



**NEUROLOGICAL INFORMATION AND ACCESS PARTNERSHIP
(NIAP)**

Service User Survey Report

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**Improving access to rehabilitation, information and advice in Nottingham City
and Nottinghamshire County**

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Executive Summary

Aim

The aim of the Neurological Information and Access Partnership (NIAP) project was to identify gaps in current neurological service provision and make recommendations for improvements and new ways of working across Nottingham City and Nottinghamshire County.

Method

Information from service users living in the Nottingham City and Nottinghamshire County areas was gathered using face to face interviews, on line surveys and a paper questionnaire. The population studied had a wide range of diagnosis, including people with Parkinson's Disease, Multiple Sclerosis, Motor Neurone Disease, Progressive Supranuclear Palsy, Epilepsy, Stroke, Acoustic Neuroma and brain injury.

Findings

One hundred and seventy two people with long term neurological conditions provided input to this report. They had a wide range of conditions and represented people living in the City of Nottingham, suburban areas and rural areas.

The majority of participant's were happy with referral procedures from GP to consultant for initial diagnosis. However it was highlighted that although most people had a six monthly review with the consultant, day to day care was still controlled by GP's, community health professionals and social care staff who it was felt did not always have a good knowledge of neurological conditions and related symptoms. Participants felt that they had been adequately involved in their care and support planning but once services had started the participant sometimes had to act as the communicator between different organisations to ensure the joining up of effective provision.

Information about voluntary and additional services had been provided to only about half the participants. The most appropriate information was provided by specialist staff and organisations. Many people knew about statutory services and regional charities such as Parkinson's Disease Society and Multiple Sclerosis Association but less were aware of additional local services such as community transport or local pension service. The participants felt they had often been left to their own devices to find information, having been told that a service existed by a friend or neighbour. Some did acknowledge that they may have been offered the information at their initial diagnosis but were not always in a good position to absorb the details at that time. Almost all respondents reported that their carers often felt neglected and unseen. Service users and their family and carers felt they were faced with daunting choices to make at a time when they are not always able to make decisions. Although the participants had difficulty getting information the majority considered that they had been offered choices and had been assisted in taking control of their lives.

Recommendations:

- A dedicated neurological information and advice service, that is easy to access, enabling those with neurological conditions to take more control and autonomy over their own lives
- Information on condition specific and wider issues such as carers rights are available at a timely intervals and not just at initial diagnosis
- Information in appropriate formats not just written. (Pod casts, web pages, verbal, DVD, Buddy system)
- Health and Social care service advisors receiving training in neurological conditions so they can recognise and deal with symptoms appropriately
- Health care professionals knowing their role and the role of others to ensure appropriate usage of individual roles, time and resources
- Promotion of clear and honest health and social care choices
- Support the implementation of local provision e.g. NHS Nottingham City Community Neurology Service providing on-going rehabilitation
- A neurological leader to monitor and implement changes in procedures for hospital and community provision and liaise with both
- Stronger links between statutory, public and voluntary sectors
- Neurological training available for health and social care professionals and GP's
- Raise awareness of information and advice services for carers and families
- Ensure that all sectors of service provision have a stakeholder role in future planning and management of services

Acknowledgements:

We would like to thank the participants who gave up their time to complete the survey and speak to the researcher. We would also like to thank the organisations who distributed surveys to their service users as well those who promoted the questionnaire on their intranet and web sites and in publications. Acknowledgement goes out to Rushcliffe Council for Voluntary Service for providing a freepost address, the NIAP service user group, Linden Lodge in-patients, the Multiple Sclerosis Therapy Centre and Parkinson's Disease Society support groups in Mapperley and West Bridgford for assisting with the project. A list of the grant holders and steering committee members can be seen in Appendix 1.

We acknowledge financial support from the Department of Health Section 64 funding stream.

