



# Parkinson's Provision

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## Healthwatch Stoke-on-Trent

Paul Astley - May 2015

**“Parkinson’s is nothing more than a severe pathological bully who is determined to do me down. I don’t give in to bullies, so we will both have a fight on our hands to the end!”**

**- Questionnaire Return 33**

## Executive Summary

This report provides an analysis of Parkinson's Provision in and around Stoke-on-Trent from a service user perspective.

When Healthwatch Stoke-on-Trent first received concerns about Parkinson's disease provision, they came from care professionals and were orientated around access to Parkinson's nurses. After discussion, and because Healthwatch represents lay service user voice, it was decided to gather the experiences and expectations of this group rather than conduct a service evaluation from a professional perspective.

The results of this conversation reveal that whilst Parkinson's patients and their supporters are in the main resourceful and stoic, the complicated nature of the condition means that they are dependent upon a myriad of different services and a need for them to be joined up. Also, professionals sometimes find Parkinson's itself difficult to understand. For example, patients found that hospital staff might not understand the importance of timely delivery of Parkinson's medication, resulting in significant problems. This spread over into primary care where over half of those with advanced Parkinson's reported that their GP didn't seem confident to offer advice about the condition. To compound this, 42% of patients reported having had their mental health impacted but only a small number had accessed services to help with this. This is particularly worrying when many of this group are more likely to be elderly and live alone, in this study 13% of respondents reported not feeling part of their local community.

Perhaps because of the above, respondents overwhelmingly report reliance upon Parkinson's nurses. This is a vital service which should be well funded and supported. With only 63.5% reporting that they can access services as they need to, it should be no surprise that on 32% of those with advanced Parkinson's consider their condition to be well controlled.

Healthwatch Stoke-on-Trent hopes that this work will raise awareness of these issues and add to the ongoing conversation about how best to design neurological services.

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## Introduction

In October 2014 Healthwatch Stoke-on-Trent received an email from a care home manager in Stoke-on-Trent.

*“I am currently a care manager on two extra care schemes, and I have grave concerns regarding the support and help that is or should I say is no longer available to Parkinson sufferers.*

*When people were diagnosed with Parkinson’s and were living on Extra care schemes, if we felt that they needed a medication review or some general support to help them deal with this condition, we would speak to the Parkinson’s team and they would arrange a home visit from a specialist Parkinson’s nurse, that service has now gone , there is no nurses out in the community anymore.*

*When I contacted the Parkinson’s team number that I was given I was informed that they only had 2 part time staff members and that they were struggling to deal with their case load , and that is before all of the customers that are now been referred into them, and that there would be a long wait for this service.*

*My customers may only need a tweak their medication, or another medication time added, but there is no one to do this, my customers are then at risk of falls, quality of life is affected, and so is confidence and independence, a lot more money is spent in hospital visits, due to falls and injuries.*

*My question is simply WHY?*

*I feel that these people have become a forgotten group and are feeling very isolated and unsupported, and as a care provider we feel very frustrated and let down.*

*Can you please advise me what to do to support our customers?”*

*Professional Testimony 1*

The above email clearly raises concerns about key areas of service provision for Parkinson’s Disease, in particular, access for those in care homes. On discussing with local stakeholders, it was discovered that neurological services were currently being reviewed at the local clinical commissioning group. This inevitably lead to the broadening out of the scope of the project. After all, one of the key recommendations of an extensive report delivered by the All Party Parliamentary Group for Parkinson’s Disease entitled, “Mind the Gap”, is to,

“support better commissioning and planning of services for people with Parkinson’s disease through the provision of evidence and guidance”

This report aims to add to evidence in the form of service-user voices sought in Stoke-on-Trent as the shape of neurological services are revisited by providers. It shows that Parkinson's patients, their friends, families and supporters are a resilient, resourceful group and there is a real need for them to be this way. As Parkinson's itself is a complicated, multi-faceted disease, so are the treatment(s) and integrated services and required to deliver them.

In this report, service users describe the services they use and how successful they are at accessing them. They describe a lack of confidence in staff such as GP's and nurses who sometimes appear short of understanding of the condition. It highlights how in this context, patients hold specialists such as Parkinson's Nurses in high regard but may not be able to access these services as they would like. The result is that Parkinson's patients in Stoke-on-Trent could be coping better if the services were more accessible and knowledge of Parkinson's more widespread to enable staff to deliver appropriate care. At the moment, some patients report not coping well at all.

This report shows importantly, that not all Parkinson's patients are the same. They vary greatly in their requirements from services according to the progression of their condition and their social situation, complicated further by the fact that they are likely to be older and as such are more likely to have issues, social and clinical, beyond Parkinson's (see context, p12). This requires care to be patient centred. All of this requires careful thought when commissioning services.

We hope that this work contributes positively towards improved outcomes for those living with Parkinson's in our community. Healthwatch Stoke-on-Trent thanks all of the contributors to this project including our volunteers, partners and patients.



Healthwatch Staff Member at the Whitfield Unit Xmas Party

## Recommendations

- Access routes for Parkinson's patients in residential homes should be audited and their design revisited;
- Information regarding the upcoming care act should be targeted at those caring for people with Neurological conditions;
- Electronic Aids could be used to remind nursing staff when to give Parkinson's patients their medication;
- Tiered support could be explored in order to ensure that those with advanced Parkinson's get the help they need;
- Help and advice should be more easily available to support self-care and this service should be well promoted;
- Help and advice should be more easily available to GP's to help them to support Parkinson's patients;
- Awareness of the condition should be heightened amongst hospital staff;
- Parkinson's patients should be signposted to mental health services more effectively. Work could be done here to investigate whether GP's are confident to refer patients;
- Support groups are incredibly valuable. Is 30% of respondents a good attendance?
- Parkinson's Advocacy could help support patients but also represent the needs of the group as well as supporting dissemination of information about the condition.

## What We Did

A meeting was set up with the original complainant to explore the situation more deeply. From there a stakeholder group was formed which met on a further two occasions to uncover common issues and plan next steps. There have been a broad variety of contributors to this project including service users and members of staff from,

- Neurological Alliance;
- Radis Care;
- Staffordshire and Stoke-on-Trent Partnership;
- Parkinson's UK;
- CCG;
- Staffs Housing.

It is important to point out, that Healthwatch staff have no clinical knowledge of Parkinson's or any other condition. In order to develop a context to work within, as well as gathering secondary sources of information through desktop research, Healthwatch Stoke talked with professionals who work with patients (but are not all specialists in the field) to better understand the issues that surround the disease. The results of these interactions are set out in a 'problem tree' found on page 12. To further develop this understanding, Healthwatch was invited to a well attended Christmas party, organised by the Parkinson's specialist, Whitfield Unit. There, staff spoke casually to a number of service users about their experiences. Although these interactions weren't recorded, the Healthwatch presence helped promote the project amongst the group and provided anecdotal insight for the project lead. A meeting was then held with a member of the Neurological Alliance to seek advice on the content of a questionnaire (p45) which already reflected the growing understanding of the context developed through the stakeholder group.

- 250 questionnaires were distributed from The Whitfield Unit;
- The questionnaire was also distributed electronically via email;
- 116 paper based were returned, some partly filled and 4 electronically;
- 16 of these were returned with additional comments or letters.

The results of this survey are summarised on page 8 and with more detail from page 18. A full account of the additional comments and letters which accompanied these surveys can be found from page 40.

To supplement this, comments recorded in the stakeholder meetings are included in the text and shall remain anonymous. Extracts of these conversations are included in this report to add additional context only.

## Findings

Firstly it is important to note that much positive feedback was received about the care given, comments can be found on page 40. This section presents a brief narrative of the findings. For full details see page 18 onwards.

*“The service provided by the Whitfield Unit @ The Haywood hospital is very good. They make you feel like a person and not a number. The staff are friendly and also encourage carers. The staff have time for you which makes you feel like part of a family. I would recommend anybody to this unit.!”*

- Questionnaire Return 33

The respondents in this study seem a resilient group of people. When Healthwatch Stoke-on-Trent visited the Whitfield Unit Christmas party in 2014, staff encountered people who appeared keen to be seen as optimistic and very grateful for the services they receive. However, Healthwatch is familiar with the pitfalls of accepting face value as factual. This is not uncommon amongst some groups of people and can be explained in many ways, for example, Dame Julie Mellor, the

*“Parkinson’s is nothing more than a severe pathological bully who is determined to do me down. I don’t give in to bullies, so we will both have a fight on our hands to the end!”*

- Questionnaire Return 33

Parliamentary Health and Care Ombudsman described the over 65’s as perhaps “fear(ing) a backlash if they raise issues” or “don’t like making fuss”<sup>1</sup>. This report shows that Parkinson’s patients are particularly reliant upon services, so it does make sense being risk adverse and not ‘rocking the boat’. This does not detract from the resourcefulness and resilience of these patients.

Although services-users appeared content with the services they use, analysis of the survey returns indicates that this isn’t the case for all with the experience differing. For example, nearly a fifth of respondents reported that they didn’t consider their Parkinson’s to be well controlled, a significant figure indeed but this becomes more pronounced when only those in the advanced stage of the disease are asked the same question, with only 32% describing it as well controlled. This dichotomy is a trend that continues throughout the study and can be explained in different ways. For example, it may well be associated with an emotional response to increasing symptoms of what is an unpleasant condition. It could equally demonstrate evidence of a struggle to address demand on services as the condition progresses.

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<sup>1</sup> James Meikle, 2014, Older People in NHS Care Suffering in Silence Says Health Service Umbudsman, retrieved on 20<sup>th</sup> March 2015 from, <http://www.theguardian.com/society/2014/apr/07/older-people-nhs-care-ombudsman>



*“About 2/3 years ago I wanted to speak to the Parkinson’s Nurses. Telephone messages were left but no phone back. I assume that this has improved. They try to contact me for 3 month visit in between consultant visits but it does not always happen. I have been several times to the physio section at the Whitfield centre. Very good and helpful. I see consultants every 6 months and feel that this is correct and should be ongoing. I ask for a copy of consultants report but this doesn’t always happen. In the early stage of Parkinson’s I had a lot of assistance from \*\*\* (Parkinson’s UK Officer), support worker. I also have a high opinion of the Parkinson’s nurses.”*

- Questionnaire Return 114

There is indeed evidence to suggest that more work could be done to support the cohort. The data gathered reveals that 63.6% of respondents agreed that they were able to access services as they need to, leaving much room for improvement. However, the advanced group reported differently, with only 40% stating they are able to access services as they need to. This does seem to have an impact with only 28% of those with advanced Parkinson’s reporting that most of the time, they are able to manage, a stark difference from the 66.3% who said that most of the time they are able to manage overall. What is remarkable about this is that, in spite of these concerning figures, only 5% in this study reported admitted to hospital as a result of not being able to access figures, however, this still impacts with four individuals reporting that they spent a total of 175 nights in a hospital bed. Multi-pathology may mean that there is no ‘one’ reason for admission however.

*“quite a lot of nurses do not know how anaesthetic affects Parkinson’s disease”*

- Questionnaire Return 111

Whilst in hospital, other issues emerge. A key theme is that perhaps as a result of the complicated nature of the condition, it is found that staff sometimes lack the skills to care for Parkinson’s patients properly. Issues around the timely delivery of medication and

misunderstanding how medications can affect the symptoms of the disease have been reported. Indeed, sometimes the symptoms of the disease itself are badly understood. One respondent describes in a comment how nursing staff don’t see the ‘real him’, when he’s ill and hallucinating, ironically as a result of medication issues. There does appear to be a skills gap which needs addressing.

*“(hospital) is a worrying time for me as the nurses don’t seem aware of the importance of Parkinson’s patients having their medication at the correct times and ON TIME as well as making sure they take it. As my husband has to receive Parkinson’s medication at seven different times of the day, I know first hand that it can be difficult to remember every time. Therefore I have purchased an alarm from Parkinson’s UK which I find is of great benefit and feel something like this would be a great help to the nursing staff and have suggested this to them but they do not take it on board.”*

Letter Extract

*“Nurses do not know the importance of medication (on time). They say they do but don’t follow through”*

**Questionnaire Return No 4**

This skills gap moves beyond the hospital and into primary care. Overall 28% of respondents reported that their GP didn’t seem confident to offer advice about Parkinson’s. 56% of those in the advanced stage of the disease reported that their GP doesn’t seem confident

to offer advice about the condition. This is a real concern, and illustrates the importance of specialists and access to them. Indeed, the data shows that Parkinson’s Nurses are overwhelmingly described as the primary source of help and advice. Good access to this vital service seems to be of critical importance in this context. Especially for those whose condition has developed beyond the maintenance stage. Only 12.7% have received a home visit from a Parkinson’s nurse, it is this issue that was brought to the attention of Healthwatch Stoke-on-Trent by care home staff who struggle to arrange for medication reviews for their residents with this reportable resulting in falls and admissions. It is easy to see how these individuals, who may be lacking the support of friends and family may risk becoming ‘the unseen’. Indeed, concerns have been raised already regarding, “access to appropriate services for people living in care homes . . . .”<sup>2</sup>. More work can be done here locally to indentify issues around Parkinson’s in residential care.

The benchmark for good Parkinson’s services orientates around integrated, person centred services and there is good evidence of attempts to achieve this. For example, there are a variety of services available to service users locally, from speech therapy to mental health services (p38 for access statistics). Surprisingly, only 6% of respondents reported accessing mental health services, this is surprising because overall 42% said that their mental health had been affected. This rises to 64% for those in the advanced stage of the condition. This suggests that while there is scope for services to be integrated, there is a clear room for improvement here and with 13% of respondents reporting not feeling part of their local communities, the social aspect of this cannot be overlooked. Indeed, the value of social and support groups in alleviating isolation and offering the opportunity to share experiences and useful information and advice for patients and carers cannot be overlooked. Only 30.4% of respondents reported accessing these services.

