# Access to and use of clinical services and disease-modifying therapies by people with progressive multiple sclerosis in the United Kingdom

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**Title**: Access and use of clinical services and disease modifying therapies by people with progressive Multiple Sclerosis in the United Kingdom.

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## Practice points

1. Level of access to MS Specialists by people with progressive MS in the UK was high at 95%.

2. The most utilised practitioners by participants for their MS were MS specialist Doctor/Nurses, General Practitioners and Physiotherapists.

3. Level of access to a regular clinical review was 74%, however, 37% received their review less than annually falling short of the recommended guidelines.

## Abstract

**Background:** According to current UK guidelines everyone with progressive MS should have access to an MS Specialist but levels of access and use of clinical services is unknown.

**Objective**: To investigate access to MS Specialists, use of clinical services and Disease Modifying Therapies (DMT) by people with progressive MS in the United Kingdom.

**Methods**: A UK wide, online survey was conducted via the UK MS Register. Inclusion criteria: age over 18 years, primary or secondary progressive MS and a member of the UK MS Register. Participants were asked about access to MS Specialists; recent clinical service use; receipt of regular review and current and previous DMT use. Participant demographics; quality of life and disease impact measures were supplied from the UK MS Register.

**Results**: In total 1298 participants responded: 5% were currently taking DMT; 23% had previously taken DMT; and 95% reported access to an MS Specialist. Most utilised services were: MS Doctor/Nurse (50%), General Practitioner (45%), and Physiotherapist (40%). Seventy-four percent received a regular review although 37% received theirs less than annually. Current DMT use was associated with better quality of life but past DMT use was associated with poorer quality of life and higher impact of disease.

**Conclusion**: Access to, and use of, MS Specialists was high. However a gap in service provision was highlighted in both receiving and frequency of regular reviews.

## Introduction

Multiple Sclerosis (MS) is a chronic inflammatory autoimmune demyelinating disease of the central nervous system resulting in axonal and grey matter loss. It is estimated that there are 130,000 people living with MS in the United Kingdom (UK).[1] At time of diagnosis, approximately 15% of people with MS are diagnosed with Primary Progressive MS (PPMS), 80% with Relapsing Remitting MS (RRMS) and 5% with Progressive Relapsing MS; and approximately 80% of those with RRMS will go on to develop Secondary Progressive MS (SPMS).[2]

Disease Modifying Therapies (DMT) are currently available to those who have RRMS, or are still experiencing relapses in the early stages of SPMS. Disease modifying therapies have been found to delay the transition from RRMS to SPMS.[3] However, there are currently no effective licensed pharmacological treatments for slowing the progression of disability in both primary and secondary progressive MS, although Ocrelizumab has been shown to decrease disability progression by 25% in people with primary progressive MS.[3] Due to the lack of available effective pharmacological treatments for disease activity in progressive MS, specialist rehabilitation services are of particular importance. Despite this, access to specialist services throughout the UK can be difficult, and people with progressive MS are often told that there is little available for them, and advised to self-manage their condition.[4] The International Progressive MS Alliance have subsequently highlighted rehabilitation for people with progressive MS as a research priority,[5] and disciplines such as physiotherapy have positive evidence in the rehabilitation of people with progressive MS.[6]

The current National Institute for Health and Care Excellence (NICE) guidelines for multiple sclerosis and Healthcare Improvement Scotland clinical standards for Neurological Health Services state that everyone with MS in the UK should have access to an MS Specialist and receive a comprehensive regular review at least annually, by a member of the multi-disciplinary MS team.[7,8] This review should cover all aspects of care including medication; symptom management; disease course; general health; participation and social care needs and does not have to be conducted in a clinical environment. Recently, MS Specialist Nurses were found to be the most consulted health care professional[9] and 86% of people with MS reportedly had access to a Neurologist or MS Nurse.[10] However, these studies did not differentiate between MS types. In some areas within the UK, such as London and Northern Ireland, a limited MS service provision has been found.[11,12] Furthermore in England and Wales 55% of patient comments regarding provision of NHS MS services were negative.[13]

The purpose of this study was to investigate access to, and use of, clinical services for people with primary and secondary progressive of MS. Specifically exploring whether people with progressive MS had access to an MS Specialist; what clinical services they used; if they received an regular review; their current and previous use of DMT and to explore any associations between these variables and quality of life and physical and psychological impact of MS.

