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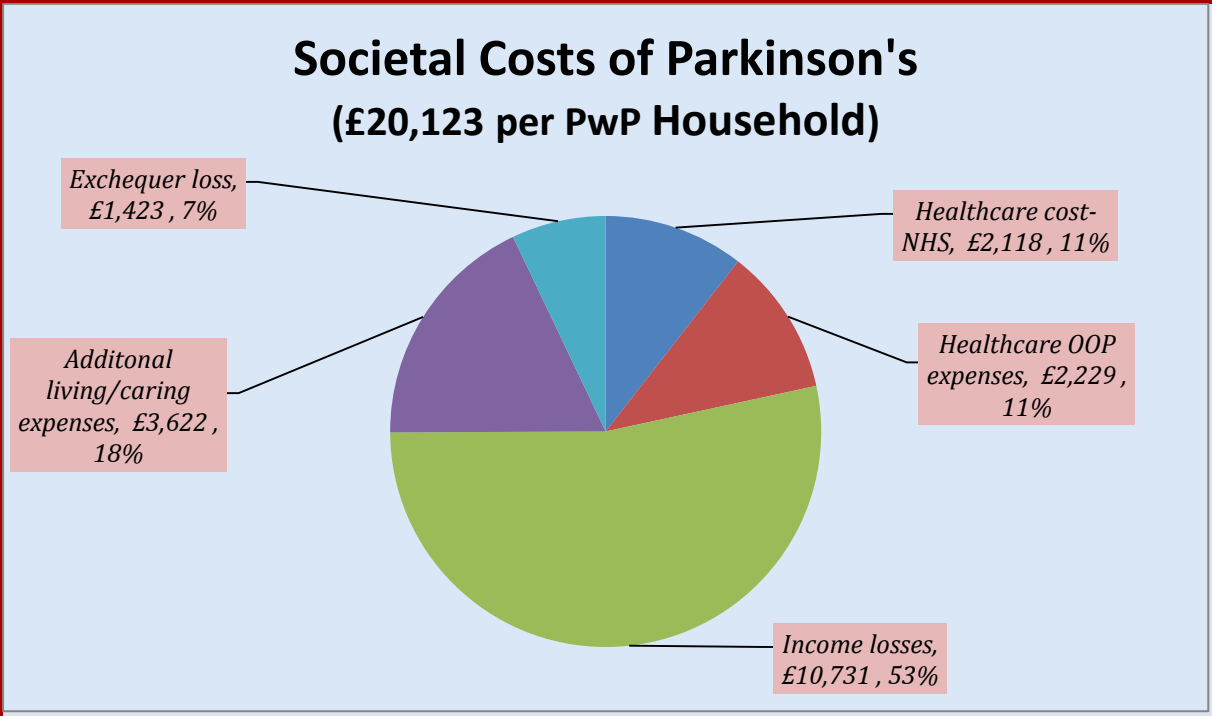
# Economic, Social and Financial Cost of Parkinson's on Individuals, Carers and their Families in the UK

***Final Report***




**Submitted By: Dr Anil Gumber**
Centre for Health and Social Care Research (CHSCR),
Sheffield Hallam University,
Montgomery House,
Collegiate Crescent,
Sheffield,
S10 2BP
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## *Research Team*[1]

***Anil Gumber (Principal Investigator)***
***Bhanu Ramaswamy***
***Rachel Ibbotson***
***Mubarak Ismail***
***Oranuch Thongchundee***
***Deborah Harrop***
***Peter Allmark***
***Abdur Rauf***

## *Our Gratitude to the Project Advisory Group Members*

***Parkinson's UK***
***Laura Cockram, Eleanor Green and Laura Conn***

***NHS Specialist Nurse Invitees***
***Lucy Partington, Tracey Watts, Debbie Nash, Dot Hardyway***

## *Our Special Thanks to the CHSCR Admin Team*

***Elizabeth Flower and Susan Dodd***

***This study is dedicated to all People with Parkinson's and their Families, with a special 'thank you' to the many people who contributed to this project. Their thoughts, openness and honesty have enabled us to gain greater insight into the costs of Parkinson's than previously understood.***

[1] Detailed profile and role of the members of research team are provided in Appendix 1.