*“I understand carer’s being in crisis because they feel alone. There is no one they can turn to, they ring the Parkinson’s Nurses, they get the answer phone but they are so stretched they are doing their best, they go to the GP who says, talk to the Parkinson’s nurses, I’ll try and get your appointment forward but that’s no good, they need someone to talk to. This is why we say to them, go to the social group and you can go and have a whinge and a moan . . . . . you can talk to somebody that’s in the same boat and by the time they go home they have one another’s phone number and if they are have a bad day, they give one another a ring and it helps.”*

**Stakeholder Group Member**

<sup>2</sup> Parliamentary Group for Parkinson’s Disease, “Please Mind the Gap” – retrieved on 8<sup>th</sup> March 2015 from [http://www.parkinsons.org.uk/sites/default/files/appg\\_report\\_please\\_mind\\_the\\_gap.pdf](http://www.parkinsons.org.uk/sites/default/files/appg_report_please_mind_the_gap.pdf)

## Headlines

- **19.5%** don't consider their Parkinson's to be well controlled overall;
- Only **32%** of those with advanced stage Parkinson's describe it as well controlled;
- Overall **63.6%** of respondents agreed that they are able to access services as they need to;
- Only **40%** of respondents with advanced Parkinson's agree that they are able to access services as they need to;
- **14.4%** of respondents report having waited for longer than 12 months for a review at some point;
- Respondents raised concerns about the timeliness of medication when in hospital. **43.75%** said staff didn't seem familiar with Parkinson's and the help they needed. Several comments also mention this issue.
- Overall, **66.3%** report that most of the time, they are able to manage;
- Only **28%** of those with advanced Parkinson's describe that most of the time, they are able to manage;
- **28%** responded that their GP didn't seem confident to offer advice about Parkinson's overall;

- **56%** of those with advanced Parkinson's responded that their GP didn't seem confident to offer advice regarding the condition;
- Only **5%** reported having being admitted to hospital as a result of not being able to access services. However, four individuals reported a total of **175 nights** in a bed;
- Although initially, **84%** respondents found medication reviews easy to get in early stage Parkinson's, **70.8%** of advanced stage patients reported easy access;
- **12.7%** had received a home visit from a Parkinson's nurse;
- **Parkinson's nurses** are overwhelmingly regarded as the primary source of help and advice;
- **42%** of respondents reported having had their mental health affected by the disease overall. In advanced patients this rose to **64%**;
- Only **6%** of respondents have accessed mental health services;
- **13%** reported not feeling included in their local community, suggesting some social isolation;
- **30.4%** have accessed social or support groups.

## Context - Who are Parkinson's Patients?

This section is intended to outline the characteristics of this group in order to support understanding of how service change might impact upon it. Healthwatch Stoke-on-Trent does not contain staff with clinical experience and this contextual piece is limited in that regard. However, Healthwatch is well positioned to describe a whole person journey because of its strategic position as a viewer of the whole health economy. To do this, it relies very much upon the social determinants of health (see p16).

*"This not being done by Mrs \*\*\*\*\* , I am her husband and do it because she is not able to control her limbs. As far as Parkinson's is concerned, we have no help or advice from anyone. I am (a) full time carer on my own. It is becoming increasingly difficult to cope as the Parkinson's worsens every day."*

**Questionnaire Return 76**

One in every 500 people have Parkinson's disease<sup>3</sup>, it is caused by a lack of dopamine in the brain and makes it difficult to coordinate body movements. The main symptoms of the condition are shaking, stiffness, slowness of movement and walking problems<sup>4</sup> (including balance) although they are much broader than this, affecting speech and the ability to eat for example. People also experience 'freezing' and 'dancing' as well as mental health issues and incontinence. To further complicate issues, the condition fluctuates in its symptoms, sometimes rapidly, making it difficult to identify and monitor. Parkinson's UK describe the disease as not being terminal, although it does worsen over time. This study acknowledges how the disease develops and changes over time from early stage through to palliative.

*"I am no longer able to use public transport because of physical freezing and Parkinson's 'dancing' in confined spaces"*

**Questionnaire Return 33**

*"I think it's very difficult for people because they don't understand how it affects somebody. I put someone into their shoes for half an hour, but they have to live with that 24/7. So when I sit you in a corner and say put your head down and don't look at anyone for two minutes, that's being frozen but for some people that can be 30 minutes and people just carry on and push past them like nothing happened. And when you try to talk to them and they can't get their words out people say 'write it down' but they've got no chance. People then get frustrated with it all and they tend then just to go into themselves and they get depressed."*

**Stakeholder Group Member**

<sup>3</sup> <http://www.parkinsons.org.uk/content/about-parkinsons>

<sup>4</sup> <http://www.bupa.co.uk/health-information/directory/p/parkinsons-disease>

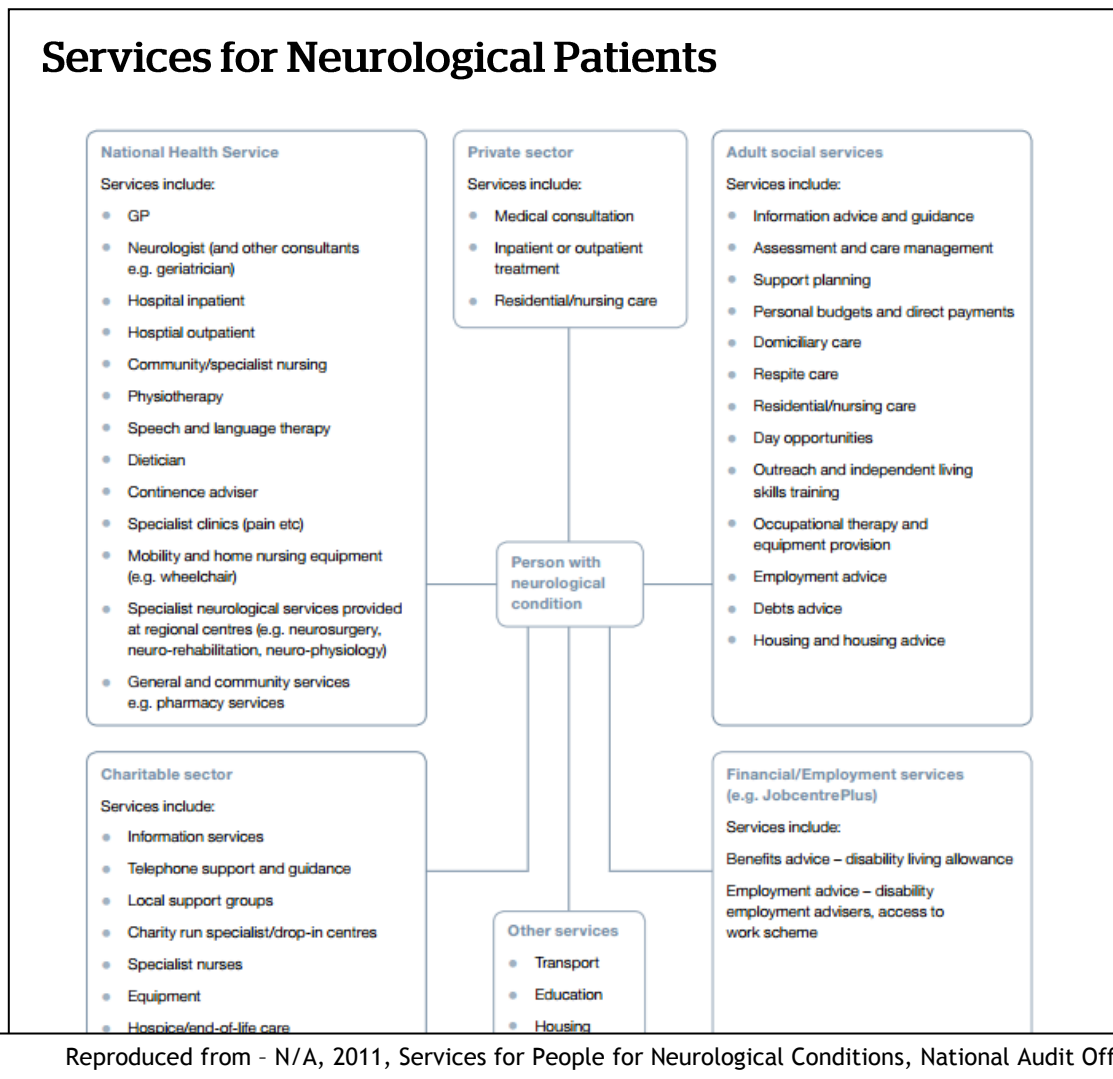
*“People who live with patients don’t understand it, families don’t understand it. Having the words up there but not being able to verbalise is far worse than not being able to walk. Sometimes you think that there may be carer breakdown here out of frustration also.”*

Stakeholder Group Member

Because there are so many symptoms associated with Parkinson’s disease it is difficult to manage. The Whitfield Unit at the Haywood hospital run a course specifically to help with this. This lack of knowledge impacts on clinical staff too. For example, the administration of medication 15 minutes either side of when it is due can have a considerable impact upon the patient. The complicated nature of the disease requires multidisciplinary working and coordination across the health economy. This is challenging and its extent is outlined in the diagram below.

*“Nurses do not know the importance of medication (on time). They say they do but don’t follow through”*

Questionnaire Return No 4



The average age of respondents for this survey is 73, although it is acknowledged that Parkinson's is not a disease exclusive to people of this age. However, for the purpose of this report, the focus will remain upon the subject group, who can be described as elderly.

“Conventionally, elderly has been described as a chronological age of 65 years”<sup>5</sup>

. . . although there are many who would argue against that view! This does however; place Parkinson's patients in a group which is more likely to have clinical and social issues in addition to the disease itself. These issues associated with the elderly are varied, from those associated with falls, stroke, osteoporosis, and dementia amongst others but often there is multiple-pathology, for example cataracts and arthritis resulting in falls<sup>6</sup>. However, when factoring in the social determinants of health, it is important that this concept of multiple pathology can be also be explored outside of the clinical.

One would imagine there are many elements which combine and the causes of pathology diverse, affected by the social determinants of health (p16). In the same way poor eyesight might lead to a fall, other factors impact upon the elderly. For example, this group may, “live alone (and) have disabilities including cognitive impairment, making them dependent of assistance in many daily life situations”. In the elderly, informal support networks are often fractured, in fact 51% of over 75's live alone nationally<sup>7</sup>.

Also, loneliness has also been presented as an important determinant of health,

“Loneliness is as bad for health as smoking. It is also associated with poor mental, physical and emotional health, including increased rates of cardiovascular disease, hypertension, cognitive decline and dementia. Socially isolated and lonely adults are more likely to undergo early admission into residential or nursing care.”<sup>8</sup>

Over half (51%) of all people aged 75 and over live alone (Ibid) nationally, with this being acknowledged over recent years with several local programmes such as ‘The Green Door’ and which encourages the elderly and isolated to take part in activities in the city. In this study, 13% of respondents reported not feeling included in their local community which represents a significant amount of social isolation.

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<sup>5</sup> Orimo et al, 2006, Reviewing the Definition of Elderly, Geriatrics and Gerontology, Wiley

<sup>6</sup> <http://www.patient.co.uk/doctor/Elderly-Patients-in-Hospital.htm>

<sup>7</sup> <http://www.campaigntoendloneliness.org/loneliness-research/>

( In Text Box) Bostock A, Steptoe A, 2012, BMJ, Association Between Low Functional Health Literacy and Mortality in Older Adults: Longitudinal Cohort Study, retrieved on 8<sup>th</sup> December 2014 from <http://www.bmj.com/content/bmj/344/bmj.e1602.full.pdf>

<sup>8</sup> <http://www.campaigntoendloneliness.org/wp-content/uploads/Loneliness-Harms-Health-campaign-launch-October-2012.pdf>

*“Dear Paul (researcher), you are my only contact. I see the GP’s and the nurses in the N/S RI and seen also the consultants, usually a different one each visit. I went the Haywood Hospital last June and was told I would go again in 6 month, still not heard from them. The staff there were very helpful. I had someone from Longton Cottage Hospital to see me and put me to (illegible) which were very helpful. Apart from the above, no one else has come to see me in 6 years”*

*Questionnaire Return 33*

Some of the elements that make this group distinct in their pathology are less obvious. The elderly have been shown to have the lowest levels of health literacy in a city which has low rates of literacy overall. This is important because some patients have been found not to understand the information presented in discharge letters, leaving them utterly reliant upon staff<sup>9</sup>. A lack of a support network would make this even more pronounced. In this study, only 30% of respondents said as they had participated in support groups.

*“A third of older adults have difficulties reading and understanding basic health related written information. Poorer understanding is associated with higher mortality. The limited health literacy capabilities within this population have implications for the design and delivery of health related services for older adults in England” - British Medical Journal 2012*

All of this means that Parkinson’s patients need special consideration because they;

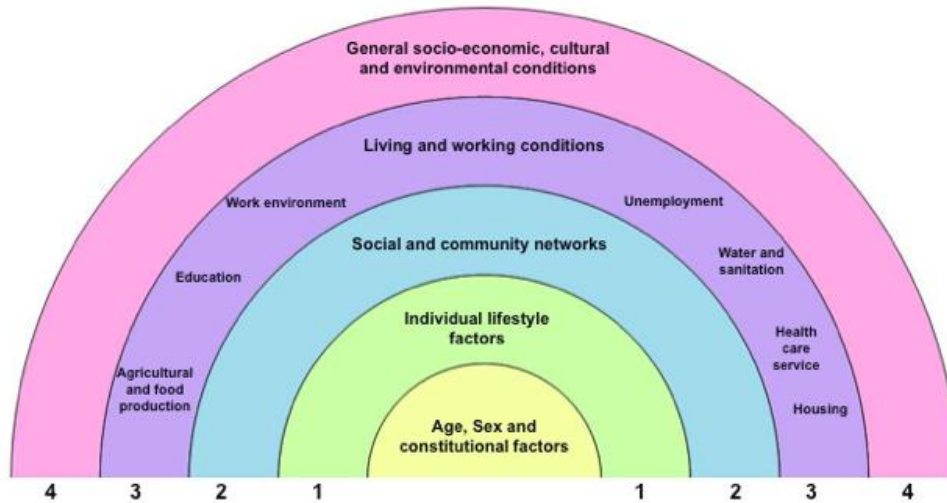
- are reliant upon multi-disciplinary working;
- require increasing amounts of support as the condition worsens;
- are helped by informal networks and professionals who might find the condition difficult to understand;
- are less likely to have a support network;
- are likely to have issues beyond Parkinson’s;
- are more likely to have low health literacy;

With earlier diagnosis meaning that more people are being referred into Parkinson’s services it seems important to consider more than the clinical when commissioning services, it needs to be patient centred in a way which acknowledges the social when delivering clinical needs.