A copy of the survey used can be obtained by contacting the author

Background

Research studies have highlighted the fragmented and disorganised health and social care services for people with neurological conditions. A project that mapped all specialist neurological rehabilitation services in the UK (Gladman et al 2008) found that services tend to be focused on diagnosis and early management with limited services for long term conditions such as Multiple Sclerosis. In 2005 The National Service Framework for Long Term Neurological Conditions (NSF- LTC) (Department of Health 2005) recommended integrated action and joint working between all agencies with the aim of providing a patient centred, coordinated and seamless service.

In 2009 the Neurological Information and Access Partnership (NIAP) was launched with financial support from Department of Health Section 64 funding stream to address the local fragmented health and social care service and to implement the recommendations of the NSF-LTC. Working across Nottingham City and Nottinghamshire County, the project was administered by Parkinson's Disease Society. The partnership involves voluntary and statutory organisations including Nottinghamshire County Council, Nottingham City Council, NHS Nottingham City, NHS Nottingham City – Nottingham CitiHealth, NHS Nottinghamshire County, Nottingham University Hospitals, University of Nottingham and neurological charities such as Multiple Sclerosis Society, Headway and Motor Neurone Disease Association. One of the important parts of this project is that the NIAP is managed by the Parkinson's Disease Society; the project manager is employed by the Parkinson's Disease Society and is therefore an independent researcher not reliant on the NHS or Social care for funding.

The aim of the NIAP was to develop an environment where seamless and appropriate access to specialist rehabilitation services, information and advice could be provided in a timely fashion for people with neurological conditions. By providing this environment it was hoped that fragmented services could be brought together, the duplication of resources could be reduced, health and social care services could be enhanced and the quality of life for people with neurological conditions could be improved. To achieve this aim a number of smaller projects were planned. One of the first was to understand from service users how they access information at present and any barriers to advice and information. This is a report of how service users access information. The second was to understand from professionals in the health, social care and voluntary sectors how they access information and how they help service users get the correct advice. A copy of the professional survey used can be obtained by contacting the author or by going to www.parkinsons.org.uk/neurosurvey

Method

Between May and August 2009, the researcher met with health and social staff and service users who access neurological services to compile a list of areas that were important to those working and living with neurological conditions. These topic areas were distilled down into a number of questions about how health and social care staff, service users, family, friends and carers access health and social care services and how they had acquired meaningful information and advice on support services. The basis to some of the questions was derived from the proposals in the original project bid as well as recommendations from the NSF- LTC. A survey, using these questions was designed with spaces for written comments as well as yes/no questions. The survey was piloted with the NIAP steering group and service users.

Following changes, 700 paper copies of the survey were distributed by hand or post to those people who were known to have a neurological condition through voluntary groups, Social Care Services and the NHS Community Rehabilitation Services. Posters advertising the project were displayed in health centres and libraries. Promotions were placed on charity web sites, publications and newsletters. The survey could be completed electronically and there was a telephone number available for people to ring if they needed help.

The paper copies of the survey were collected by post and the internet survey was collated by 'Survey Monkey'. The University of Nottingham transferred the data to an Excel data base and completed the analysis using descriptive analysis. The field notes and hand written comments from the survey were analysed using a thematic approach, where comments and quotes made by different people but on the same theme were grouped together. As more interviews were completed the researcher added the comments and quotes to the existing themes if appropriate or started a new theme. Once all interviews were completed the themes were reviewed for completeness and checked by a second researcher. The quotes have been anonymised and are printed in italics.

Findings

172 (146 paper, 26 electronic) surveys were returned with 93 (54%) being completed by the respondent.

Participant characteristics

The survey allowed participants to place themselves in an age range. The results are shown in Figure 1. This demonstrates a good range of ages from 18 years old to over 86 years of age. Although ethnic minority groups were contacted the majority of those completing the questionnaire were white British (158, 92%).