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# *Abbreviations*

| Abbrev | Full | Section first mentioned |
|---|---|---|
| ADL | Activities of daily living | 2.3.3 |
| A&E | Accident and Emergency | 5.2 |
| BME | Black and minority ethnic | 1.4 |
| CHSCR | Centre for Health and Social Care Research | Cover page |
| DH | Department of Health | 1.1 |
| DVLA | Driver & Vehicle Licensing Agency | 6.2.3 |
| DWP | Department for Work and Pensions | 6.1.2 |
| EQ-5D | EuroQuol-5 dimension tool | 2.3.2 |
| HRQoL | Health-related quality of life | 2.3.3 |
| H & Y | Hoehn and Yahr | 1.3 |
| LTC | Long-term condition | 1.1 |
| NHS | National Health Service | 2.1 |
| NICE | National Institute for Health and Care Excellence | 1.1 |
| NR | Not Reported/Recorded | Table 3.3 |
| ONS | Office for National Statistics | 4.1 |
| OOP | Out-of-pocket | 3.1 |
| PD | Parkinson’s disease | 1.1 |
| PDNS | Parkinson’s Disease Nurse Specialist | 2.3.2 |
| PDQ | Parkinson’s Disease Quality of Life Questionnaire | 2.3.2 |
| PSSRU | Personal Social Services Research Unit | 3.1 |
| PwP | People/ person(s) with Parkinson’s | 1.1 |
| QALYs | Quality-adjusted life years | 3.1 |
| QoL | Quality of life | 2.1 |
| SES | Socio-economic status | Table 2.3.1 |
| SF | Self-financed | Table 5.1.2 |
| UK | United Kingdom | 1.1 |
| WAV | Wheelchair Accessible Vehicle | 6.2.1 |
| WHO | World Health Organization | 1.3 |

# *Executive Summary*

## Introduction

The trend towards rising numbers of (older) people diagnosed with long-term conditions, such as Parkinson's in the United Kingdom (UK) continues. To address the needs of the currently estimated 127,000 people with Parkinson's the Government has to be responsive to the direct financial expenditure for commissioning health and social care services, and to understand how the condition will affect society as a whole.

This report details the main findings of research conducted through a survey of people affected by Parkinson's looking at health and social care costs incurred during the past 12 month period. The data is enriched by five in-depth interviews with people with Parkinson's and their caregivers who responded to the survey, providing a longitudinal view of their lived experience of the condition from the time around diagnosis up till the time of interview.

The survey questioned key accountable and non-accountable costs relating to the quality of life and wellbeing of the respondents, economic and financial costs, plus their utilisation of health services. Although many of the survey respondents lived alone, the majority were older and married, so 'the household' in the context of this study refers to a mean average size of 2 people.

The findings from the interviews allows for a view of the less tangible costs, such as the psychological impact, in addition to specifics of social and financial strain to the individuals, their family and to society as their Parkinson's has progressed.

The research implications are summarised into recommendations for implementation by those who write policy from a national health and social care perspective, and to those in the voluntary sector considering the support needs of people with Parkinson's.

## The research and main findings

The study was undertaken largely utilising Parkinson's UK resources to seek responses. The profile of respondents mirrors the membership of the charity; largely white, married (with mainly female spouses in the role of caregiver), and with qualifications beyond GCSE. Whilst most people are over 65 years and retired, the age group of respondents from this study is younger than those involved in most studies, with people in the earlier stages of Parkinson's than in the literature reviewed. The responses were received mainly from England (80.3%), then Scotland (11.2%), Wales (5.5%), and Northern Ireland (1.2%), with only 5% people from ethnic minorities.

Not all sections of the 853 returns were filled. As each survey requested information about people with Parkinson's as well as their carers, analysis has been conducted on available data from up to 776 people with Parkinson's and their 546 carers. Where appropriate, a further breakdown into the four Home Countries has been performed in the main report. In some cases however, the low number of responses received from individual countries make further breakdown of figures unrepresentative of the population. In these cases, the figures are presented at aggregate level.