<sup>9</sup> Groene et al, 2012, An Analysis of Vulnerable Patient Handover Practices at Discharge from Hospital, BMJ



## Context – Social Determinants of Health



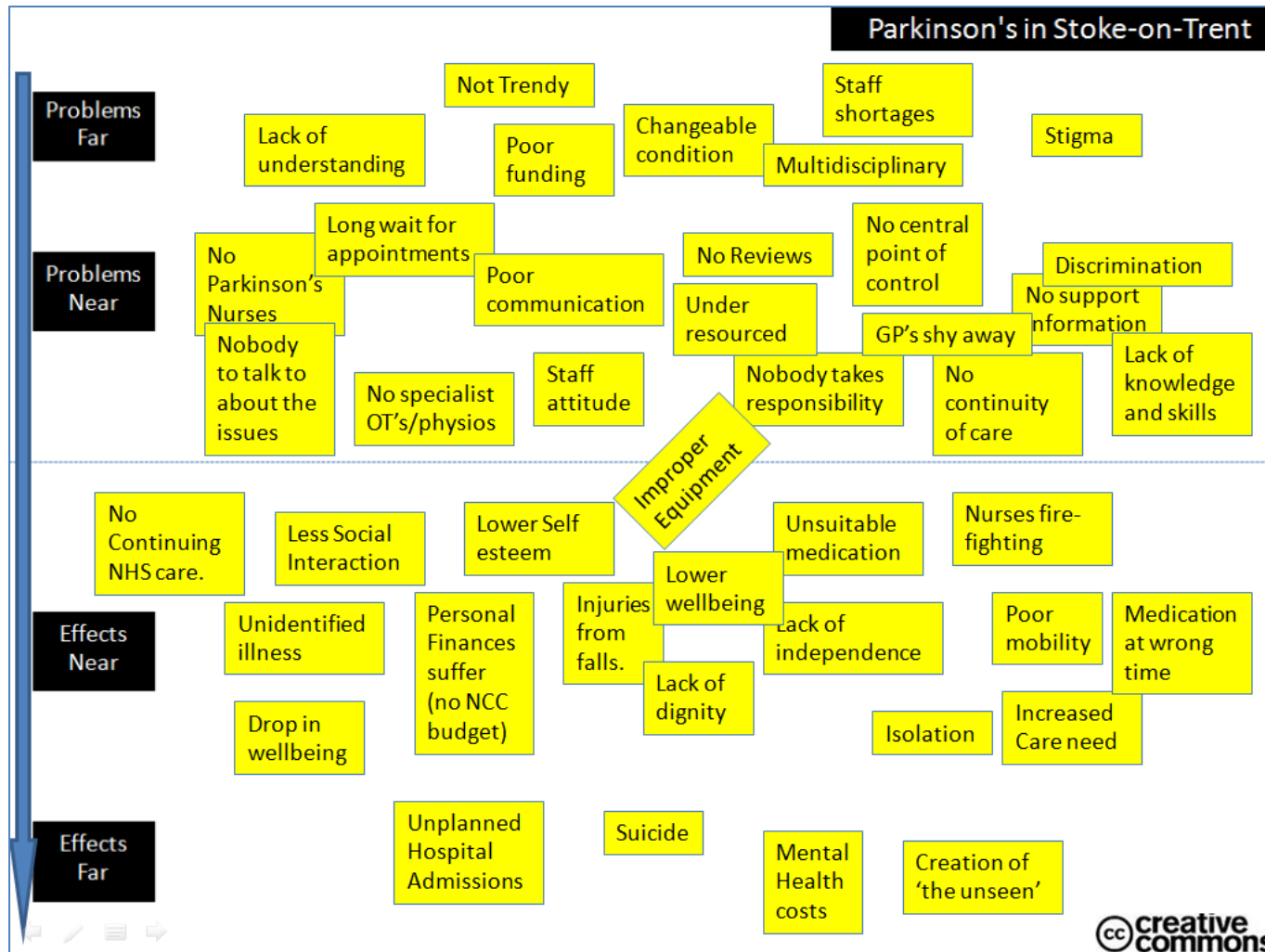
Dahlgren & Whitehead 1991 Policies and strategies to promote social equity in health. Stockholm: Institute of Future Studies.

The Social Determinants of Health are important in this report; they are illustrated in the above diagram. For example, unemployment could impact upon wellbeing and mental health; poor housing could affect physical or mental health. A successful discharge from hospital will be impacted upon by many of the above, for example, an individual who has poor social and community networks would be more vulnerable after leaving hospital without proper support from services. Crisis is often seen to come about when personal, informal networks fail; this is when services fill the gap.

*“I arranged for a carer (neighbour) before I returned (from hospital) and also have a wonderful friend and helper living next door. I consider myself most fortunate.”*

*Questionnaire Return from HW Stoke  
Discharge Project - 32*

## Context - Problem Tree



The stakeholder group had a session to explore some of the issues surrounding Parkinson's. The diagram on the left is the result of this workshop.

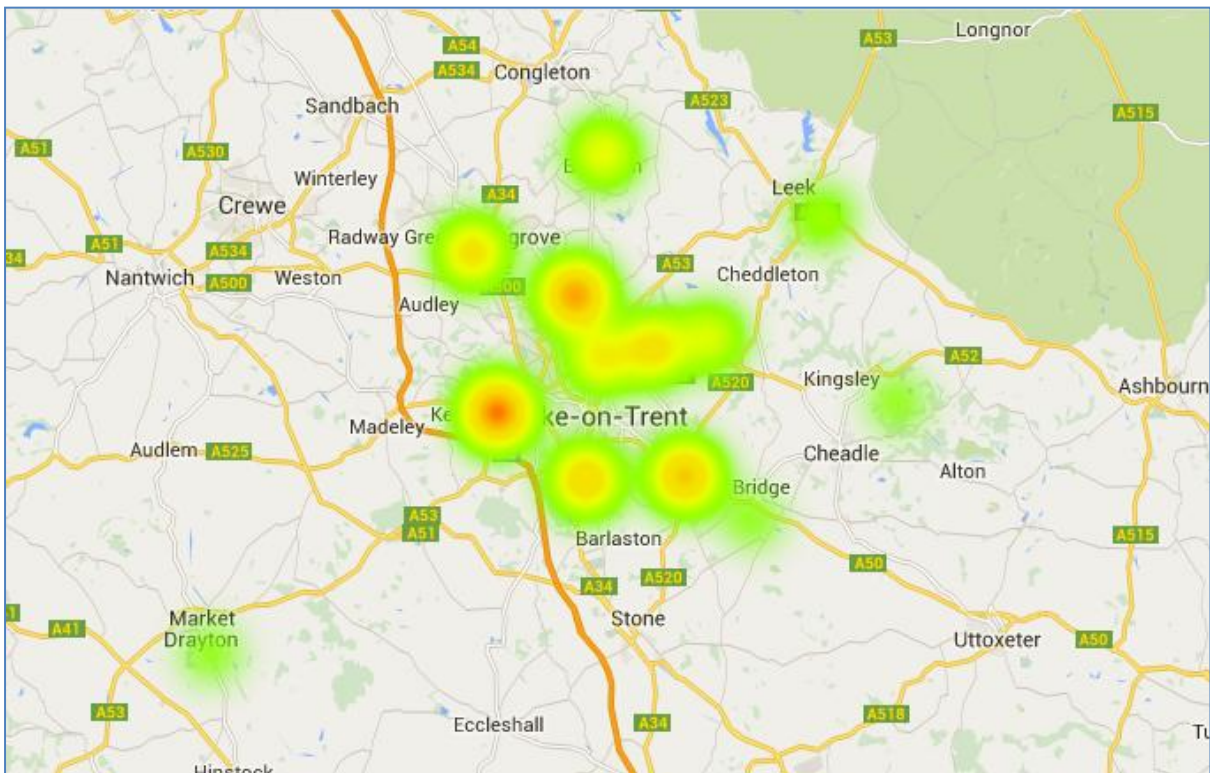
Items at the top of the diagram are said to be the far cause of problems with those towards the centre, problems which are closer and easier to tackle. Underneath this are the effects of these problems with the 'far' effects being the final result.

Much of what can be seen in the diagram is reflected in the context section (p12)

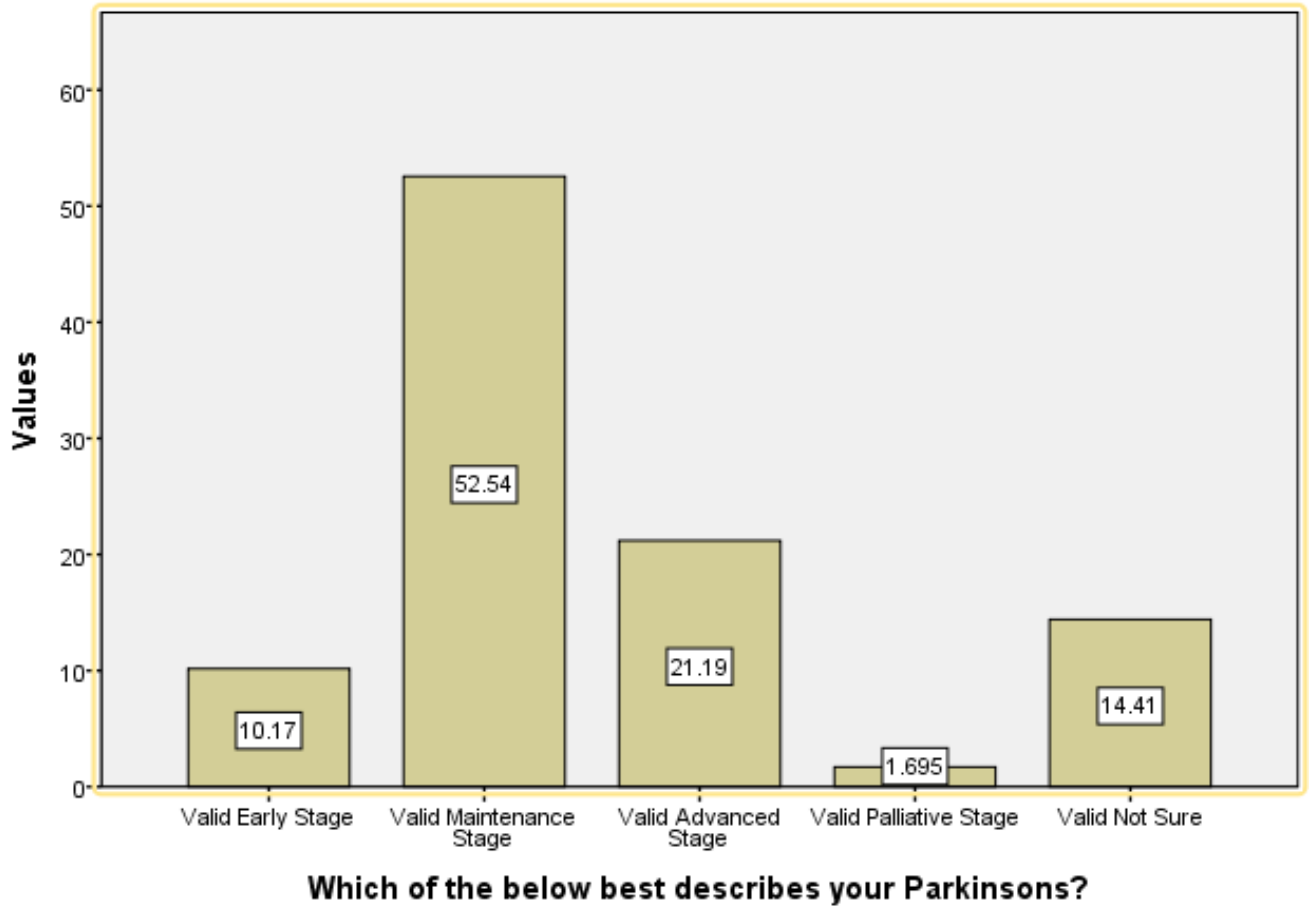
## Appendix 1 - Results

### Our respondents.

- There were 120 respondents made up of 116 paper returns and 4 via an internet-based survey. Some of these were partially filled in. There are also a variety of comments which can be found from page 40.
- Average age of respondents was 73.
- The respondents are spread across Stoke-on-Trent and Newcastle-under-Lyme. The below heat map uses the first part of the patients postcode to roughly plot their locations.



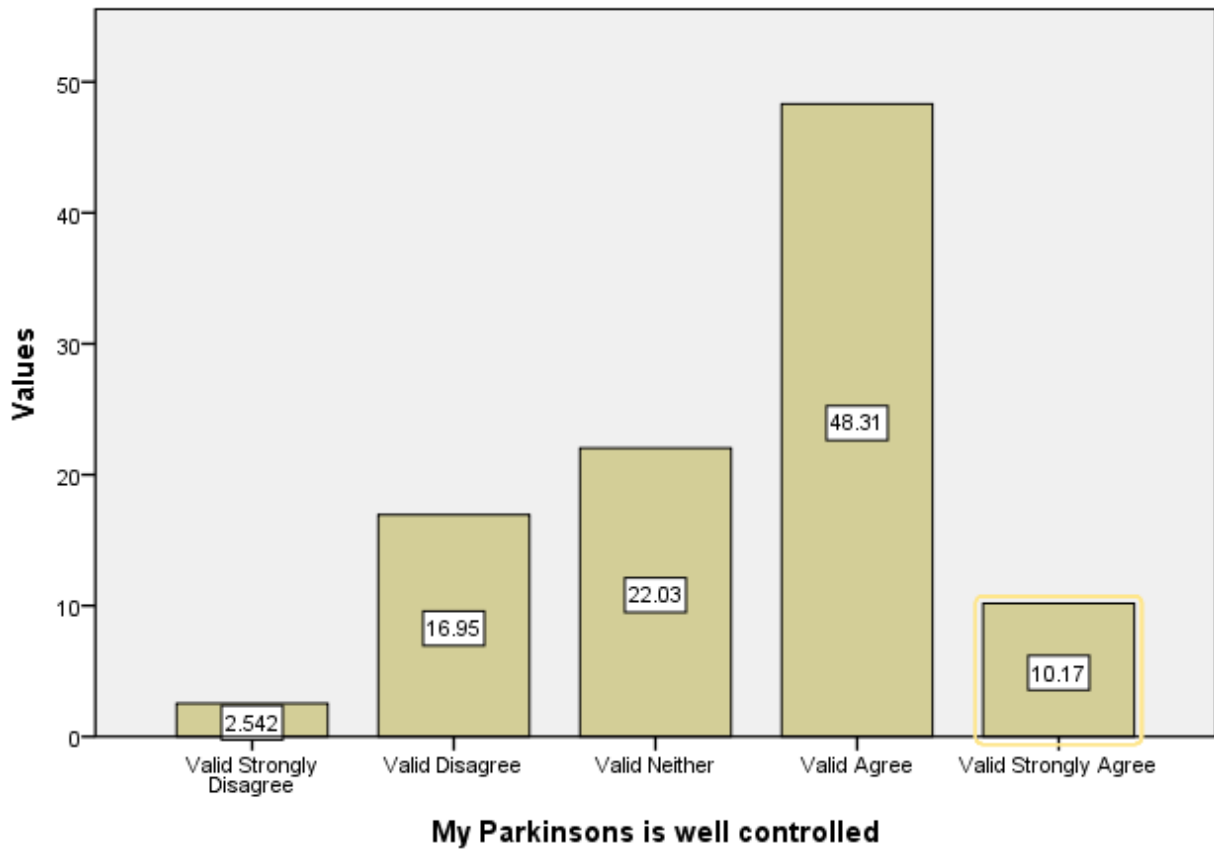
**Which of the below best describes your Parkinsons?  
Valid Percent**



