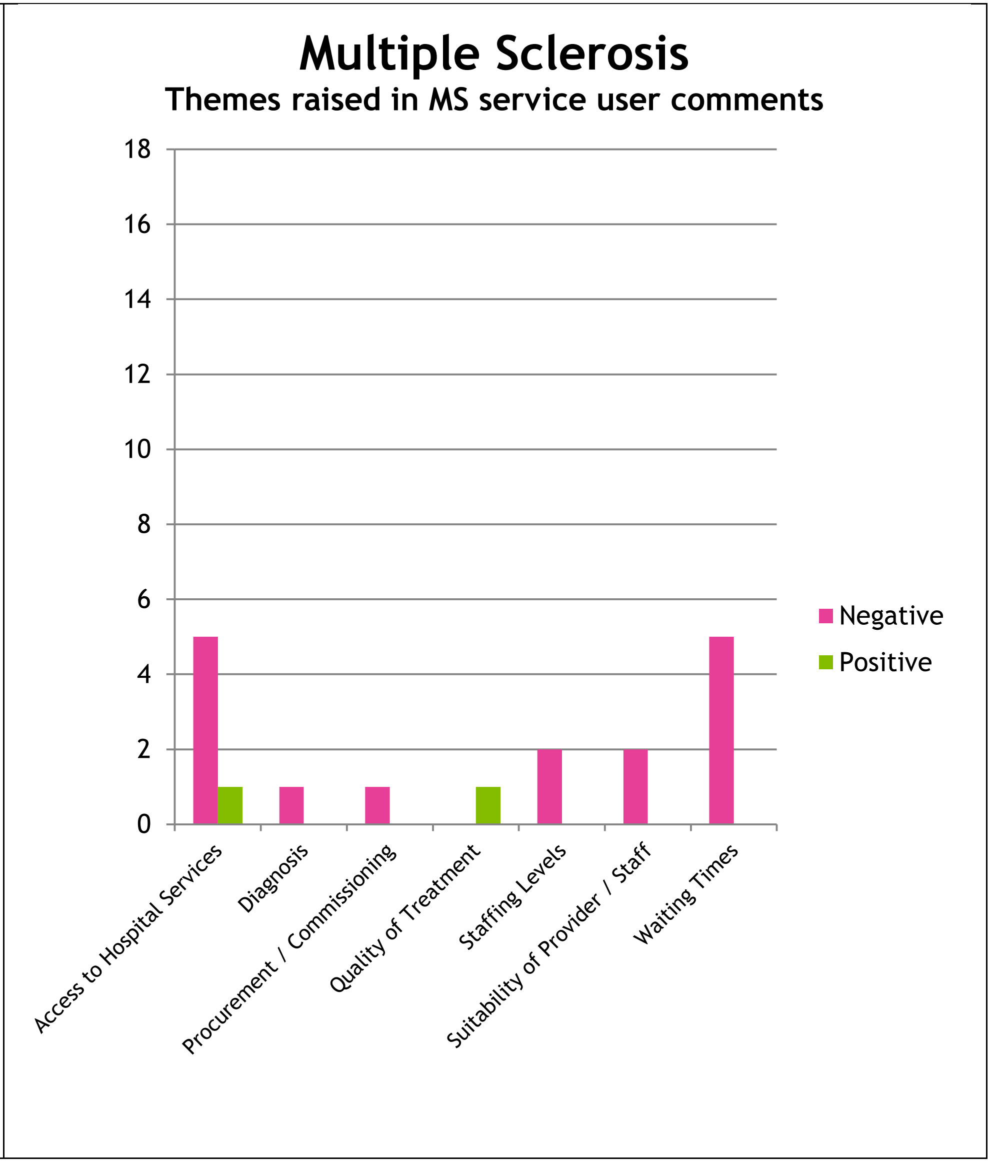
Waiting times

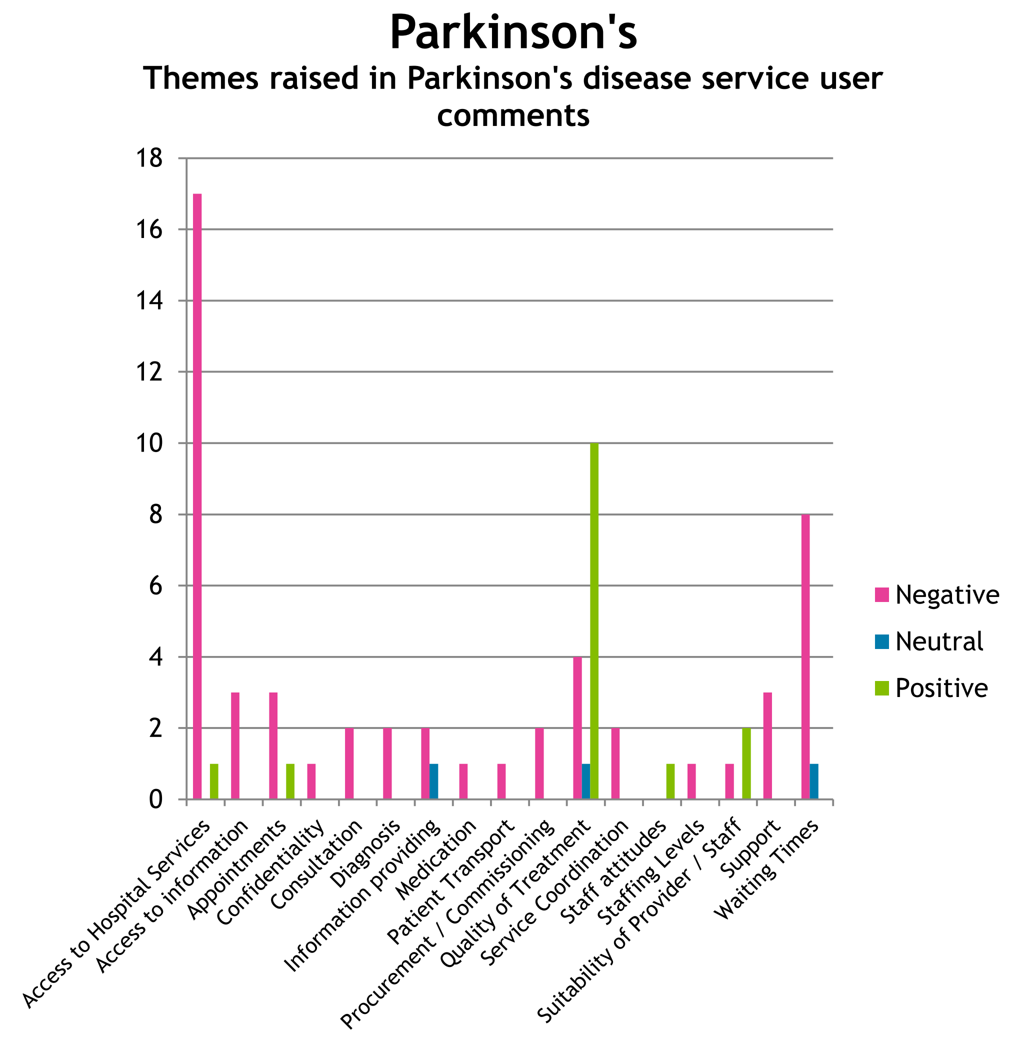
Patients with long term conditions were finding that their regular appointments at SaTH were being spread out without explanation, some moving from 3 months to 8 months. They were not sure if it was a clinical decision or due to service pressures. Some patients reported multiple appointment cancellations.