The research findings of the survey have been organised into four categories, with information from the five in-depth interviews adding salient comments to help understand aspects of living with Parkinson's that illustrate the figures, or that are harder to account for. The interviews utilised a conceptual social framework developed by a group of people affected by Parkinson's for a different study providing a perspective that counters the negative, linear medical model to consider strategies utilised by people as the condition progresses. Other qualitative information received from individual questionnaires has been considered as additional material in the Appendices, and will be analysed more fully as a separate account.

- **Direct and indirect health service costs**

A high proportion of people with Parkinson's continually used NHS services to consult professionals during the past 12 months (e.g. GP, neurologist and specialist nurse; in total 22 consultations), to undergo investigations e.g. blood tests or scans, obtain medication or acquire large pieces of equipment/health care packages. Other NHS costs included emergency and unplanned hospital admissions for people with Parkinson's, especially in the later stages, spending longer in hospital once admitted than the non-Parkinson's person.

Private payment was used for items not easily or regularly accessible through the NHS, e.g. sessions with podiatrist/chiropodists, chiropractors, optometrists or physiotherapists, small equipment such as mobility aids or pill timers, and also for out-of-pocket expenses such as travel and parking to health venues. For example, one of the interviewees, MA, pays for private chiropodist visits as podiatry in the local hospital was only available every four to six weeks, and he requires management at least monthly, stating: *'... and even in between then I'm suffering*'.

Things like physiotherapy and exercise might be through private means e.g. specialist clinic, leisure centre or subsidised through Parkinson's UK.

There was a £1,285,354 cost to the NHS and £161,920 for out-of-pocket expenses over the past 12-month period for those who completed the survey. This averaged out to £2,388 direct healthcare costs per person with Parkinson's. Taking into account out-of-pocket expenses towards travel and equipment purchased, the total annual healthcare cost per person with Parkinson's elevated to £4,347.

- **Social care costs**

Households with people affected by Parkinson's paid towards alterations in accommodation to adapt to changes in mobility conditions, or even moved from their previous home, most of which were self-financed capital expenditure. The changes were not easy, with some people feeling forced into the situation as can be seen in MA's statement about his move:

> '*I'm now in a bungalow because I couldn't manage the stairs where I was before. So I've moved into a sheltered housing… At first I wasn't going to accept this property because I thought oh it's going to be too small, too cramped, but I felt well yes I can't carry on where I am now…there was a risk of me having a fall [steep stairs]… So I had to really bite the bullet and say well my health is not, is obviously not going to get any better, it's only going to get worse. So I need to not only think now but look ahead to the future. …but it was a case of I had no choice. It's something I had to do because I couldn't have continued where I was'*.

Other costs included payments for daily living assistance such as personal care, transport to appointments or shopping, house cleaning and gardening. Additional utility (mainly energy) costs and use of takeaway or ready meals added to their expenses.

Some of the social care costs were accessed through the local authority, but much came from family or out-of-pocket expenses of the people affected by Parkinson's. The total annual mean out-of-pocket expense was estimated at £3,622 per household that included a person with Parkinson's.

- **Societal costs**

Societal costs were noted mainly in terms of productivity loss arising from altered working patterns, with nearly one quarter of households reporting reduced monthly income. Parkinson's directly impacted on employment and working conditions, with half those diagnosed, and one-third of family members decreasing their working hours, seeking more manageable or adaptable positions, or giving up work completely.

The interviews permitted an insight into the psychological costs of oncoming symptoms, even prior to diagnosis. For example, MA, self-employed to install and service hands-free kits in cars for mobile phones, or radio systems stated:

> '*I noticed when I was doing installations that I was having problems sort of feeding cables through small gaps whereas previously I would've done it say in a matter of a few seconds. It would take me several minutes to do the same thing. Because I didn't seem to be able to, I didn't have the dexterity in my hands. Using tools was becoming more difficult…I would have to give myself longer on the job which isn't always a good thing…You've got a limited amount of time to do it so it increased the pressure on me as well'*.
>
> '*As a result the business was starting to suffer. I ended up having to sell my house because I couldn't afford the mortgage…I eventually had to give up self-employment and I then when to work for my local authority'.*

For CC, it was his loss of concentration and inability to word-find on tours he was guiding at the museum he worked at that affected his work prior to diagnosis.