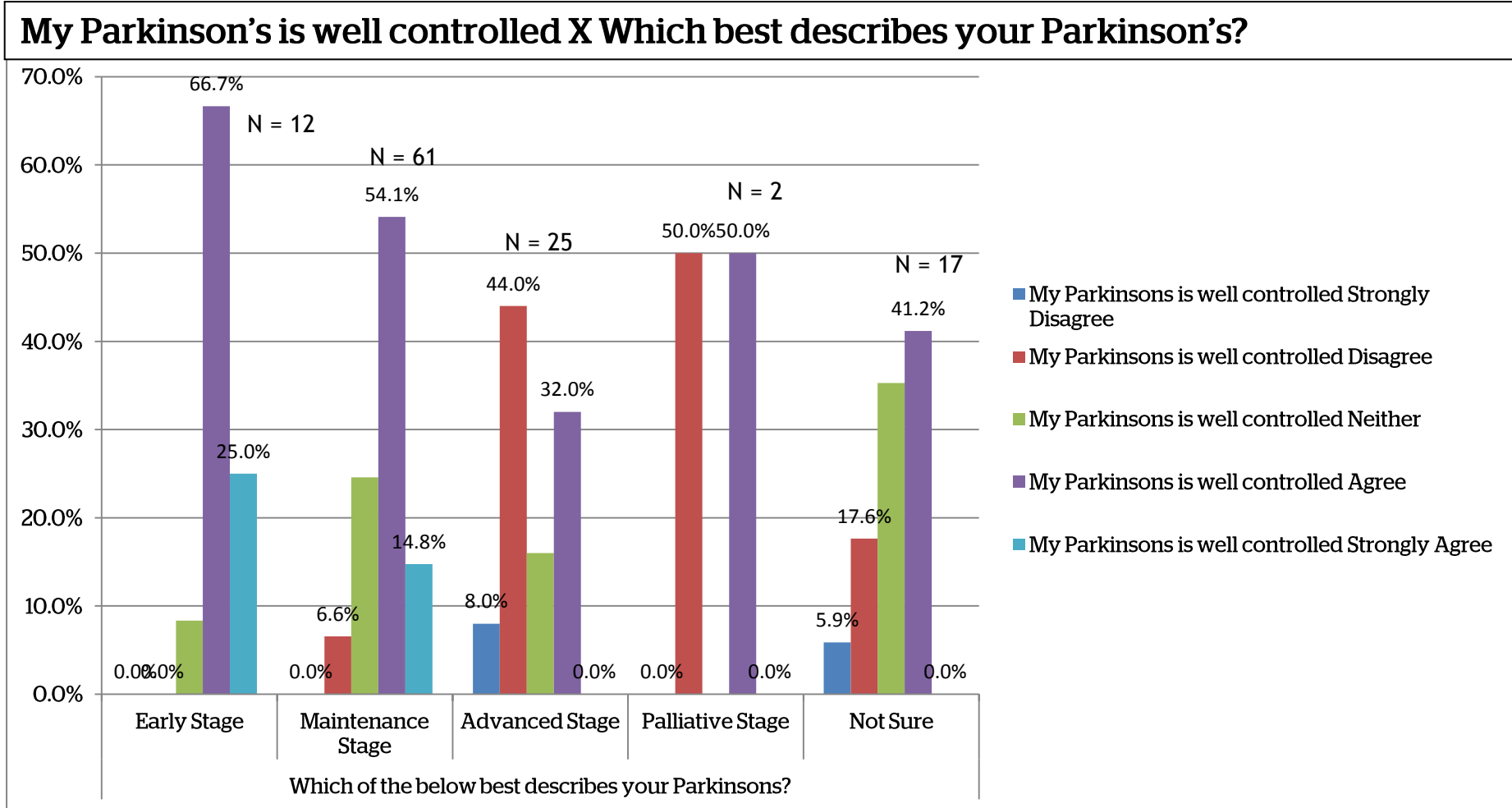
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Of those who answered this question, half described themselves as having maintenance stage Parkinson's. 21%, or 25 people described having advanced stage. 10% are relatively new to Parkinson's with early stage and 15% were unsure. This 'not sure' group is useful as it can be used as a control.

**My Parkinsons is well controlled**  
**Valid Percent**

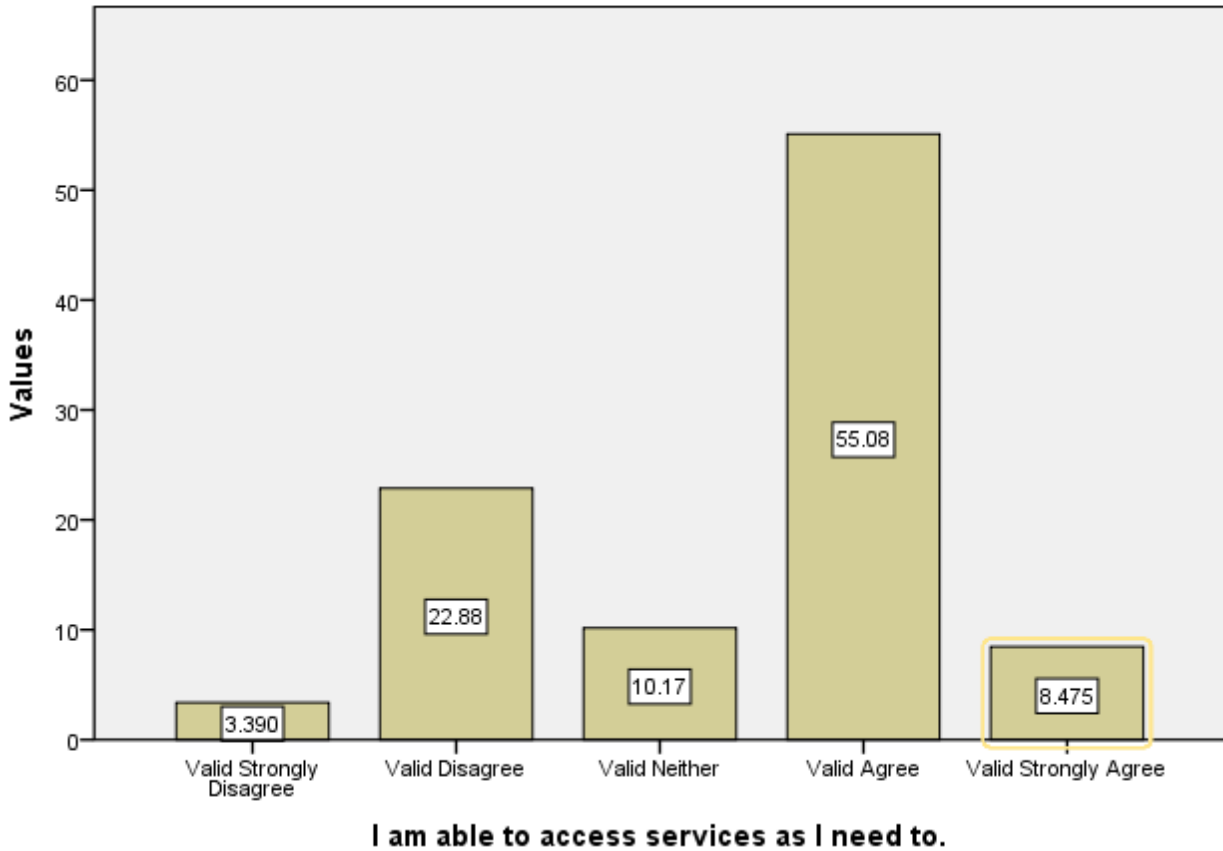


Over half, 59.5%, described their Parkinson's as being well controlled and 19.5% disagreed that this was the case. Just under a quarter found this difficult to define.



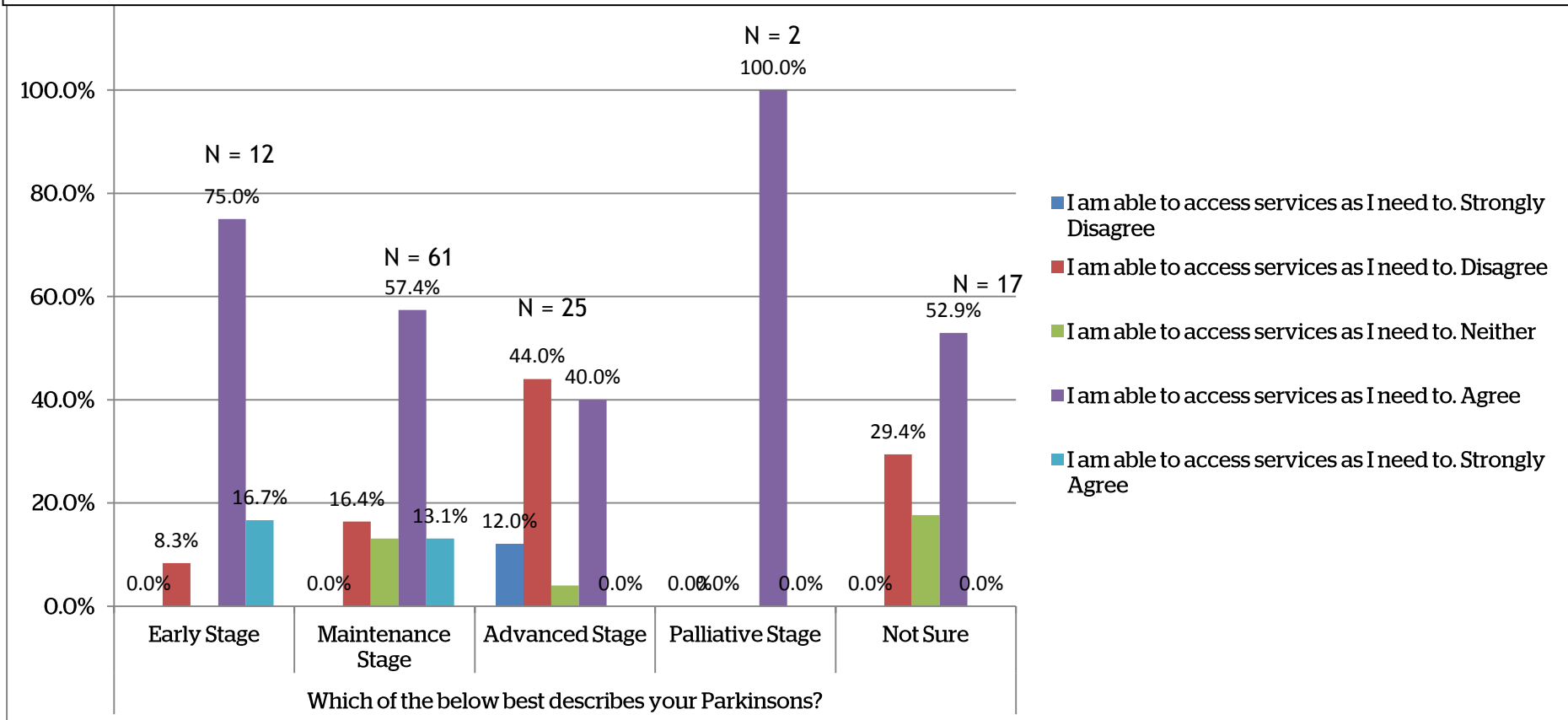
Amongst the cohort, there is much variation responses when asked how well controlled their Parkinson's is. Here it can be seen that although 92% of those who describe themselves as having the condition in its early stages agree that it is well controlled, this is in stark contrast to the advanced stage group with 52% disagreeing that this is the case. A clear pattern is identifiable apart from palliative stage, whose numbers are too low to be considered relevant.

**I am able to access services as I need to.**  
**Valid Percent**



63.6% of respondents described being able to access services as they need to. Just over a quarter, 26.3% disagreed that this was the case.

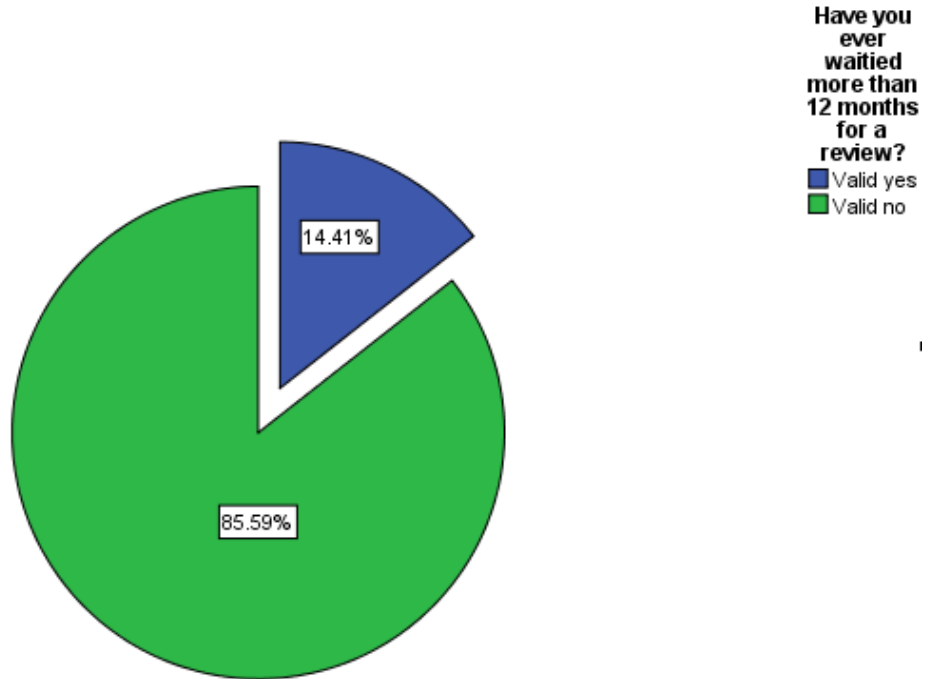
## I am able to access services as I need to X Which best describes your Parkinson's?



The above table shows a pattern in which the ability to access services as required falls away from early stage, in which 91% agreed that access was sufficient, to 40% with advanced stage. In the advanced group 56% of respondents reported disagreeing that they could access services as required. Palliative stage has numbers too low to suggest an identifiable trend.