## Methods

The UK MS Register is an online register funded by the MS Society. People with MS become members voluntarily, and answer both regular and online surveys.[14]

Members self-report their MS diagnosis type, demographical information and complete self-report outcome measures, such as the EQ-5D-3L Health Questionnaire (EQ-5D-3L) and the physical and psychological sub-scales of the Multiple Sclerosis Impact Scale-29 version 2 (MSIS-29) every three months. Data are anonymised using the Secure Anonymised Information Linkage system.[15] At the time of this study there were 11,041 people on the UK MS Register with 4,384 people active on the Register in the previous six months.

*Design and participant recruitment*

A cross-sectional survey design was used. The survey was available on the UK MS Register from August to October 2015. To be eligible for inclusion a participant had to be 18 years old or over, living in the UK, diagnosed with progressive MS and registered on the UK MS Register. Potential participants were identified by the UK MS Register, and emailed informing them of the survey. The survey was accessed only via the UK MS Register, and completion was regarded as informed consent. Ethical approval was obtained from the College of Medical, Veterinary & Life Sciences Ethics Committee, University of Glasgow and the study underwent peer review by the information governance panel of the UK MS Register (South West - Central Bristol Research Ethics Committee, Ref: 11/SW/0160).

The survey was in two sections. The first asked about access to, experiences and opinion of physiotherapy services and complementary therapies in the UK, and has been described elsewhere.[16] The second section asked if a participant had access to an MS Specialist: defined as a clinician with MS Specialist skills. Participants were also asked which clinicians they used in the previous three months for their MS. Participants were asked if they received a regular review for their MS; how often that

review took place; who normally undertook the review; and where the review normally took place. Finally, previous and current use of DMT was explored and participants were asked to select whether they were currently taking, or had previously taken, any of the following: Beta-interferon (Rebif, Avonex, Betaferon), Glatiramer acetate (Copaxone), Dimethyl fumarate (Tecfidera), Teriflunomide (Aubagio), Natalizumab (Tysabri, Antigren), Fingolimod (Gilenya, Novartis), Mitoxantrone (novantrone), and Alemtuzumab (Lemtrada). A copy of the survey is available on request. Due to the structural progression of the survey not all participants answered all questions.

*Access*

This study explored two components of access: the opportunity to enter into the service (regardless of organisational barriers such as waiting times and distance to travel) and the utilisation of services.[17] In this survey these two terms were referred to as 'access' and 'use' respectively. Whilst these terms were not explicitly explained the meaning was implied by questions asked, for example "Which of the following clinicians could you see if you wanted to?" implied the availability of the opportunity to see a clinician and "Which of the following clinicians have you seen in the past three months for your MS?" implied the utilisation of services. Barriers to accessing physiotherapy were explored in some detail and have been published elsewhere.[16]

*Access to an MS Specialist*

Participants were asked if they had access to an MS Specialist service. If they answered 'yes' they were then asked which clinicians they had seen recently for their MS. If they answered 'no' they were then asked which clinicians they could see if

they wanted to. Included in this list were 'MS Specialist Nurse' and 'MS Specialist Doctor/ Neurologist'. The answers of those who reported having access to an MS Specialist service and of those who reported they could see an MS Specialist Nurse or Doctor were combined. This gave the total level of access to MS Specialists of this cohort.

*Additional data from UK MS Register*

In addition to data collected from the survey, the following data routinely collected by the UK MS Register were accessed: type of MS; age; gender; time since diagnosis of MS; quality of life measured by the EQ-5D-3L; the physical and psychological sub-scales of the MSIS-29; Lower Super Output Area codes [England and Wales] and Output Area codes [Scotland] (there were no available geographical data for participants from Northern Ireland). Lower Super Output Area codes and Output Area codes, which are used to tabulate census and statistical data by the Office of National Statistics, were combined with data available from the Office for National Statistics and the Scottish Office for National Statistics[18,19] to generate the following: rural or urban dwelling, and Strategic Health Authority for participants in England (in 2013 NHS England divided England into ten regions called Strategic Health Authorities each of which contained multiple NHS trusts). Rural dwelling was defined as a settlement with a population of 10,000 or less.[20]

The EQ-5D-3L is a self-report measure of quality of life generating an index ranging from -1 to 1, a higher index indicating a better quality of life.[21] The MSIS-29 is a 29-item self-report measure with physical and psychological sub-scales to measure the impact of MS.[22] The physical sub-scale ranges from 20-80 and the psychological sub-scale ranges from 9-36. A lower score indicates a lower impact of MS.