Survey data calculated on an average a working person with Parkinson's lost 62.1 workdays per annum as a consequence of having Parkinson's, with caregivers losing on an average 18.9 workdays annually. Working persons with Parkinson's also reduced weekly hours by 12.4 and this reduction for caregivers was 10.7 working hours per week. This worked out to an average annual loss of £1,981 per household for those who continued to work. One in three people with Parkinson's were forced to take early retirement, or unable to work due to illness/incapacity or looking for a job adaptable to the needs of their Parkinson's. This accounted for annual earnings loss of £6,013 per household. Several informal caregivers were not enrolled with the Department for Work and Pensions for carer allowance, thus they were providing unpaid care to people with Parkinson's. This resulted in an annual earning loss of £1,235 per household. A considerable number of PwP and carers experienced discontinuance of their state benefits and pensions resulting in an additional loss of annual income of £1502 per household. Thus, direct and indirect annual employment earnings/income loss totalled £10,731 per household.

Utilising early retirement figures of people with Parkinson's and their carers, it has been calculated that the working lifetime earnings loss to a person affected by Parkinson's who takes premature retirement at any age averages £43,170 per household.

- **Quality of life and wellbeing issues**

The majority of respondents with Parkinson's noted a decline in their health status over the year, compared with about half of the carers (adding to their task of managing basic household needs), and only a third of people with Parkinson's reported their health status as good or very good, with up to two-thirds reporting a need for help with activities within and outside the house. Compared to the general population of their age, this was observed in lower quality-adjusted life years (QALY) and mean wellbeing scores (life-satisfaction, life worthwhile, happiness and anxiousness) in carers, but more so in people with Parkinson's, worsening in those who had been diagnosed for longer.

One of the in-depth interviewees, LA, noted her fatigue issues in an interview, affecting her enjoyment of her occupation as a Greenspace officer (project-work spread her working hours differently each day).

> *'...Because I kept irregular hours, I've always eaten my dinner late. If I was working in the evening I would have a snack late afternoon/teatime before I went back out to work and then I'd come back in after work and have my main meal then. I've noticed a big difference being off since October because I'm now eating at more what would be described as regular times'.*

There was also some fear expressed of facing a potential future that affected participation in activities with the local support group for Parkinson's. LA's account is a common issue in people with progressive conditions:

> '*And the reason for that [non-attendance at meetings, although a member of Parkinson's UK] is I have a fear of meeting people who are at a much more advanced stage of Parkinson's, which I could potentially be as well. I mean they're all different, as you're probably aware, everybody with Parkinson's is different and quite unique, so there's no saying how it will go, but it's just the fear factor of seeing somebody*'.

The social framework highlighted the positives that kept people well, and socially or politically engaged; for example, those involved in the local Parkinson's UK branch network gain from their contributions. Hence in an interview with AL and his wife, who have become the organisers of events for their local Parkinson's group, AL notes:

> '*…I think a lot of the phone calls I get, people contact me because I'm the name in the... I'm the one that organises, and we go to the odd forum, and Parkinson's has become my life really'.*
>
> AL's wife adds: *'Actually if we want to talk about expenses, financial yes, but the actual benefit from belonging to the Parkinson's group and being the coordinator I think outweigh all of that. I think they've been extremely important*'.

There is pride in contributions individuals make to the charity impacting on their wellness, e.g. in his interview CC proudly recounted raising £1,200 in a sponsored walk for the charity.

Where markers of independence are lost, e.g. AL noted:

> *'...Last week DVLA took the licence away on medical grounds…so where we'll be taking buses and taxis and the like, so there will be expenditures on that*', people approach it with pragmatism or humour: *'...But then again we won't have to insure the car*!

The interviews were able to add a perspective of the impact of priority changing behaviour. Some lessening life quality e.g. alterations to holiday destination to ones closer to home (a financial saving on travel, but increased insurance prices), transport or hotels that cannot always accommodate needs (psychological cost from stress of planning), creating fewer opportunities for people to go out with friends and associates (social costs), but for others creating gains from new social sets.