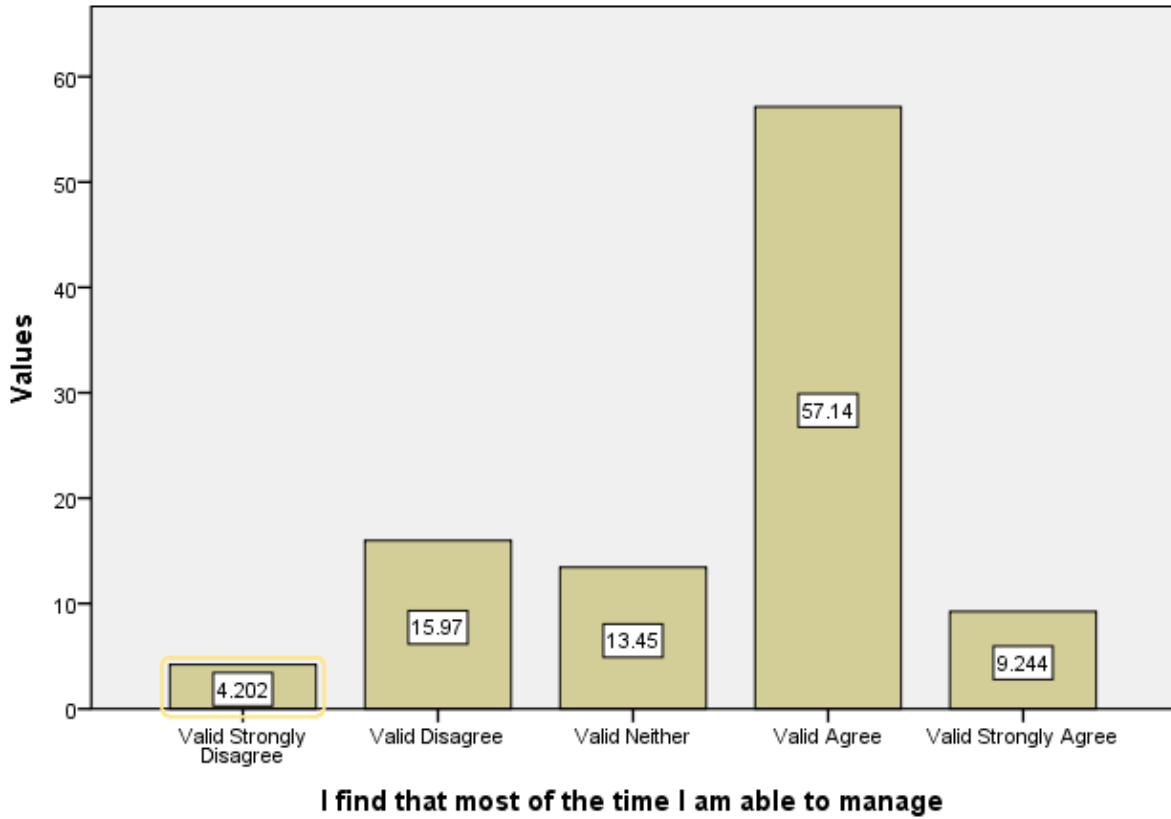
**Have you ever waited more than 12 months for a review?**  
Valid Percent



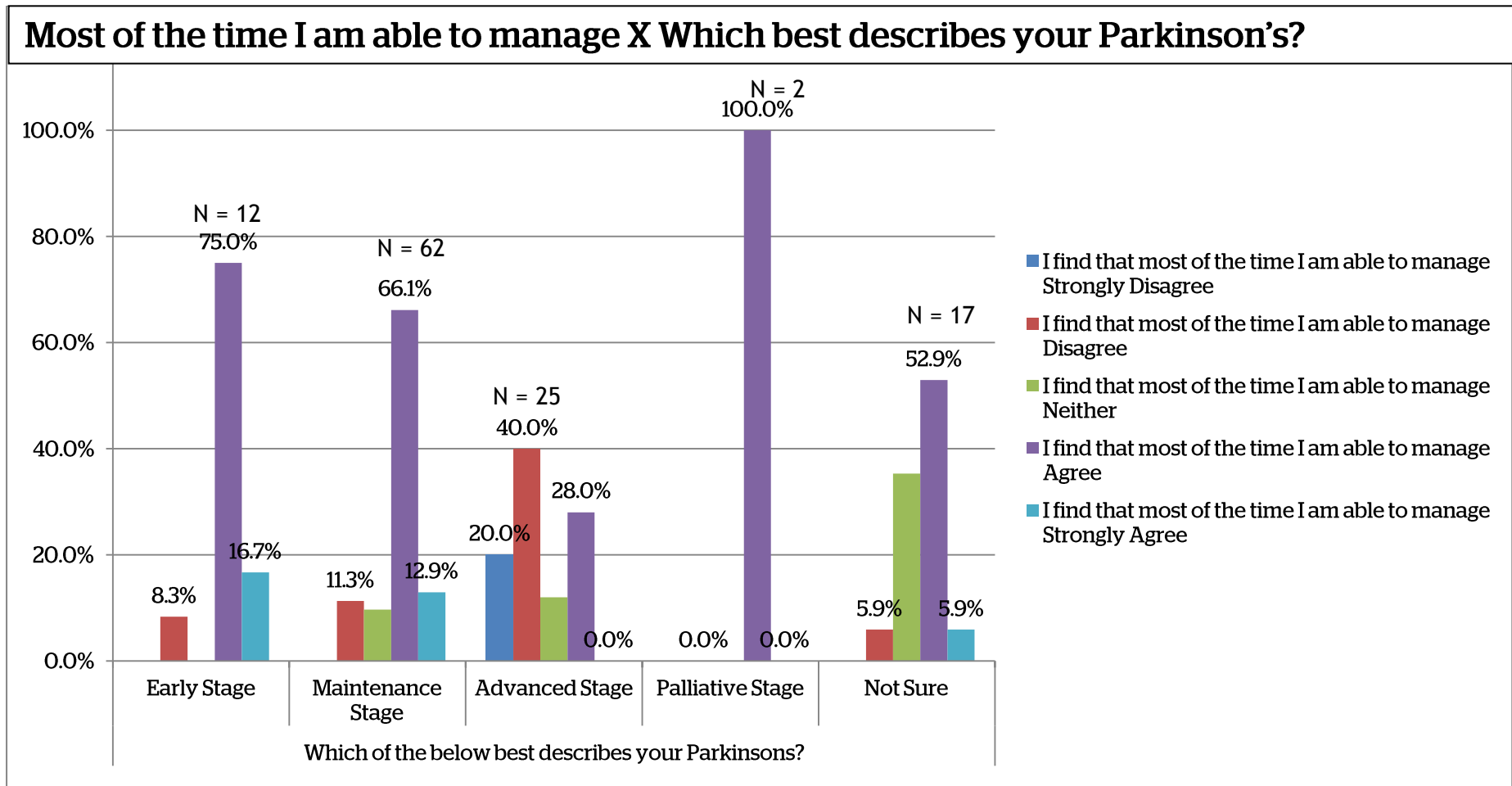
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Overall 85.6% of patients said they had not had to wait beyond 12 months for a review. 14.4% reporting having done so.

**I find that most of the time I am able to manage**  
**Valid Percent**



Overall 66.3% of respondents reported being able to manage most of the time. Just over 20% disagreed with this statement.



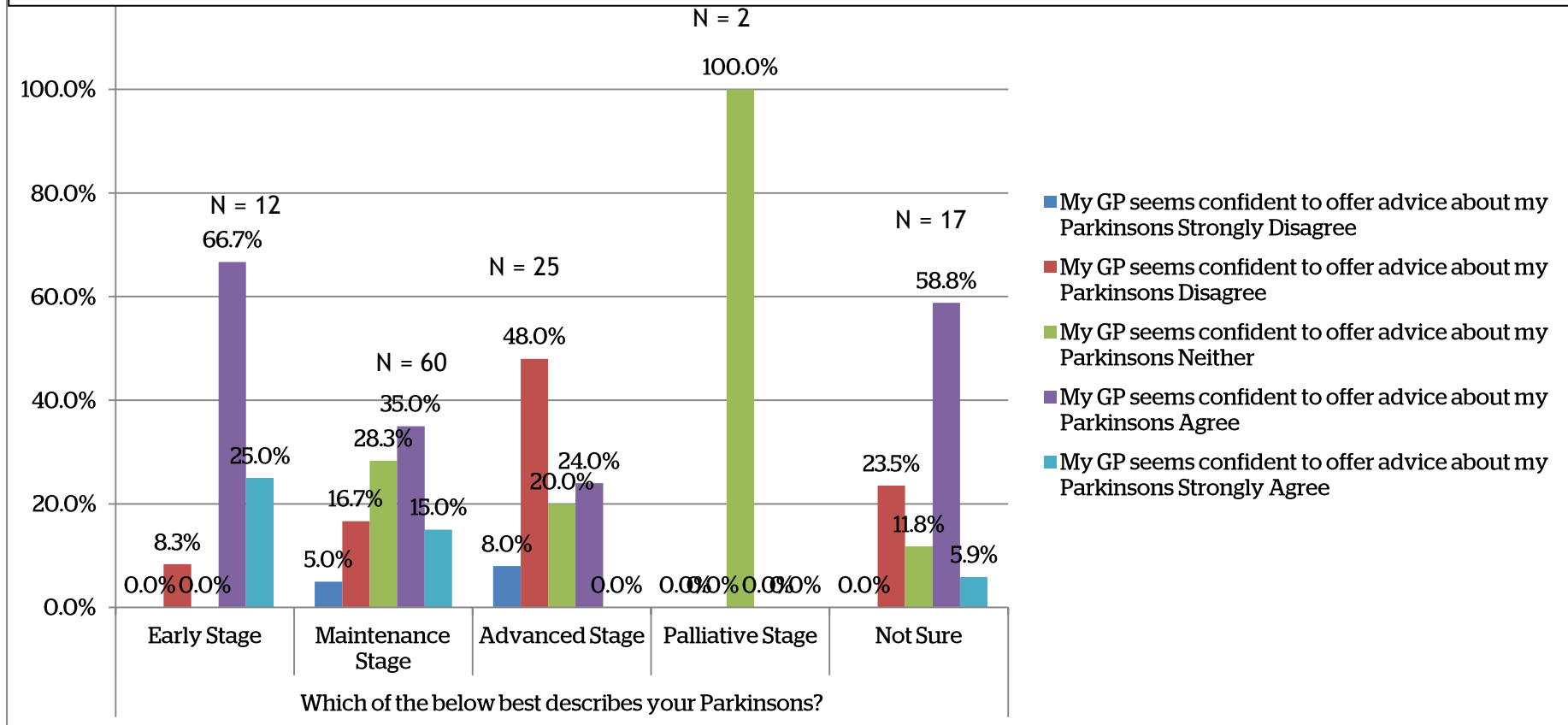
The above table shows that although early stage Parkinson's report being able to manage well (91.7%), this falls away as the condition progresses to 79% in those with maintenance stage and only 28% in advanced stage. 60% of people with advanced stage Parkinson's disagreed that they are able to manage.

**My GP seems confident to offer advice about my Parkinsons**  
Valid Percent



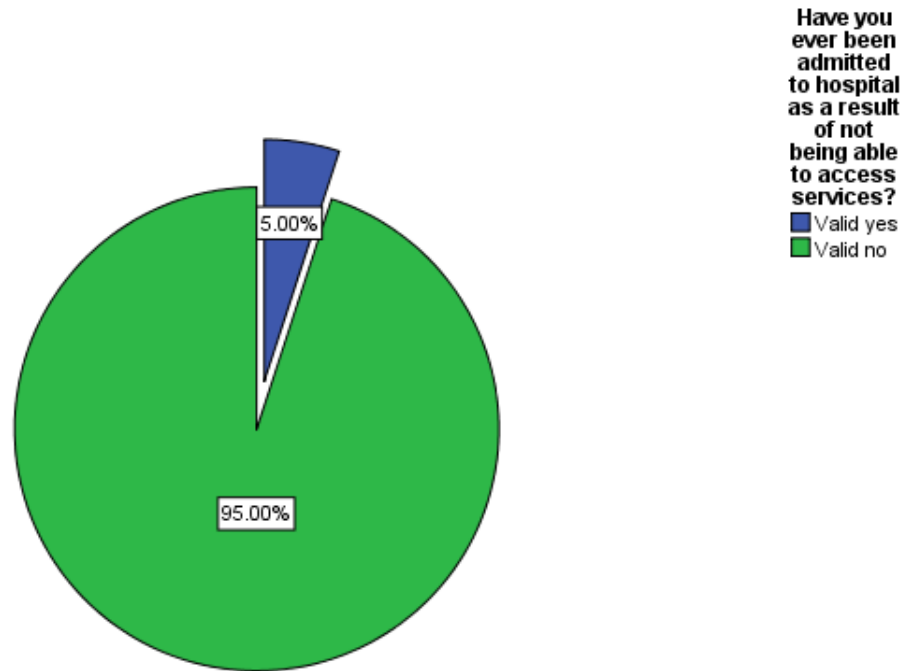
Overall, just short of half of respondents (49.2%) agreed that their GP is confident to offer advice about Parkinson's. Over a quarter (28%) disagreed that their GP seems confident to offer advice about Parkinson's.

## My GP seems confident to offer advice about my Parkinson's X Which best describes your Parkinson's?



Within the cohort there is considerable variation in how they perceive their GP's confidence in dealing with Parkinson's disease. 91.7% of early stage agreed with the statement but this falls away to 24% in those with advanced stage, 56% disagreeing. Indeed, in the maintenance stage group, 21.5% disagreed that their doctor seemed confident to offer advice about their Parkinson's.

**Have you ever been admitted to hospital as a result of not being able to access services?...**



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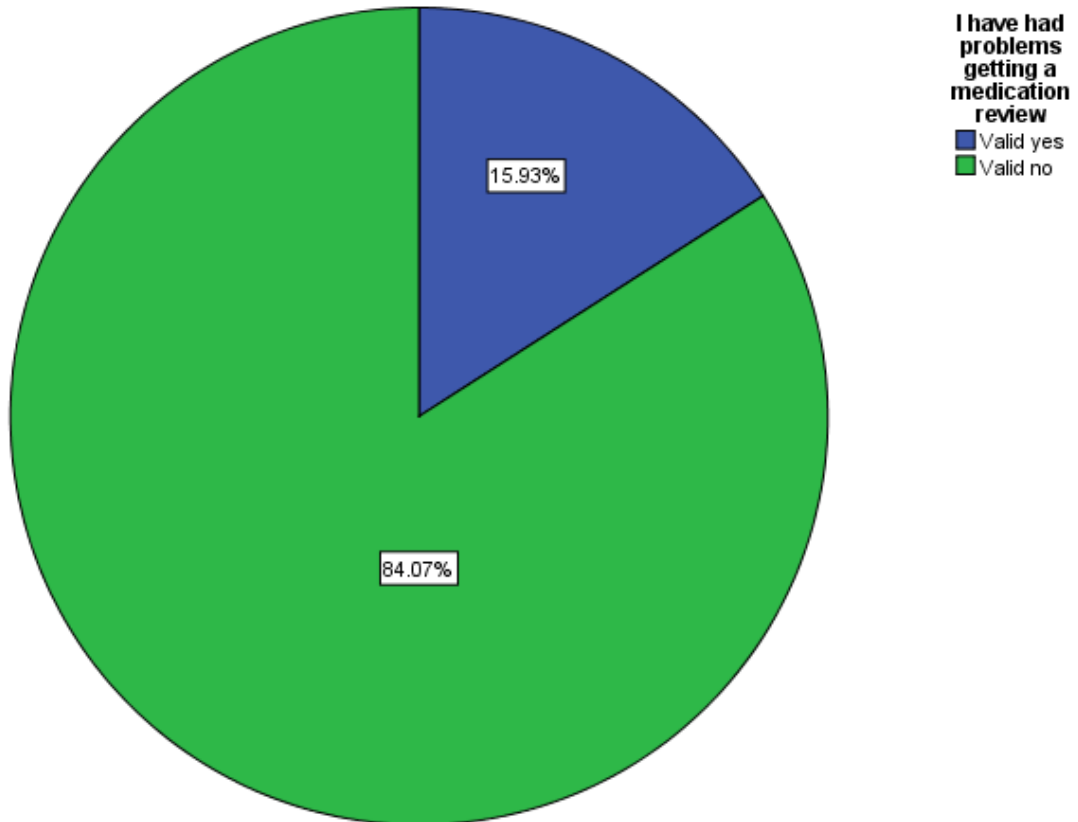
A small number of respondents, 5%, reported being admitted to hospital as a result of not being able to access services. 3 Maintenance Stage, 2 advanced stage and 1 not sure. Four of the five reported a total of 175 nights in hospital.