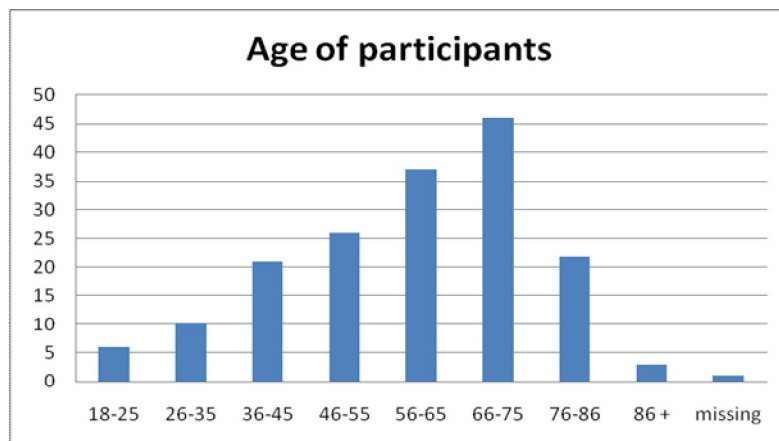


Table 1: Age of participants

Thirty seven (21%) of the participants lived alone, 12 (7%) lived in residential care and 116 (67%) were owner occupiers. Very few (4, 2%) of participants were still living with their parents. There were 92 (53%) responders living in the City of Nottingham and 72 (42%) in Nottinghamshire County.

Diagnosis and time to treatment

The participants were asked their main neurological condition. The results can be seen in Table 2. As expected the more commonly occurring conditions were well represented in the sample (Parkinson's Disease and Multiple Sclerosis) however it was encouraging to see that a number of the less well known conditions were represented in the survey. The survey asked participants what year they had been diagnosed. The oldest recorded condition diagnosed was 1961 for a female, aged 66 to 75 years with Multiple Sclerosis (MS). Unsurprising due to the conditions studied the majority of participants received their diagnosis relatively recently with the median being in 2006. Well over half of the population (107, 62%) said that they had been referred to a consultant/specialist within 0-6 months of reporting their symptoms to their GP. An additional 19 (11%) had been referred within the first year, with 81 (47%) receiving treatment within one month: the majority of these participants had had a stroke. For other conditions the time was varied. For example three

of those with Multiple Sclerosis were treated within 24 hours whilst 8 were within one year. This could be because treatment is not always needed at the onset of a condition with time frames and management varying from one person to another.

Diagnosis			
Parkinson's Disease	29	Sensory Gangi poliopathy	1
Multiple Sclerosis	28	Spinal Vascular Myopathy	1
Stroke	21	Viral infection of spinal cord	1
Progressive Supranuclear Palsy	13	Multiple System Atrophy	1
Epilepsy	10	Guillian Barrie Syndrome	1
MND	8	Lewy Body Dementia	1
Brain Injury	5	Angina	1
Huntington's Disease	4	Water on brain	1
Alzheimer's Disease	3	Myalgic Encephomyelitis	1
Acoustic Neuroma	3	Limb Girdle MD	1
Spinal muscular atrophy	3	Frontal Lobe Dementia	1
Migraine	2	Neuroferritinopathy	1
Hydrocephalus/SB	2	AUM around Spinal cord	1
Menniers Disease	2	Cerebral Palsy	1
FSH MD	2	Cavernous Angioma/Epilepsy	1
Stammer	2	Duchenne MD	1
Becker MD	2	No diagnosis yet	3
Brain Tumor	1	Missing	13
		Total	172

Table 2: Participants self reported neurological condition

The fieldwork interviews highlighted that most people were content with the transition between reporting symptoms to their GP and referral to a consultant, and being given a diagnosis was very important for most people. Although it was an upsetting time for all participants, being given a diagnosis allowed the participant to start to plan their lives, it opened access to some services and help from specialist groups. Table 3 show the time people waited for a diagnosis. We have highlighted the cases and conditions where it took many years for a diagnosis to be given.