## Conclusion

From the completed surveys by people affected by Parkinson's, this study was able to calculate an annual health and social care cost of Parkinson's to society by adding direct (mainly NHS) and indirect (mainly out-of-pocket) healthcare costs, non-healthcare expenses (paid for by the households), employment earnings losses (including unpaid caregiver earning loss), and cuts to benefits or pensions since registering with the Department for Work and Pensions as an elderly, disabled person or carer. The total societal cost was £20,123 per household, and excluding the NHS costs and exchequer loss, the annual direct financial burden on a household affected by Parkinson's averages £16,582. As the majority of households receiving gross annual income under £30,000, the direct financial impact of Parkinson's on their household budget was enormous. Monetary impact in terms of reduced income and savings and increased borrowings including mortgage equity release was the most felt; this was followed by the changed priorities for spending, reduced social activities and holidays and reduced spending on festive gifts.

The survey questions yielded over 750 variables for analysis. There is a strong message that as the condition progressed, and as people aged, whether diagnosed with Parkinson's or caring for someone with the condition, life quality and finances undergo a reduction.

The results have yielded recommendations for policy making based on improved understanding of the economic and social consequences of Parkinson's, the main ones being:

- That policy makers resolve inconsistencies in the provision of services, and funding accessible to people with Parkinson's across the UK. This includes consideration of identified work-related and benefit-related issues, impacting on households due to the Department for Work and Pensions, and Local Authorities regulations.
- The development of a positive, empowering model to achieve the social policy drive whereby people with long term conditions share management, including acknowledged support available from non-health resources such as voluntary organisations.
- Finding means that enable people living with, or affected by Parkinson's to remain independent and well for as long as possible through consistent provision of health and care services from diagnosis across the health, social care and independent sectors
- To commission investigation into longer term societal and human capital costs, studying the needs of people newly diagnosed, right through to those in the advanced stages of the condition, and their support networks.

# 1. Introduction

## 1.1 Background

The 21st Century has seen epidemiological and demographic changes that have resulted in an unprecedented shift towards an ageing population, particularly in the developed world (Lutz *et al*. 2008). The global population of those aged 60 years and over is projected to more than double in size from its current level, to nearly 2.1 billion by 2050; and the number of people aged 80 years or over, the "oldest-old" persons will grow much faster to reach 434 million by 2050 (United Nations 2015).

The population in the United Kingdom (UK) is estimated to increase from 14.9 million in 2015 to 23.2 million in 2050 (United Nations, 2015) with one in seven people projected to live over the age of 75 (Government Office for Science, 2016). Whilst life expectancy has doubled and people are living longer than before, these statistics come with a rise in the diagnosis of people with long-term and multiple health conditions in the UK (Government Office for Science 2016; Department of Health 2012).

Parkinson's[2] (also known as Parkinson's disease or PD) is one of these long-term conditions (LTC) largely affecting the older population. It is a neurodegenerative condition, currently diagnosed when the part of the brain that controls movement is affected by a deficiency of a neurotransmitter dopamine resulting in specific motor symptoms; but it is also evident from the presence of non-motor symptoms such as depression, fatigue and pain that manifest before the motor features (Schrag *et al*. 2014). There is no cure for Parkinson's, but early diagnosis can help in enabling the person to self-manage their condition through support from health professionals, carers and families (Baker and Graham 2004). The progressive, and variable nature of Parkinson's from both the motor- and non-motor symptoms experienced over the course of the condition substantially impact on quality of life, requiring diverse strategies of intervention and support.

There are an estimated 127,000 people diagnosed with Parkinson's in the UK and this population is projected to rise to 161,000 by 2020 (Parkinson's UK 2009), and even the projected figure is considered an underestimate. The estimated cost for management is large, in terms of financial, social and psychological costs.

Over a decade ago, the UK government committed itself to improving community health, but to do this requires an understanding of the direct financial outlay for commissioning services (Department of Health 2006). The delivery of both health and social care provision to address the management of Parkinson's, especially in an ageing population, has the potential to incur a sizeable economic and financial cost to individuals, families, the Government, and society.