**Whilst in hospital, staff seemed familiar with Parkinsons and the help I needed**  
Valid Percent



Of the n=12 who answered this question, only 43.75% said that staff seemed familiar with Parkinson's and the help they needed. The same amount, 43.75% said they disagreed with this statement.

**I have had problems getting a medication review**  
Valid Percent

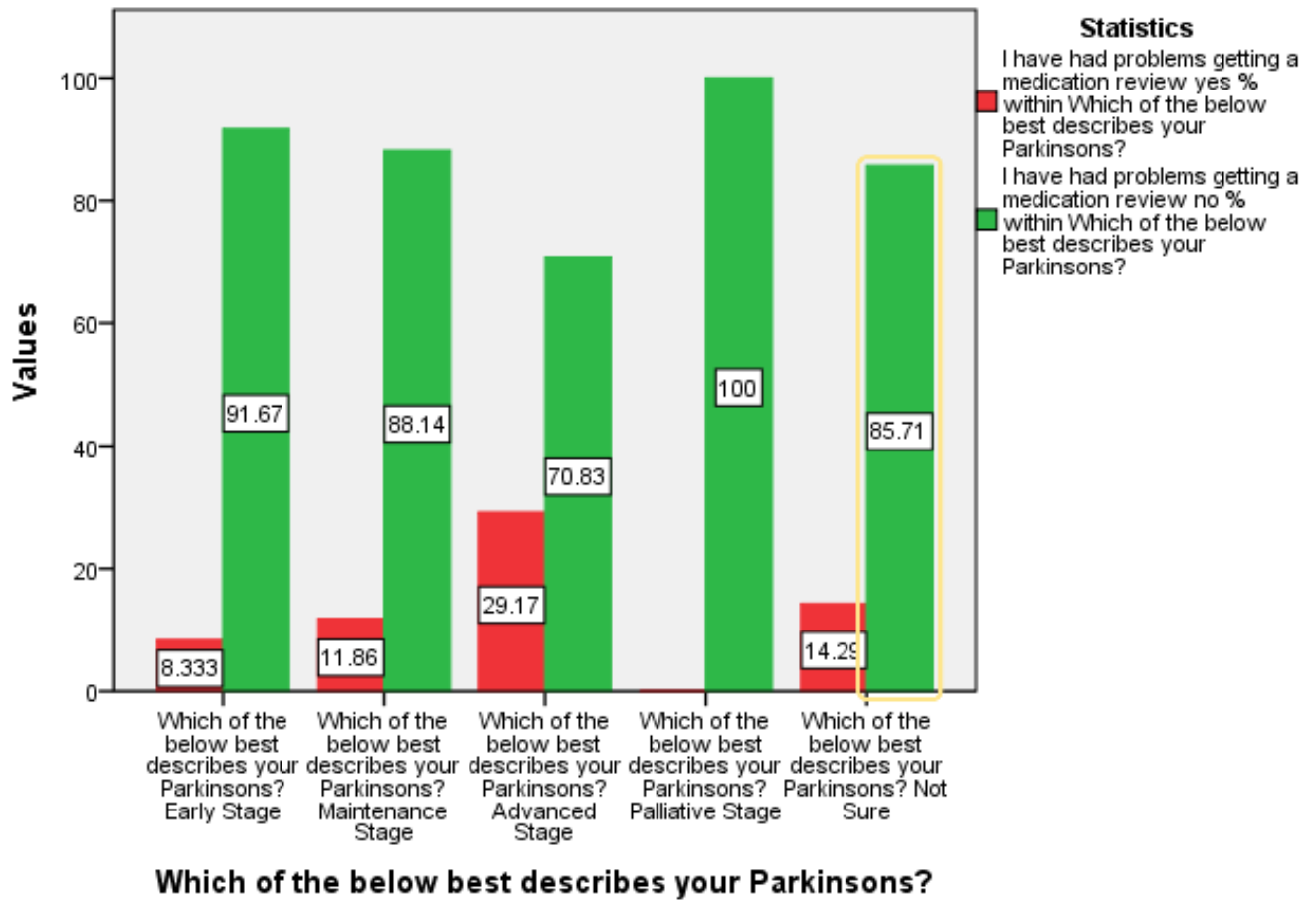


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84% of respondents reported not having any difficulty getting a medication review. 16% reported doing so.



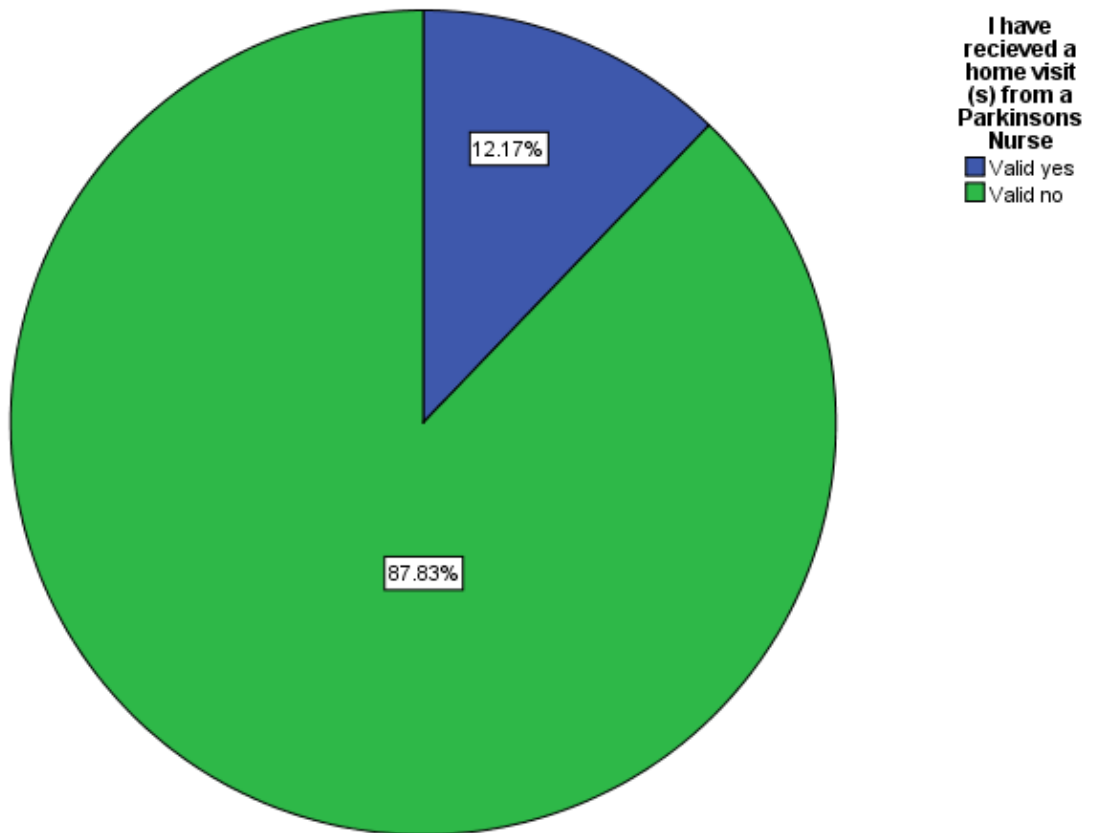
**I have had problems getting a medication review \* Which of the below best describes your Parkinsons? Crosstabulation**



The above table shows that although most have not experienced problems getting a medication review, it does become more likely as the condition progresses. 29.1% of those with advanced Parkinson’s report having had difficulty.

The numbers (n=2) are too small in the palliative group to be meaningful.

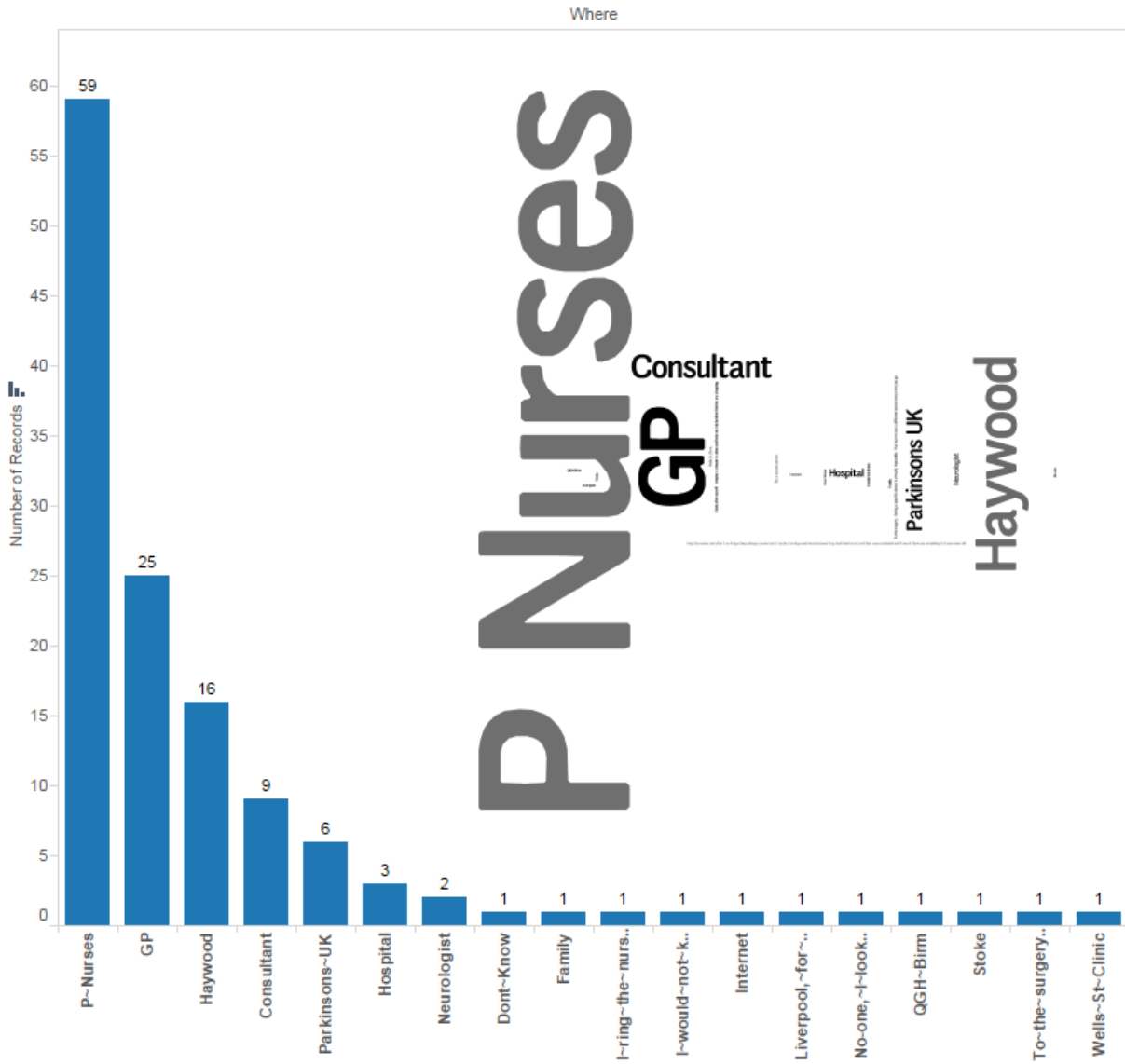
**I have recieved a home visit(s) from a Parkinsons Nurse**  
**Valid Percent**



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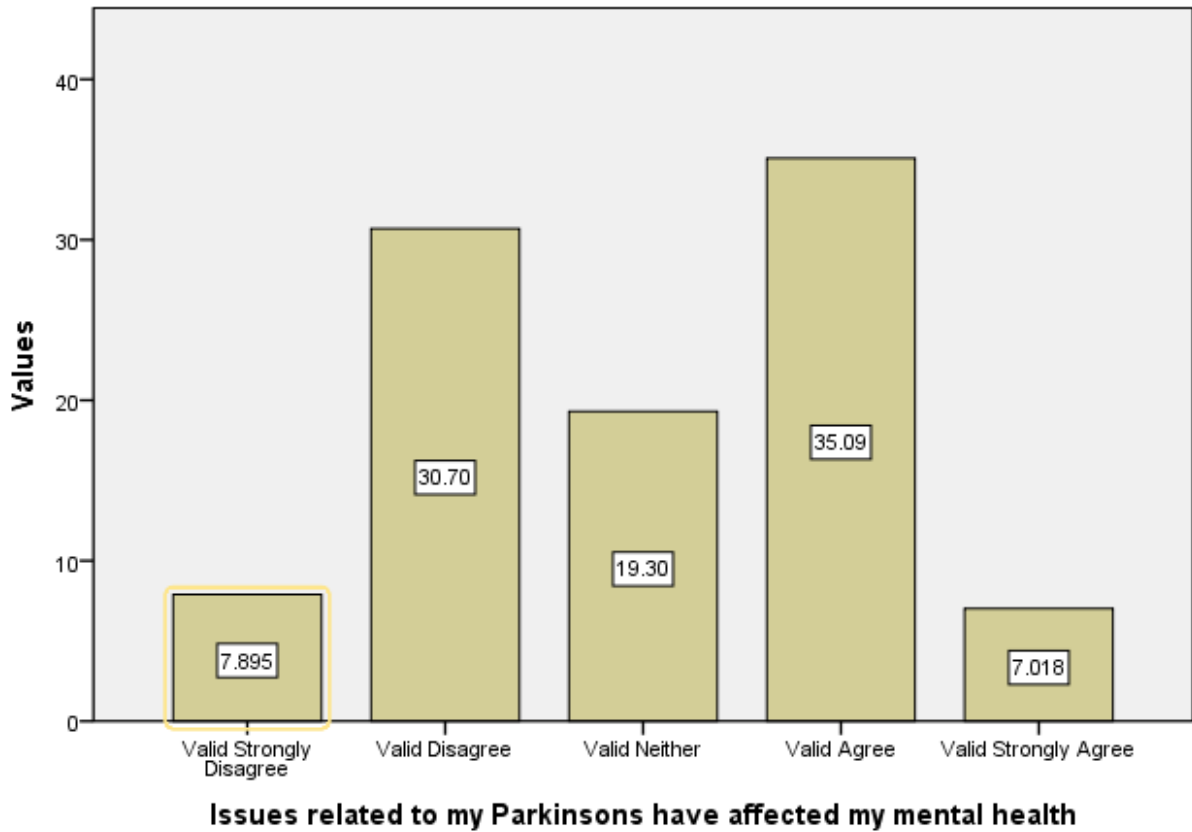
Most people had not received a home visit from a Parkinson's Nurse.