*Data analysis*

Data were analysed using IBM SPSS v22. Descriptive statistics were used to characterise demographic data and all outcome variables. The responses to individual questions are presented as percentages. Data were tested for normality and due to non-normal distribution Chi-square and Mann-Whitney tests were used as appropriate. A significance level of $p<0.05$ was used.

## Results

In total 2,538 registrants with progressive MS were emailed by the UK MS register, and 1,298 participants completed the survey generating a 51% response rate; England (n=1,030), Scotland (n=130), Wales (n=104) and Northern Ireland (n=21). Participants had a mean age of 59 (SD 8) years and time since diagnosis of 16 (SD 9) years; the female to male ratio was 1.7: 1; 37% had PPMS (n=486) and 63% had SPMS (n=812). Mean EQ-5D-3L index was 0.49 ± SD 0.2, indicating a poorer quality of life compared to general population of the same age who would have an approximate index of 0.8.[23] The mean MSIS-29 physical and psychological sub-scores were 55.97 (SD 12.64) and 19.96 (SD 6.10) respectively indicating that this sample was moderately affected both physically and psychologically by their MS (Table 1). Compared to those with SPMS, people with PPMS were younger, had a shorter time since diagnosis, had a higher EQ-5D-3L index and lower psychological and physical scores on the MSIS-29 (all $p<0.005$).

In total 95% (n=1,184) of participants reported that they had access to an MS Specialist, and 96% (n=959) of those who had access reported they would be able to

197 access the specialist if their symptoms or needs changed. Figure 1 shows access to
198 MS Specialists across the UK. Access to an MS Specialist ranged from 92% in
199 Yorkshire and the Humber and the East Midlands to 98% in Wales.

200 Overall, 81% (n=1046) of participants reported using clinical services for their MS in
201 the previous three months. The most commonly used clinical services were MS
202 Specialist Doctor/Nurse (50%, n=517), General Practitioner (45%, n=467), and
203 Physiotherapist (40%, n=414) (Figure 2). Of the participants receiving clinical
204 services for their MS: 46% (n=481) were receiving a single service and 54% (n=565)
205 were receiving more than one service. From those who answered the question 20%
206 (n=88) of participants reported they were currently taking DMT (PPMS n=18, SPMS
207 n=70), and 24% (n=303) reported that they had previously taken DMT (PPMS n=37,
208 SPMS n=266). These numbers equated to 5% and 23% of the total sample
209 respectively.

210 In total, 74% (n=917) of participants received a regular review; 56% (n=505)
211 received that review annually; 63% (n=569) had their review performed by an MS
212 Specialist Doctor and 27% (n=248) reported it was performed by a nurse. A total of
213 90% (n=819) reported usually receiving their review in a hospital or clinic (Table 2).
214 Ninety percent of participants who were currently taking a DMT received a regular
215 review: 6% received their review twice a year, 51% once a year, 41% less frequently
216 than once a year and 2% did not know (not shown in tables).

217 There was a statistically significant association between access to an MS Specialist
218 and receiving a regular review ($p$<0.001) (Table 3). Access to an MS Specialist was
219 not associated with MS type, past or present DMT use, or urban/rural dwelling (Table
220 3).

Participants who were in receipt of a single clinical service, as opposed to multiple services, for their MS had a better quality of life as measured by the EQ-5D-3L index ($p$<0.001), and less of a physical and psychological impact of MS as measured by the MSIS-29 ($p$<0.001). Use of single or multiple services was, however, not dependent on MS type (n=1045, $p$=0.165) or whether a participant lived in a rural or urban location (n=1003, $p$=0.972) (not shown in tables). Participants who were currently taking DMT for their MS had a better quality of life ($p$=0.016) than those who were not taking DMT. Those who had previously taken DMT, however, had a poorer quality of life (p<0.001), and greater physical (p<0.001) and psychological ($p$=0.006) impact than those who had not taken DMTs (Table 4). There were no differences in quality of life and disease impact scores between those who did and did not have access to an MS Specialist or access to a review and there was no difference in the psychological or physical impact of MS between those who were and were not currently taking DMT (Table 4).