Time to get diagnosis	number	condition
0-6 months	77	
6 mon-1 year	25	
1-2 years	17	
3 years	11	
4 years	3	Limb Girdle MD, MS, PD
5 years	5	MS, Migraine, MS, PD, Epilepsy
6 years	2	PSP, MS
7 years	1	Hydracephalus/SB
10 years	3	PD, Neuroferritinopathy, MS
12 years	1	MS
missing	22	
still waiting	5	
Total	172	

Table 2: Time to get diagnosis after seeing GP

Medication, support and service reviews

Once participants had been referred to the specialist and had been given a diagnosis most were regularly reviewed for their medications, with 130 (76%) having a medication review at least once a year and 98 (57%) every six months. One hundred and fifty four participants reported at least some sort of medication review. However only 149 participants could tell us how often they had a review. Most of the reviews were completed by the Consultant (72, 47%) or GP (61, 40%). The results for the other reviews can be seen in Figure 2. Regular medication reviews, at least every six months are recommended by clinical guidelines for Stroke (Royal College of Physicians, 2008) and Parkinson's Disease (The National Collaborating Centre for Chronic Conditions, 2006). Although participants received regular reviews this was felt inadequate by some who commented that they had had problems with their medication between reviews and didn't know where to get advice. A number of participants commented that they felt their GP did not know enough about their condition to complete the medication review. One service user suggested that pharmacists might be able to adjust and advise on medication. Others found the specialist health care professional i.e. specialist nurse very helpful over the phone, but others did not know this service existed.

“We did used to feel that 6 months was too long to be left each time they changed tablets, we didn't know if deterioration was down to the disease or wrong combination of medication” Parkinson's service user

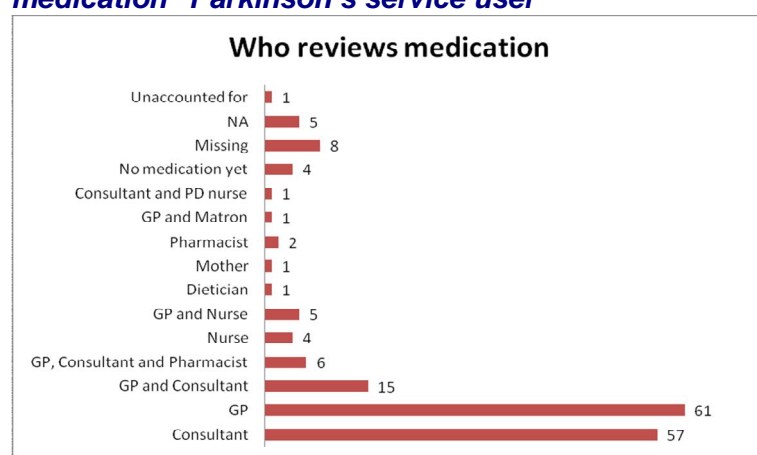


Figure 2: Medication reviews

As well as medication reviews the majority of people received a review of the support they needed at home (141, 82%). In addition to this 12 participants said they either didn't need a review or it was not applicable.

Experiences in obtaining rehabilitation, advice and information

In this population whilst only 66 (39%) had been given information about their condition at the time of diagnosis, 134 (77%) had been offered treatment from hospital services, 92 (54%) treatment from community services, 94 (55%) from Social Services and 76 (44%) had been offered services from a voluntary sector organisation. It has to be taken into account some people may not need clinical services and some respondents may not be able to distinguish between different services. Although these figures look like the majority of people received some sort of service there were six participants who did not receive any service and seven who were unaware of the voluntary sector services. Whilst people had received treatment from the larger organisations such as the NHS the fieldwork interviews highlight that many people had to find out about these services themselves.

“I have had to discover many of the available services and support for myself with the aid of family. Had I been living alone I would never have known about any of these services”

Services that are less well known such as help with getting back to work and adult education were accessed by far fewer people (38, 22%). For working age participants this may be because the information is not offered or that the participants assume there isn't a service so don't ask.