**Where do you normally go for help and advice about Parkinson's?**



When asked where people go for help and advice about Parkinson's the overwhelming majority replied relying upon the nurses, followed by the GP.

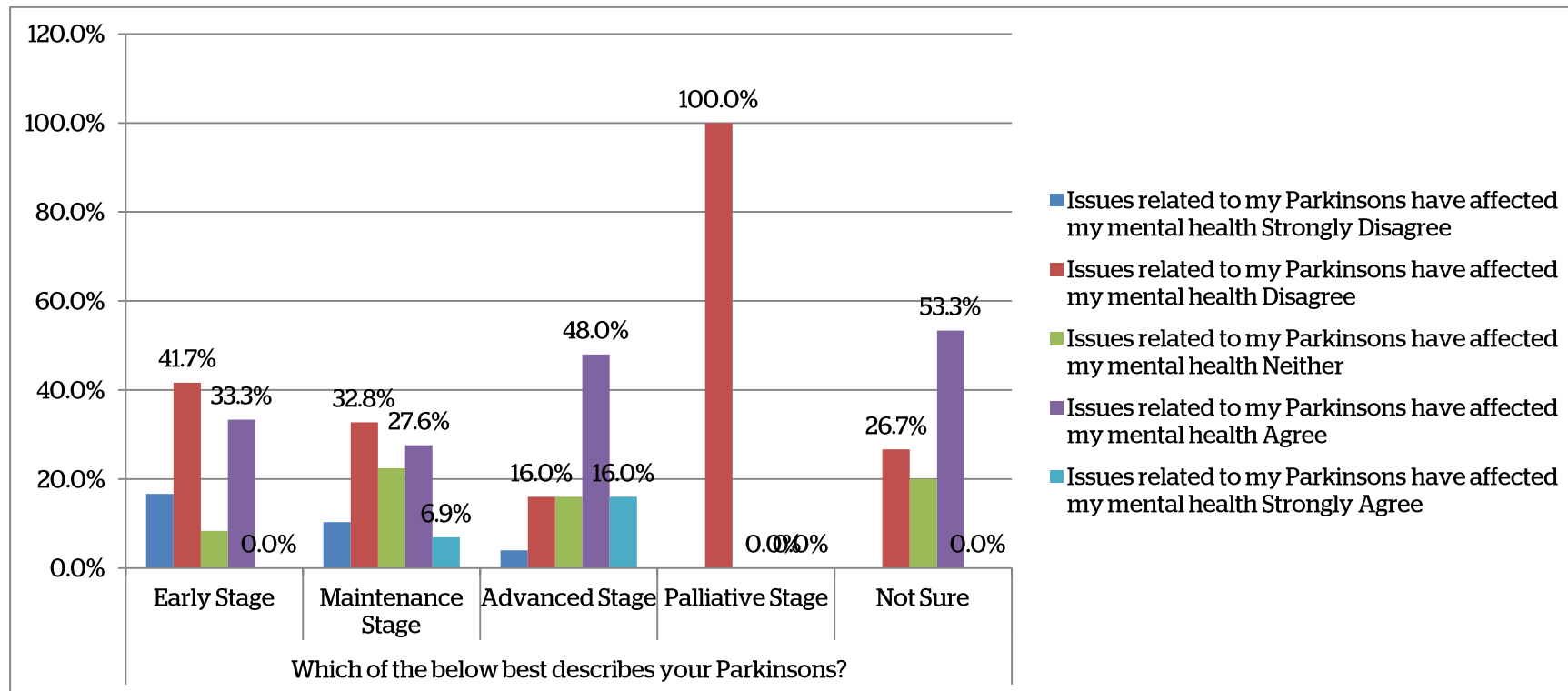
**Issues related to my Parkinsons have affected my mental health**  
Valid Percent



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Overall, 42% of respondents reported that issues related to Parkinson’s disease have affected their mental health. 38% disagreed with this.

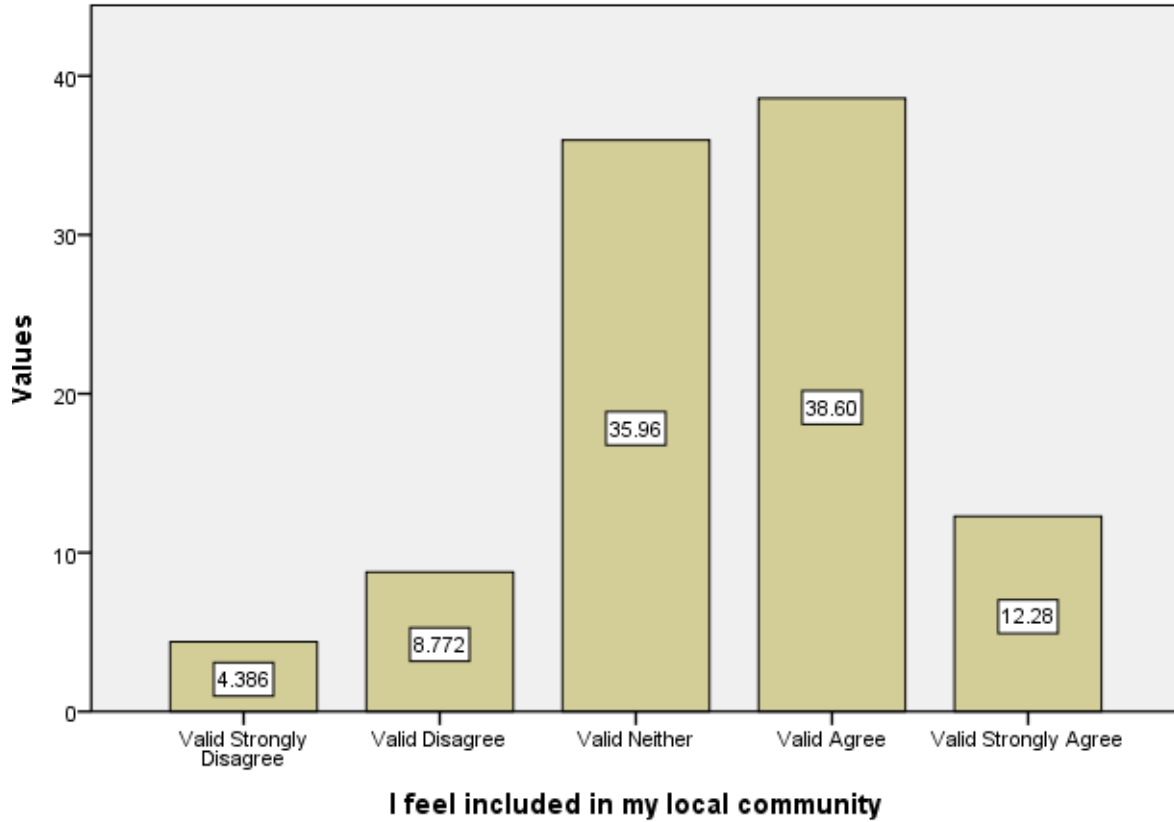
## Issues related to Parkinson's have affected my mental health X Which best describes your Parkinson's?



Both early (33%) and maintenance stage (34.5%) patients described issues related to Parkinson's disease affecting their mental health. This rises to 64% in the advanced stage group. The palliative group has numbers too low to be considered useful.

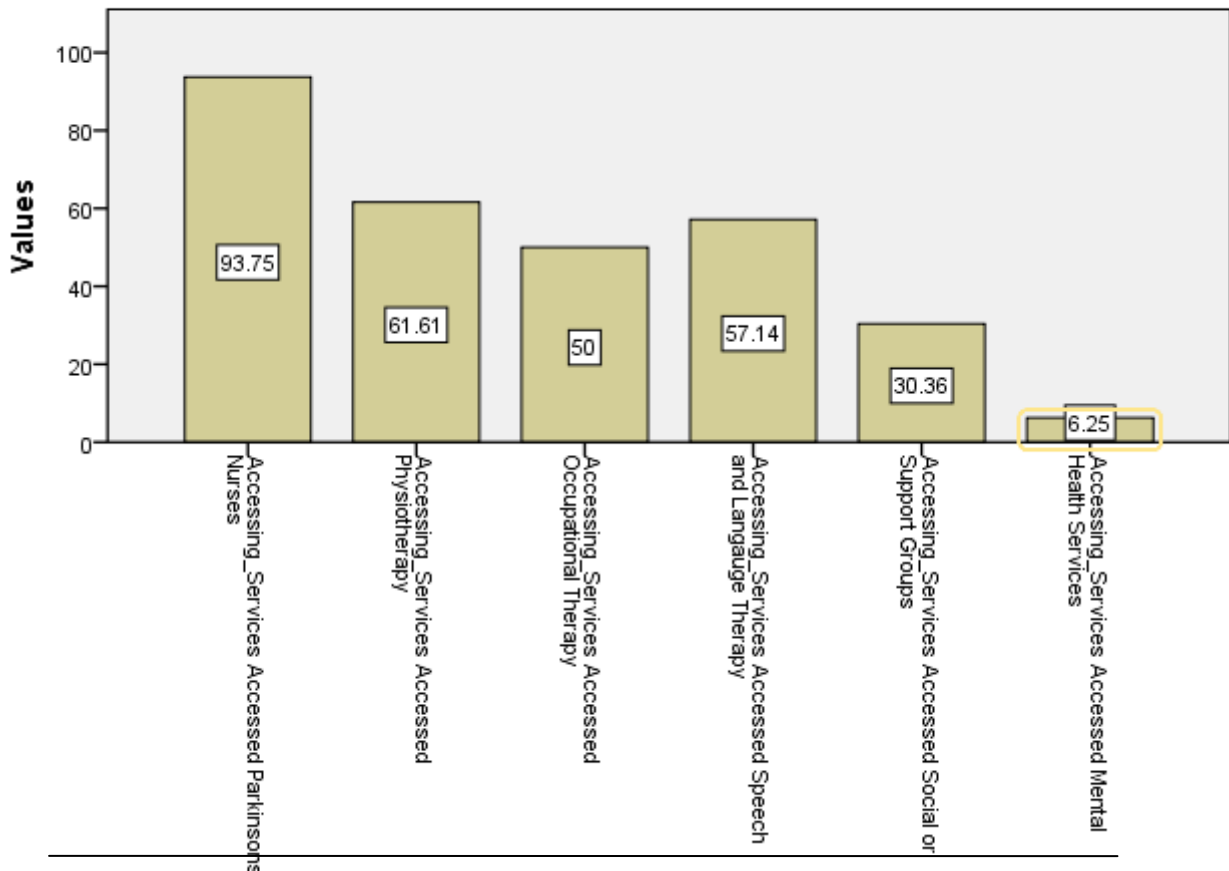
Interestingly 53% of the 'not sure' group which can be considered mixed reported having had their mental health affected.

**I feel included in my local community**  
Valid Percent



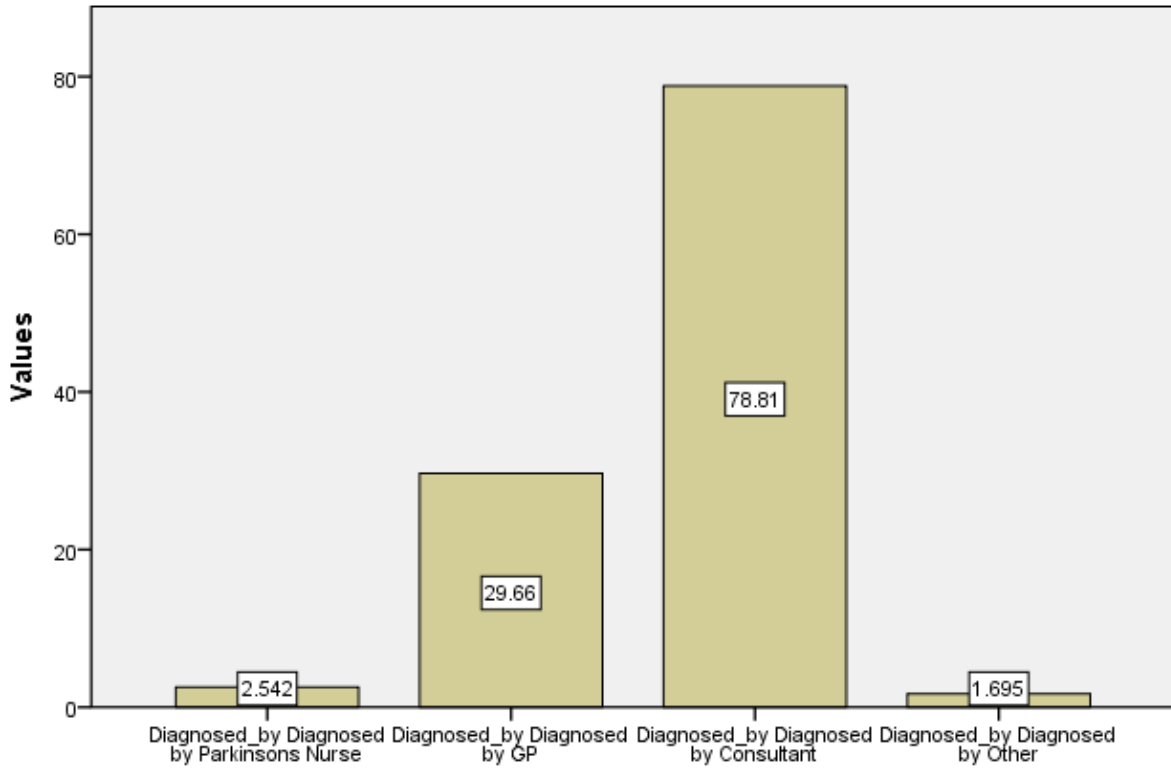
Half of respondents agreed that they felt included in their local community. 13% disagreed that this was the case.