## Discussion

This study had the largest sample solely of people with progressive MS to be surveyed to date, and was the first to investigate access to, and use of clinical services for people with progressive forms of MS across the UK.

In this sample of 1298, access to an MS Specialist was high (95%) and was similar across the UK (Figure 1). This was slightly higher than the outcome of a survey carried by the MS Society in people with all types of MS in the UK which reported 86% of participants had access to a Neurologist or MS Nurse.[10] A previous study conducted in London reported a lack of access to MS related services amongst

those severely affected by MS[11] however the present study indicates that 95% of people with progressive MS have access to an MS Specialist. This difference in results may indicate improvements in service provision, since Edmonds et al.[11] carried out their study and that the people in this sample were not severely affected by their MS. Interestingly there were no differences in quality of life and disease impact measures between those who did and those who did not have access to an MS Specialist. However, there were only a relatively small number of people who did not have access in these analyses so results should be interpreted with caution.

While access to MS Specialists was high not all received a regular review, as is recommended by current guidelines and standards.[7,8] Just under three quarters of participants received a regular review and 37% of these received their review less frequently than annually. This is a breach of the National Institute for Healthcare and Excellence guidelines and the Healthcare Improvement for Scotland clinical standards. With the potential advent of pharmacological treatments for PPMS disease activity [3] a regular clinical review will in the future be particularly important in the care of people with progressive MS. Indeed of those who were currently receiving a DMT 90% were in receipt of a regular review but only 57% received that review once a year or more frequently. However, it should be noted that there were no differences in quality of life or disease impact measures between those who did and did not receive a regular review.

Use of clinical services in this study's participants was high. The three most utilised clinical services were, MS Specialist Nurse or Doctor, General Practitioner, and Physiotherapist (Figure 2). This finding was similar to two previous studies surveying people with all types of MS in the UK and in Europe.[9,24] This may indicate that

people with progressive MS are using the same kind of clinical services to those with RRMS.

Similar proportions of participants received multiple services (54%) or a single service (46%) for their MS. Those who received a single service for their MS had a better quality of life and lower psychological and physical impact of MS compared to those who received multiple services which may be a reflection of clinical need and in turn likely to be associated with disability level.

There was no association between rural or urban dwelling and access to an MS Specialist or receiving a regular review. Previous research by Lonergan et al. in the Republic of Ireland found a lack of access to services was associated with rural dwelling.[25] These researchers however surveyed people with all types of MS, and in addition 37% of the population live rurally in the Republic of Ireland, compared to 18% in the UK[26] which may explain the differences in results reported. Furthermore, the lack of association between rural and urban living and access to an MS Specialist may be due to the definition of access used in this study being the opportunity to see a clinician regardless of personal and organisational barriers.

Five percent of this sample was currently taking DMT and 23% had been prescribed them previously. This result is lower than previously reported by the MS Society which found 56% of all people with all types of MS in UK were taking DMT.[10] This difference is expected as prescribing guidelines state that DMT are not effective in progressive forms of MS when relapses are not present [27] and that those on DMT currently may have been prescribed them whilst in the relapsing remitting phase of MS. The five percent of participants still taking DMT does however, contribute further to the importance of a regular clinical review as there are potentially a large

number of people with MS inappropriately taking these drugs in the UK. Furthermore those taking DMT had a better quality of life compared to those who were not. Those who had previously taken DMT however, had a poorer quality of life and a greater physical and psychological impact of MS compared to those who had never taken them. These differences were however small and may be an indication of the stage of disease, as those who are no longer taking DMT may have more advanced disease, and transitioned into the secondary progressive phase for which DMT are no longer appropriate.