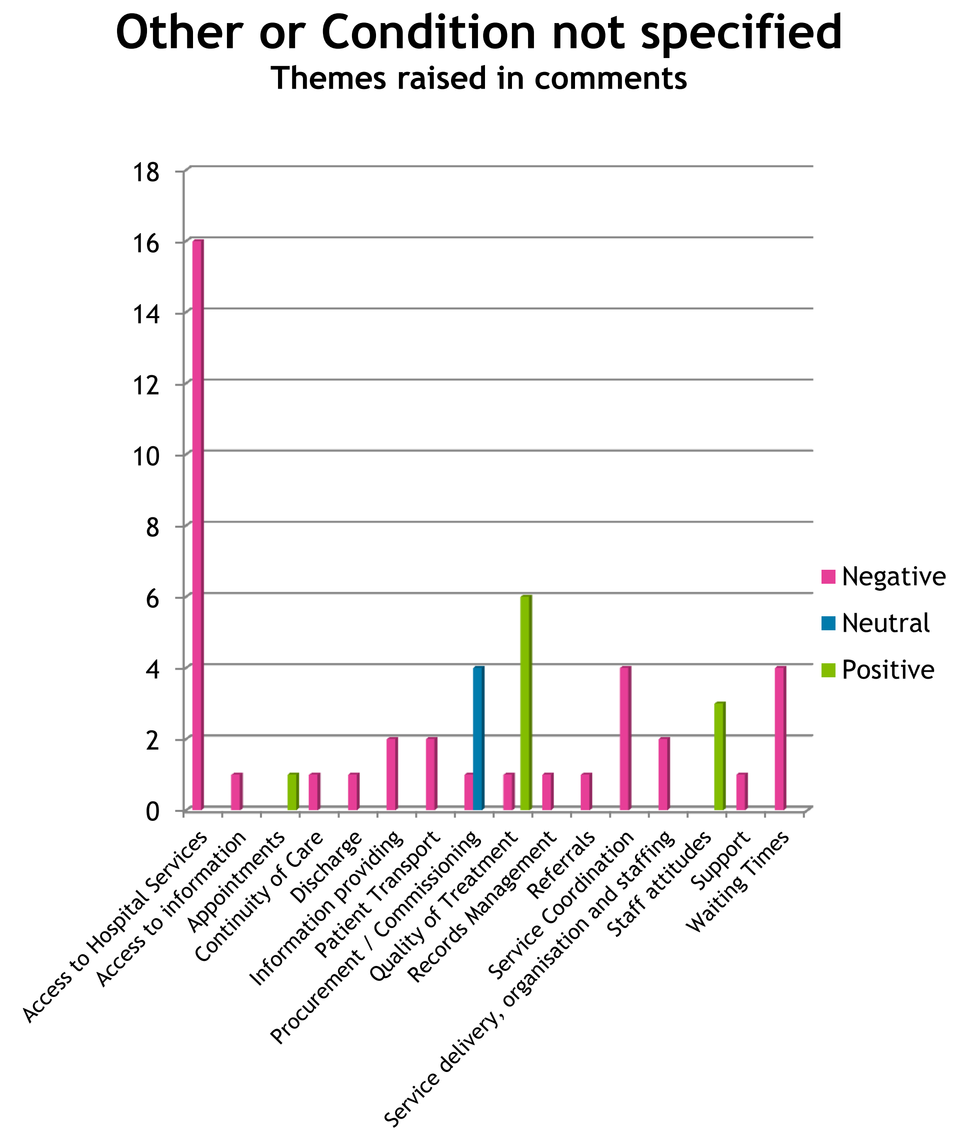
It was commented that those referred into the service often have their driving licences suspended pending the outcome of investigations. This can have a challenging socio-economic effect on people and their families if they are waiting for any length of time for the initial consultant appointment.

Themes raised by type of service






Parkinson's
Themes raised in Parkinson's disease service user comments
0
2
4
6
8
10
12
14
16
18
Access to Hospital Services
Access to information
Appointments
Confidentiality
Consultation
Diagnosis
Information providing
Medication
Patient Transport
Procurement / Commissioning
Quality of Treatment
Service Coordination
Staff attitudes
Staffing Levels
Suitability of Provider / Staff
Support
Waiting Times
Negative
Neutral
Positive


Other or Condition not specified
Themes raised in comments
0
2
4
6
8
10
12
14
16
18
Access to Hospital Services
Access to information
Appointments
Continuity of Care
Discharge
Information providing
Patient Transport
Procurement / Commissioning
Quality of Treatment
Records Management
Referrals
Service Coordination
Service delivery, organisation and staffing
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