“You can't ask for what you don't know”

Providing information at the correct time is important if people are to engage with their own treatment plans. There has been considerable importance over the last few years placed in giving people information about their condition. This is usually in the form of a leaflet. In this present study very few people who were diagnosed in the 1960's, 1970's and 1980's received any information leaflets and yet most of the Parkinson's Disease patients diagnosed during 2000 and 2009 received information at the time of diagnosis. However people with less commonly occurring conditions appear to receive less information. For example 5 people diagnosed with Progressive Supranuclear Palsy during 2003-2007 said they did not receive any leaflets. It has to be remembered that these results are limited as people tend to forget over a period of time what they have received and many people diagnosed in the 1960's who may have been given information will have passed away. As well as having to get information themselves the participants stated that they learnt from other service users and specialist charity condition specific groups. A significant number felt that they gained the best information by a 'lucky' meeting with one very informative person. This person was quite often a condition specific nurse, or community worker. However not all conditions have such people and some are restricted to a location.

“Very little help from medical professionals. Most information was found through the Progressive Supranuclear Palsy Association and their website”

“When an Epilepsy nurse was introduced to service at hospital lots of barriers felt overcome (much more personable approach)” Epilepsy service user

Participants reported that they would like more information about statutory benefits, local transport schemes and self help/support groups. In the interviews a very small group expressed that they felt that medical consultants should provide more advice about condition specific and voluntary services. When this comment was played back to other service users many expressed concern that they wanted a medical consultation and not social or care package information that they could get elsewhere. One participant suggested that “*starter information packs*” could be provided. Although this seems like an excellent idea in hindsight once the diagnosis has been absorbed, other participants felt that they needed information in small parts over a period of time.

“I did not know about the existence of carers allowance until recently. Apparently could have been claiming for last two years” MND carer

As well as getting information, the survey asked people if they knew how to contact services, 98/155 (63%) of those who responded said they knew how to contact services. Almost half of the population surveyed felt that they had good access to information and but in face to face interviews the respondents reported that the information was not personalised to meet their individual needs. There was some indication from the face to face interviews that younger participants might not be able to get adequate information. We examined the survey results. We split the sample at aged 55 years. There were 62 people under 55 years and 109 over 55 years, with one age missing. Thirty (48%) people in the younger group said they had adequate information and a higher proportion 67(62%) in the older group said they had adequate information. There was no statistically significant difference between the groups (Chi squared $p= 0.167$). There was also an indication that people with lesser know conditions might not be able to get information. We split the sample into those with MS, PD

or stroke (78) and other conditions (98) and compared their access to information and found no difference between groups (Chi squared $p= 0.97$). This highlights that many factors including degree or severity of condition, age, mental ability can lead to people not being able to access information. Many people expressed a barrier being the format information is presented. The survey highlighted the need for information in different media such as one to one, internet and DVD. People do not always want to accept information, or want to know, when they are newly diagnosed and individual needs change over time so information needs to be accessible at convenient times.

“In my case I did not want to know anything about PD initially”

“If you are suffering and feeling poorly you haven’t always got the energy or capacity to source extra help.”

It should not be assumed that, because someone is perceived as being capable and normally self sufficient, that this is the same at times of crisis as personal circumstances affect peoples ability in different ways.

“I haven’t seen a consultant or attended the hospital for my MS for 8 years. I have never been offered any support.. My wife died 6 months ago and I know that I will get to a point where I cannot look after myself – I have no idea what I will do then or where I will go for help – it scares me”

Understanding of conditions by health and social care professionals

Thirty one participants failed to respond to the question about the level of condition understanding. Of those who answered, 42 (25%) thought that there was enough understanding by professionals. Again this understanding was more prevalent for the conditions such as Parkinson’s Disease or Multiple Sclerosis less reported by people with conditions such as Progressive Supranuclear Palsy.

“Happy with current care and treatment” -Parkinson’s Disease service user

Many participants commented that health and social care staff should have more understanding of the symptoms of the conditions as well as diagnosis. They felt as this would allow them to treat service users more effectively and meet their individual needs.

“If they don’t already exist I think that regular workshop/training days provided for both health and social services staff about each neurological condition would be helpful”

“They don’t always understand the frustration caused due to loss of speech and mobility” – MND service user

Care and support

We asked about support for carers. However the term carer has come to describe a number of different people. We aimed the survey at carers such as family and friends but some respondents replied in relation to paid professional workers, home care staff and care homes.