### \$Accessing\_Services Frequencies Percent of Cases

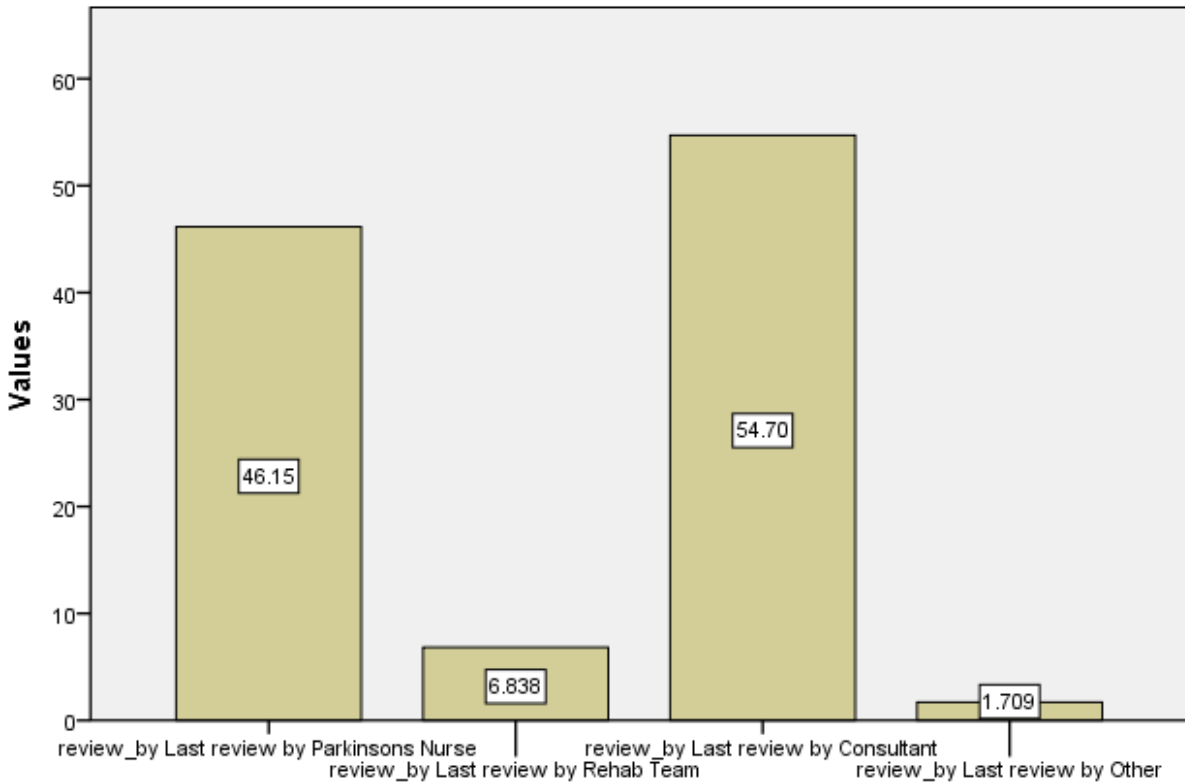


Most patients had seen a Parkinson’s nurse and half or over a physiotherapist, occupational or language therapist. 30.4% had accessed social or support groups. Only 6.25% had accessed mental health services.

### \$Diagnosed\_by Frequencies Percent of Cases



### \$review\_by Frequencies Percent of Cases





## Appendix 2 – Comments

### Hospital

*My husband has Parkinson's disease and has to take medication many times a day. He has been admitted to the Royal Stoke hospital several times over the past two years with problems unrelated to Parkinson's. This is a worrying time for me as the nurses don't seem aware of the importance of Parkinson's patients having their medication at the correct times and ON TIME as well as making sure they take it. As my husband has to receive Parkinson's medication at seven different times of the day, I know firsthand that it can be difficult to remember every time. Therefore I have purchased an alarm from Parkinson's UK which I find is of great benefit and feel something like this would be a great help to the nursing staff and have suggested this to them but they do not take it on board. As my husband is not able to self medicate, on occasions I have arrived at visiting hours to find medication still by the bed and sometimes on the floor. On another occasion my husband's medication was due after the ward drug round. At the time when his medication was due, I enquired, was told he have been given it and shown his chart with the drugs signed off as taken. Thankfully the Nurse I enquired with had due diligence to check with her colleague who had signed off the drugs as had been administered, she told her that the medication was locked in the drugs cupboard to be given at the correct time as she was on her break. This is a worrying situation that the drugs had been signed off and not administered. In children's wards parents are allowed to stay with their children. I cannot see why this cannot be adopted for people with the type of illness that my husband suffers from especially due to the complex nature of the condition. I believe this would be of benefit to both patient and nursing staff. I also feel that to have a relative with them as much as possible is a great help to patients as I have stayed with my husband when allowed - not all the wards will let you. I appreciate that ward staff are under pressure but a relative with a person with advanced Parkinson's condition could offer support and reassurance to the patient and be of assistance to answer any questions, for example, during ward rounds. There also seems to be a lack of Parkinson's nurses at the hospital. When my husband was in hospital last September for three weeks I know the ward asked for the Parkinson's Nurse to contact them for specialist advice and to my knowledge they did not get in contact. We live mid way between stoke and derby, over ten years ago my husband was referred to a consultant at derby hospitals by our GP. There appease to be a lack of communication between hospitals. Whilst in hospital also noticed the following. Why is it that patients are moved around the bays on the ward? This is most distressing for Parkinson's patients who like familiar surroundings and moving them leads to confusion. The changeover sometimes is in the evening when patients are settling down for bed. Is there any need for this? I'm sure this does not help their recovery.*

**Letter Received**

*Although quite well now, I had a terrible experience last year. I was on morphine patches, pain killers for my back pain and my medication for Parkinson's was increased. There was a mistake on the quantity on my behalf on how much I was taking. My GP confessed that he knew very little about Parkinson's disease and so I was accidentally overdosing. The outset was I suffered horrendous hallucinations for weeks plus a really bad fall gashing my leg deeply. After another two falls I was admitted to Longton cottage hospital where they sorted out all my medication and so now thank god, I am much better. I now live in an elderly care village which has 24 hour care when needed. It has a very safe and friendly environment and has given me a new lease of life.*

**Questionnaire Return 53**

*I had a short stay in hospital last year. I was diagnosed with Angina. I was in overnight and had my normal medication in morning. I was admitted and did not receive any more medication for 24 hours. I begin to wonder if anyone understands a thing about Parkinson's.*

**Questionnaire Return no 16**

*(Q5 Access to Parkinson's Services) Other than nurses who are good don't know any other. (Q16 Mental Health) Only when hospitalised then have bad hallucinations and people seem to think that's the real you and don't listen. Wife insists they see the real me. (General Comment) In hospital now waiting to go to rehab. Nurses do not know the importance of medication (on time). They say they do but don't follow through. This stay tablets were always late, wife would ask about 3 o'clock, meds at 3.15, told given early at 2.45, wife said she's seen none given at 3.45, came and apologised, she'd forgotten to give them. At 6pm asked if wife would be here for 7pm meds, said could be. She said 7pm was handover and everything gets put back because of it. So could wife give them, said ok, same all the time.*

**Questionnaire Return no 4**

*I wanted to explain that \*\*\*\*\* has had operations for prostrate, kidney stones and hernia repair. As a result of the aesthetic/pain represent, his Parkinson's goes off the scale and doesn't remember anything about what we was like after operations until he then after quiet a few days, does he go back to pre-operation. My point being quite a lot of nurses do not know how anaesthetic affects Parkinson's disease.*

**Questionnaire Return 111**

## Appendix 2 – Comments

### Services and Access

*Dear Paul, You are my only contact. I see the GP's and the nurses in the N/S RI and seen also the consultants, usually a different one each visit. I went the Haywood Hospital last June and was told I would go again in 6 month, still not heard from them. The staff there were very helpful. I had someone from Longton Cottage Hospital to see me and put me to (illegible) which were very helpful. Apart from the above, no one else has come to see me in 6 years. All the people who I am in contact with are all very good and appear to know what they are doing.*

**Questionnaire Return 31**

*This not being done by Mrs \*\*\*\*\*. I am her husband and do it because she is not able to control her limbs. As far as Parkinson's is concerned, we have no help or advice from anyone. I am full time carer on my own. It is becoming increasingly difficult to come as the Parkinson's worsens every day.*

**Questionnaire Return 76**

*(Q15) See neurologist 6 monthly but only deals with medication. Parkinson's nurse available but extremely busy as x2 cover such a large area MORE needed. Should see 6 monthly in between neuro appt but this always goes and we mostly contact them. (we'll leave message and they get back to me)*

**Questionnaire Return 81**

*After attending an appointment with one of Dr Ellis assistants in March 2014, with regards to my stop-go foot problem. I received a report stating as I would be recalled in 4 months. I am still waiting!!!*

**Questionnaire Return 84**

Contact [Paul.Astley@healthwatchstoke.co.uk](mailto:Paul.Astley@healthwatchstoke.co.uk) for more information.

*About 2/3 years ago I wanted to speak to the Parkinson's Nurses. Telephone messages were left but no phone back. I assume that this has improved . They try to contact me for 3 month visit in between consultant visits but it does not always happen. I have been several times to the physio section at the Whitfield centre. Very good and helpful. I see consultants every 6 months and feel that this is correct and should be ongoing. I ask for a copy of consultants report but this doesn't always happen. In the early stage of Parkinson's I had a lot of assistance from \*\*\* (Parkinson's UK Officer), support worker . I also have a high opinion of the Parkinson's nurses.*

**Questionnaire Return 114**

## Appendix - Comments

### General Comments

*(q4) usually reasonable but some days chaotic (q5) much by phone (q6) 2 years when N Staffs reorganise it in the past. Own GP at time also having difficulty. (q8) by phone for advice and request for assessment (q9) current GP seems better informed than me in day to day management (q13) but assigned locum neurologist tend to be tick box approach (q16) We all have the occasional off day, A change of routine can be unsettling for me, otherwise ok. (q17) Has reduced in recent years through immobility. Learn much by phone and second hand contacts. (general comment) I was diagnosed in 2007 and began L-dopa treatment (via madopar) in 2008 (hindsight suggests actual onset began in 2006). A persistent problem is an intermittent distonia of the left foot/ankle which strikes without warning and more recently whole body pain on walking as indicated. My chief supporter is my loyal wife who refuses to be labelled as a carer. Without her loving aid I would be lost. I am no longer able to use public transport because of physical freezing and Parkinson's 'dancing' in confined spaces. My wife does not drive. Also, use of internet is mine alone when physically able, chief source of info here Parkinson's UK; I avoid 'snake oil' sites. I am well aware of the underlying ongoing deterioration and limitations of symptomatic treatment (a source of sadness). My sympathies are with early onset and juvenile sufferers for whom discovery of a cure will be a real life changer. For me, Parkinson's is nothing more than a severe pathological bully who is determined to do me down. I don't give in to bullies, so we will both have to fight on our hands to the end! PS - Internal delays of return written referral letters to GP's etc after clinical appointments a common issue.*

#### **Questionnaire Return 33**

*The service provided by the Whitfield Unit @ The Haywood hospital is very good. They make you feel like a person and not a number. The staff are friendly and also encourage carers. The staff have time for you which makes you feel like part of a family. I would recommend anybody to this unit.*

#### **Questionnaire Return 21**

*I have good days and bad days. I also have rheumatoid arthritis which doesn't help. I can't walk far, my legs won't let me.*

#### **Questionnaire Return 20**

## Parkinson's Services

1  
2

Your Age	<input type="text"/>	Postcode (first part)	<input type="text"/>
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3 Which of the below best describes your Parkinson's?

3

Early Stage	Maintenance Stage	Advanced Stage	Palliative Stage	Not Sure
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4 "My Parkinson's is well controlled"

4

5 Strongly Agree	4 Agree	3 Neither Or N/A	2 Disagree	1 Strongly Disagree
------------------	---------	------------------	------------	---------------------

5 "I am able to access services for Parkinson's as I need to"

5

5 Strongly Agree	4 Agree	3 Neither Or N/A	2 Disagree	1 Strongly Disagree
------------------	---------	------------------	------------	---------------------

6 Have you ever waited more than 12 months for a review?

6

YES	No
-----	----

7 "I find that most of the time, I am able to self manage"

7

5 Strongly Agree	4 Agree	3 Neither Or N/A	2 Disagree	1 Strongly Disagree
------------------	---------	------------------	------------	---------------------

Turn Over



8

**“In times of crisis I am able to access the services I need”**

<b>5</b> Strongly Agree	<b>4</b> Agree	<b>3</b> Neither Or N/A	<b>2</b> Disagree	<b>1</b> Strongly Disagree
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9

**“My GP seems confident to offer advice about my Parkinson’s.”**

<b>5</b> Strongly Agree	<b>4</b> Agree	<b>3</b> Neither Or N/A	<b>2</b> Disagree	<b>1</b> Strongly Disagree
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10

**Have you ever been admitted to hospital as a result of not being able to access services?**

<b>YES</b>	<b>No</b>
------------	-----------

11

**How many days were you in hospital for?**

12

**Whilst in hospital, staff seemed familiar with Parkinson’s and the help I needed (with medication for example).**

<b>5</b> Strongly Agree	<b>4</b> Agree	<b>3</b> Neither Or N/A	<b>2</b> Disagree	<b>1</b> Strongly Disagree
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13 **“I have had problems getting a medication review”**

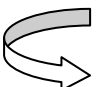
14 **“I have received a home visit(s) from a Parkinson’s Nurse”**

15 **Where would you normally go for help and advice about Parkinson’s?**

16 **“Issues related to my Parkinson’s have affected my mental health”**

17 **“I feel included in my local community”**

Turn Over





### Which of these services have you accessed?

18

<b>Parkinson's Nurses</b>	<input type="checkbox"/>	<b>Physiotherapy</b>	<input type="checkbox"/>
<b>Occupational Therapy</b>	<input type="checkbox"/>	<b>Speech and Language Therapy</b>	<input type="checkbox"/>
<b>Social or Support Groups</b>	<input type="checkbox"/>	<b>Mental Health Services</b>	<input type="checkbox"/>

### Who diagnosed your Parkinson's?

19

<b>Parkinson's Nurse</b>	<input type="checkbox"/>	<b>GP</b>	<input type="checkbox"/>
<b>Consultant</b>	<input type="checkbox"/>	<b>Other</b>	<input type="checkbox"/>
<b>Comment -</b>			

### Who conducted your last review?

20

<b>Parkinson's Nurse</b>	<input type="checkbox"/>	<b>Rehab Team</b>	<input type="checkbox"/>
<b>Consultant</b>	<input type="checkbox"/>	<b>Other</b>	<input type="checkbox"/>
<b>Comment -</b>			

Please free to send us any comments you would like to add.

**THANKYOU!**