[2] Parkinson's UK consider it good practice to use the word Parkinson's in preference to the term Parkinson's disease or PD when undertaking to describe the condition, or to refer to individuals with the condition as person with Parkinson's (PwP). Throughout this report we will refer to people as individuals with Parkinson's, or PwP, unless in a specific context e.g. patients.

There is a lack of research in estimating this total financial burden on society in the UK. As, a parallel, the cost of dementia in the UK sees an annual economic burden of £26.7 billion, with an average cost of £32,350 per case (Alzheimer's Society 2014); and about 50% of the cost was associated with unpaid informal care (health care costs £4.3 billion, social care £10.3 billion and informal care £11.6 billion). The extent of the financial burden may be similar to the Parkinson's-related expenditure borne by individuals with the condition and their families.

Much of Parkinson's care is informal, meaning that this impact on quality of life is not restricted to the individual with Parkinson's, but extends to carers, family, and friends (Williamson *et al*. 2008). Information sought, especially at diagnosis, or when there is a change in circumstances, is often un-costed as it is resourced via the Internet, and through the voluntary activities of Parkinson's-related charities.

Given the large, and increasing numbers of people with Parkinson's (PwP) in the UK, it would be of benefit to understand the various dimensions of the cost of care, management and effective treatment available in the UK to the individual with Parkinson's and to society. The National Institute for Health and Care Excellence (NICE) guideline on Parkinson's Disease was issued almost a decade ago (NICE 2006) without much description of the economic impact of the condition on UK finances. Therefore, there is a need to carry out a detailed cost of illness study to assess both the economic and social burden of disease on the people immediately affected by Parkinson's as well as in the wider society. This proposal will use a household approach, enhanced through in-depth case study interviews, to focus on both the direct and indirect impact on income, living conditions, and wellbeing of the households, as well as on the individuals with Parkinson's and their carers.

## 1.2 Aims and Objectives

The main aim of the study was to provide estimates of economic, social and financial cost of Parkinson's on people with condition and their families. The key study objectives were:

- To assess the economic cost of Parkinson's in the UK.
- To utilise the improved understanding of the economic and social consequences of Parkinson's on the individuals and their families, as well as on the ageing society to provide evidence to inform Government and policy makers where to improve care.
- To investigate various dimensions which include treatment cost borne by the government, direct and indirect healthcare costs to PwP, social care costs borne by the local government and paid/unpaid carer costs to the PwP households and societal costs in terms of productivity loss arising due to inability of PwP and family carers to attend to work.
- To examine the impact of Parkinson's on quality of life and personal wellbeing of PwP and their caregivers.
- To explore and estimate through in-depth case studies both accountable and non-accountable medical, non-medical, and indirect costs to the patients and their families over the year as well as over the individual's lifespan as a result of the progression of the condition.
- To assess the financial impact of treatment and care on PwP households.
- To ensure the findings and key messages reach the target audience in an accessible and effective manner by delivering a number of communication outputs.

## 1.3 Conceptual Framework

To make an assessment of direct, indirect and intangible costs of Parkinson's on people affected by[3] the condition, one needs to look beyond the bio-medical model. This study utilises a conceptual social framework to identify the costs to the individuals and their immediate families.

Cost-of-illness studies can be undertaken using one of two methods: (1) the prevalence approach to estimate a condition's total cost in a given year, or (2) the incident approach, to estimate a lifetime cost. Although more difficult to determine, this second approach is of greater use when considering the expense of a condition such as Parkinson's, as the full costs (financial and social) can only be experienced over a period of several years (Drummond 1992). Also, if the progression of Parkinson's (based on the subtype of presentation and age at diagnosis) results in the development of different symptoms over time (van Rooden *et al*. 2010; Selikhova *et al*. 2009), this will create variations in how a person manages as an individual.

Cost-of-illness studies that only use survey data, or that measure lost production using a human capital model (by multiplying the total period of absence by the wage rate of the absent worker), cannot tell us where resources should be devoted for a condition to be treated adequately (World Health Organization [WHO] 2009; Drummond 1992), and the focus towards disease burden estimated through measurements of morbidity and mortality do not depict how illness influences the welfare of an individual (WHO 2009). Living with Parkinson's can impact on people's mood, communication, and confidence in addition to the physical symptoms they seek support for, and much of health and social care costs are spent on these impacts.