“Outside carers have not been informed of my condition and needs and quite often they are unaware of how to care for me. My family carers have found it difficult to find support for their roles or access available support” – Hydrocephalitis patient

“The carer does not get much support for themselves”

Just over a third 67 (39%) of those replying to this question thought that there was adequate information for carers. This question provoked the most negative comments to a question. The interviews highlighted that carer's needs are not taken into account and that they are the ones left feeling inadequate, worn out and not knowing where to turn. There were many comments describing how information on benefits and carer rights is not accessible and the systems being too complicated and confusing.

“Carers seems to be inconvenient to health professionals” – MS carer

Choices and communication

A large majority of people responding felt that they had been given adequate support to live at home. 113 (66%) people said they had been sufficiently involved with the planning of their care/support and of the others 15 said that they would like to be more involved. When asked about choices where treatment was received there was a mixture of responses with 66 (38%) participants recording that they had been given a choice, 59 saying they had not and 29 saying they were given some choice. It is recognised that people are happier and more able to live an independent life when they are capable of making choices for themselves. When asked “do you think that being given clearer choices would help you take more control over managing your condition” the question was misinterpreted by a few people affecting adequate reporting. 77 (45%) of responders said they would like more control over managing their condition. Some respondents answered it in regard to having choices about managing their symptoms rather than, as intended, managing choices such as care and support.

“No choices with MS just get on with it”

“My consultant, GP, MND nurses have all been very clear in what I can do and the help I can receive”

When asked about adequate communication between different services 77/142 (54%) thought that it was sufficient. However the main lack of communication seems to be between health and social care services.

“Lack of communication between the two sectors affects the way services could be delivered”

“More communication could improve level of care and make it more effective”

During the interviews with individuals there was a lot of dissatisfaction voiced around hospital staff not informing GP's in a timely fashion of hospital admissions which could then hinder progress when discharged. An interesting point that was mentioned only twice but seems very pertinent was that the service user may have to act as the service co-ordinator. This role is a move away from how most people would accept services in a passive role.

“I feel I need to be the link between different HC & SC professionals to be sure effective communication occurs”

Additional results tables can be seen in Appendix 2

Conclusion

The results of this survey highlight the need for better integration between voluntary sector, social care and health care with the aim of providing service users with neurological conditions better access to appropriate information and advice so they can make choices of their own.

We consider the results generalisable to other service users in the UK as the survey was completed by a large group of participants who have a wide range of conditions. They responded to adverts in the press, mailings and websites. There were some limitations to the survey: some people did not complete all of the questions and others provided contradicting answers. For example, although three respondents initially said they had never been referred to a consultant they later said their medication was reviewed by their consultant. Some said they hadn't received leaflets at consultation stage and later said they had received condition specific at this stage. Another limitation was that although we celebrated the variety of conditions it also meant that people with migraine and stammer completed the survey, many of whom said that they had never been referred to a consultant. It is maybe that these people did not require this level of intervention at this stage.

The main findings of this project confirm the findings of other studies (Gladman et al 2008) which have shown fragmented services, often dependent on the post-code lottery but does not confirm that people with better known conditions always get the best services and advice. It would appear that it is often a lucky encounter with one very knowledgeable person that can open doors. Once a person with a long term neurological condition has services and support it appears that they often have to co-ordinate their own care. This may be appropriate for some conditions but for others where communication is affected this situation is not appropriate. This project highlights that referral times to consultants is mostly within those recommended by clinical guidelines, and that people on the whole received regular medication and support reviews but that some health professionals that might be seeing the patient weekly often do not understand the conditions and cannot advise on medication difficulties. It would seem imperative that health and social care professionals and GPs are better trained in neurological conditions.