*Study Limitations*

The open and voluntary nature of the UK MS Register and online surveys leave the sample open to bias to the motivated and those with a vested interest. In addition those who are more severely disabled and find it difficult to access services may not be on the register. The diagnosis and type of MS was self-reported, however in future the UK MS Register will be linked with clinical data from the NHS. The concept of access is multi-faceted and even though the definition of access as the opportunity to see a clinician was implied by the questions asked, it was not implicitly defined which may have affected responses. For example if they felt that even their clinician was not available due to a long waiting list they may have selected that they did not have access. A programming error lead to the responses regarding access and use of MS Doctor and MS Nurse being combined and were thus combined in the results. There were no geographical data available for participants in Northern Ireland which limited the analysis comparing participants living in a rural and urban setting. Participants may have encountered problems with memory recall when asked regarding the regularity of review. This may have resulted in errors in reporting with those who more recently received their review being more likely to

report it. Lastly due to the conditions of ethical approval it was not possible to examine the demographics of those who did not respond to the survey to determine if they were typical of those registrants of the UK MS Register with progressive MS.

## Conclusion

This was the first survey of its kind examining access and use of clinical services by people with progressive MS in the UK, and had the largest sample of people with progressive MS to date. Access to an MS Specialist was high and use of clinical services for participant's MS was also high. However a gap in service provision, which is breaching national guidelines, was found in relation to regular reviews and health care providers in the UK should address this. Furthermore investigation should also establish the effectiveness and patient satisfaction of services used.

## Disclosures/ Conflict of interest

The Authors declare there is no conflict of interest.


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Table 1. Demographics of survey participants.

| | Total (n=1298) | PPMS (n=486) | SPMS (n=812) | Difference between PPMS and SPMS |
|---|---|---|---|---|
| Age (years) | 59 (8) | 60 (8) | 58 (9) | $p<0.001$[a] |
| TSD (years) | 16 (9) | 12 (8) | 19 (9) | $p<0.001$[a] |
| Gender | | | | |
| *Female* | 824 | 246 | 578 | $p<0.001$[b] |
| *Male* | 474 | 240 | 234 | - |
| Country [where known] | | | | |
| *Scotland* | 130 | 57 | 73 | $p=0.343$ |
| *England* | 1030 | 372 | 658 | - |
| *Wales* | 104 | 40 | 64 | - |
| *N. Ireland* | 21 | 9 | 12 | - |
| EQ-5D-3L index | 0.49 (0.20) | 0.52 (0.20) | 0.48 (0.20) | $p=0.001$[a] |
| MSIS-29 - psych | 19.96 (6.10) | 19.35 (6.05) | 20.31 (6.11) | $p=0.004$[a] |
| MSIS-29 - phys | 55.97 (12.64) | 54.46 (13.27) | 56.88 (12.12) | $p=0.002$[a] |

Abbreviations: n: number of responses; TSD: Time Since Diagnosis; EQ-5D-3L: EQ-5D-3L Health Questionnaire; MSIS-29 psych: Multiple Sclerosis Impact Scale-29 psychological sub-scale; MSIS-29 phys: Multiple Sclerosis Impact Scale-29 physical sub-scale

Figures where applicable are mean and SD. Not every participant had demographic data available, for example country of domicile. Mean time between survey completion and most recent EQ-5D-3L and MSIS-29 completions were 39 (120) and 19 (111) days.

[a]Statistically significant as calculated by Mann-Whitney tests.

[b]Statistically significant as calculated by Chi-square test.

Table 2. Survey responses regarding a regular review for progressive MS.

| Question | Answer | n | % |
|---|---|---|---|
| Are you offered a regular clinical review for your MS? (n=1243) | Yes | 917 | 74 |
| | No | 287 | 23 |
| | Don't know | 39 | 3 |
| On average; how often is your review? (n=912) | Twice a year | 57 | 6 |
| | Once a year | 505 | 55 |
| | Less frequently than once a year | 341 | 37 |
| | Don't know | 9 | 1 |
| Who usually undertakes your review? (n=911) | MS Specialist Doctor/Neurologist | 569 | 63 |
| | GP | 8 | 1 |
| | Nurse | 248 | 27 |
| | Physiotherapist | 12 | 1 |
| | Occupational therapist | 6 | 1 |
| | The person can vary | 58 | 6 |
| | Other | 10 | 1 |
| Where does your review normally take place? (n=911) | At home | 43 | 5 |
| | In a hospital or clinic | 819 | 90 |
| | In a community centre | 10 | 1 |
| | GP surgery | 20 | 2 |
| | Other | 19 | 2 |

Abbreviations: n: number of participants; GP: General Practitioner.