“2008 questioned tremors with GP – told old age. Saw physiotherapist for neck pain re whip lash who recognised signs of PD”

Getting appropriate information is still a problem for this population. Service users need to be signposted to appropriate agencies that can respond in a way that the service user can access. This information could be written, verbal, face to face, DVD, web page, or podcast. It needs to be available when needed and not just at time of diagnose. Information giving services who provide information may need to recognise that this population need help to use the information; they may need it explaining a number of times and may need the advice giver to be proactive. It would seem that a place where people can access all services and start on the appropriate routes to good care would be appropriate to this group of service users. The people manning the 'first point of call' would need to be well trained to facilitate clear, appropriate and timely referrals to clinical services. In addition to this the information and advice available to this 'first point of call' would need to be dedicated to neurological if they are not just to become yet another person to take details and not provide any assistance. Implementation of neurologically trained service advisors within health and social care will ensure that clearer pathways are created into provision assuring appropriate services are accessed by professional staff and service users in a timely fashion.

The Information Prescriptions offered by the NHS Nottinghamshire County were suggested as an example of a facility which offers advice and information on neurological services. There is at present no dedicated service in Nottingham City.

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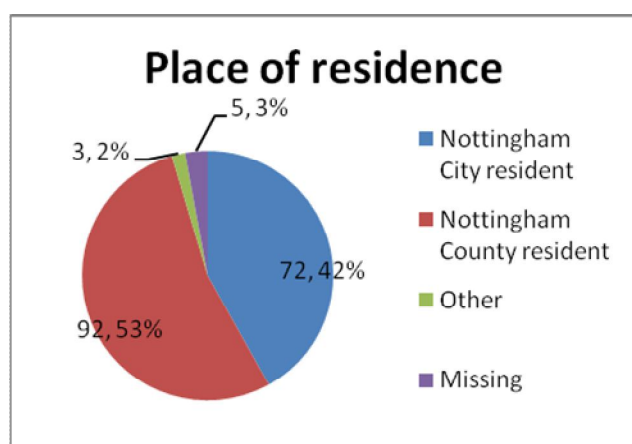
Appendix 1: Grant Holders and Trial Steering Group members

Name	Organisation
Julie Folkett	Parkinson's Disease Society
Dr Pip Logan	University of Nottingham
Gill West	Parkinson's Disease Society
Julia Pollard	NHS Nottingham City – CitiHealth Nottingham
Sally Parker	NHS Nottingham City – CitiHealth Nottingham
Anna Marriott	NHS Nottinghamshire County
Pauline Greaves	Multiple Sclerosis Society
Paul Watts	Parkinson's Disease Society
Mandy Shiel	Nottinghamshire County Council
Helen McCloughry	NHS Nottingham City – CitiHealth Nottingham
Annabel Taylor	NHS Nottingham City – CitiHealth Nottingham
Mo fowler	Progressive Supranuclear Palsy Association
Joanne Williams	NHS Nottingham City
Jake Jacobs	Nottingham City Council
Julia Webster	Nottingham University Hospitals
Cheryl George	NHS Nottinghamshire County & Bassetlaw PCT
Alison Attenborough	Nottingham University Hospitals
Nina Marshall	NHS Nottinghamshire County

Appendix 2: Additional results

Age range	number
86 +	3
76-86	22
66-75	46
56-65	37
46-55	26
36-45	21
26-35	10
18-25	6
missing	1
Total	172

Residence	number
Owner Occupier	116
Private rent	5
Parents home	4
Supported /sheltered housing	8
council rented/ housing assoc	22
Residential home	12
missing	5
Total	172



Ethnic origin	number	%
British	158	92%
any other white	2	1%
Indian	6	3%
any other mixed	1	1%
Caribbean	3	2%
missing	2	1%
Total	172	100%

Time from GP to consultant	number
0-6 months	107
6 mon -1 year	19
1 year -2 years	8
more than 2 years	7
Never been referred	9
missing	22
Total	172

Time to get treatment	number
24 hours	39
1 week	22
1 month	20
1 year	34
Treatment not required at time	32
missing	25
Total	172

Medication reviewed	number
six monthly	98
yearly	32
every 1 to 2 years	8
longer than 2 years	11
never had one	10
missing	13
Total	172

Review of support	number
six monthly	75
Yearly	44
1- 2 years	9
longer than 2 years	13
na	8
Not needed	5
missing	18
Total	172