Table 3. Associations between access to an MS Specialist and MS type, past and present DMT use, rural or urban living and receiving a regular review.

| | n | *p* |
|---|---|---|
| Access to MS Specialist and PPMS or SPMS | 1248 | 0.473 |
| Access to MS Specialist and past DMT use | 1227[a] | 0.371 |
| Access to MS Specialist and current DMT use | 362[a] | 0.175 |
| Access to MS Specialist and urban/rural dwelling | 1201 | 1.000 |
| Access to MS Specialist and regular review | 1233 | <0.001 [b] |

Abbreviations: n: number of responses; PPMS: Primary Progressive Multiple Sclerosis; SPMS: Secondary Progressive Multiple Sclerosis; DMT: Disease Modifying Therapies.

[a]n is significantly higher than results of current and past DMT use reported in main text (88 and 303 respectively) as Chi-square test also includes the participants who answered no.

[b]Statistically significant result from Chi-square test.

Table 4. Differences in EQ-5D-3L and MSIS-29 scores in those with and without access to a MS Specialist, regular review, receiving more than one MS service, and current and past DMT use.

| Access to MS specialist | yes | | no | | |
|---|---|---|---|---|---|
| | n | med | n | med | *p* |
| EQ-5D-3L index | 1154 | 0.57 | 62 | 0.50 | 0.245 |
| MSIS-29 phys | 1180 | 56.00 | 64 | 58.50 | 0.581 |
| MSIS-29 psych | 1167 | 19.00 | 63 | 19.00 | 0.832 |
| Access to review | Yes | | no | | |
| | n | med | n | med | *p* |
| EQ-5D-3L index | 898 | 0.57 | 276 | 0.57 | 0.642 |
| MSIS-29 phys | 914 | 56.00 | 286 | 58.00 | 0.187 |
| MSIS-29 psych | 903 | 19.00 | 285 | 19.00 | 0.410 |
| Single/multiple services | single | | multiple | | |
| | n | med | n | med | *p* |
| EQ-5D-3L index | 469 | 0.57 | 548 | 0.50 | <0.001[a] |
| MSIS-29 phys | 478 | 55.00 | 563 | 59.00 | <0.001[a] |
| MSIS-29 psych | 473 | 18.00 | 555 | 20.00 | <0.001[a] |
| | yes | | no | | |
| Current DMT use | n | med | n | med | *p* |
| EQ-5D-3L index | 87 | 0.57 | 346 | 0.50 | 0.016[a] |
| MSIS-29 phys | 87 | 56.00 | 359 | 60.00 | 0.050 |
| MSIS-29 psych | 85 | 20.00 | 357 | 20.00 | 0.960 |
| | yes | | No | | |
| Past DMT Use | n | med | n | med | *p* |
| EQ-5D-3L index | 296 | 0.50 | 912 | 0.57 | <0.001[a] |
| MSIS-29 phys | 302 | 59.00 | 935 | 56.00 | <0.001[a] |
| MSIS-29 psych | 299 | 20.00 | 925 | 19.00 | 0.006[a] |

Abbreviations: n: number of responses; med: median; EQ-5D-3L: EQ-5D-3L Health Questionnaire; MSIS-29 psych: Multiple Sclerosis Impact Scale-29 psychological sub-scale; MSIS-29 phys: Multiple Sclerosis Impact Scale-29 physical sub-scale; DMT: Disease Modifying Therapies

Not all participants had EQ-5D-3L or MSIS-29 data available. This accounts for slight variation in n.

[a]Statistically significant as calculated by Mann-Whitney tests.

444 Figure 1: Access to MS Specialists across the UK

445

446 Figure 1. Access to MS Specialists by people with progressive MS within Scotland,

447 Northern Ireland, Wales and the Strategic Health Authorities in England.

448

449

450 Figure 2. Clinical services used for MS in the past three months.

451 Figure 2. Clinical services used by participants for their MS in the prior three months.
452 Abbreviations: MSDr/NS: MS Doctor or MS Nurse; GP: General Practitioner; Physio:
453 Physiotherapist; OT: Occupational Therapist; Cont NS: Continence Nurse; NS oth:
454 Nurse other; Dr oth: Doctor other; Orth: Orthotist; SW: Social Worker; Oth: other;
455 Psych: Psychologist; SLT: Speech and Language Therapist; Diet: Dietician
456