***A journey with Parkinson's as conceptualised by people affected by the condition***

Since 2008, work has been ongoing in Sheffield, UK to utilise the experience of people affected by Parkinson's to consider factors that support management of the condition (Ramaswamy 2010). A social framework has since been developed by co-researchers affected by Parkinson's for an ongoing project looking at supporting wellness throughout the course of the condition. The co-researchers mapped their journey with Parkinson's from a period prior to diagnosis (a stage missed by surveys, and often ignored by clinicians) towards what they considered as their future years (see Appendices 2 and 3 for modified version of the framework).

The socially constructed framework counters the negative language and linear focus of the medical models currently utilised by health professions to describe and understand Parkinson's. In medical models, Parkinson's is either categorised on a one to five (1 - 5) scale along a pathway from diagnosis to decline (Hoehn and Yahr [H&Y] 1967); follows a

[3] The term 'affected by' is inclusive of people with the diagnosis of Parkinson's, their friends, family and carers, plus professionals who deliver services to improve the quality of life of people with the condition.

stepwise worsening in the person's symptomatic presentation of the condition as certain milestones are reached e.g. Levodopa-induced dyskinesia, H&Y stage 3 (a point at which falls occur), a movement disturbance known as freezing, and cognitive decline, each also affected by other factors e.g. age, co-morbidity (Evans *et al.* 2011); or provides a clinical scale of categories that place individuals according to the increasing therapies and support needs to be required (McMahon and Thomas 1998).

The social model provides a novel and more adaptable perspective. It considers the positive strategies of management utilised by people affected by Parkinson's over its time-course as the condition progresses.

Although widely accepted that the progression of an individual will vary, health professionals anecdotally quantify the timeline of progression of Parkinson's in five-year periods i.e. the earlier stage described from diagnosis to the first five years; the mid-stage being between five and 10 years, and from 10 years onward, or a point where a person has developed dementia or severe disability, when they are considered to be in the later stages of Parkinson's (Hawkes *et al*. 2010; Jancovic and Kapadia 2001).

To a health professional, such classification helps in the planning of interventions and support a person with Parkinson's might need as the years pass, especially with regard to direct costs of services available to them, yet it lacks insight into specific ways people will personally adjust to accommodate to their changing lives, with no understanding of some of the intangible costs of ill health (Rice 1967). The purpose of conducting telephone interviews with one person from each of the home countries of the UK - England, Scotland, Wales, and Northern Ireland, in addition to an online survey was to gather in-depth information about such incidental costs and provide some idea of variations in how people manage their Parkinson's outside the traditionally offered services.

## 1.4 Data and Methods

***Study Design***

A mixed-method approach was employed to assess the economic impact of Parkinson's on individuals, their carers, and families. This included (a) UK wide mailed/online survey and (b) in-depth interviews with PwP and carers from varied socioeconomic environments. Such case studies probed further in order to reconstruct the scenarios for lifetime costs and burden on PwP at various stages of the progressive condition. These in-depth interviews provided an understanding as to how the progression of Parkinson's affects wellbeing, including daily living, managing the economic condition and finances, health care and social life.

The quantitative survey spread across all four countries of the UK has provided an estimate on the key cost drivers of health care, social care, and informal care components. The key cost and economic burden indicators included health and social service utilisation during the last 12 months. The survey questionnaire and in-depth interview schedule, as well as topic

guide, were designed after consulting experts and advisors to the project; the questionnaire was later piloted at a focus group meeting with PwP in Sheffield.

In addition to recording the country a person lived in, certain question were asked for the following reasons:

1. Age at onset, a factor linked with a difference in how Parkinson's progress over time (van Rooden *et al.* 2010; Selikhova *et al.* 2009). People diagnosed below the age of 40, or over the age of 75 are considered to have either slower progression, or a more rapid progression of Parkinson's respectively. In order to pick up any impact in the cost of Parkinson's financially and socially for people according to their age, this was asked in the online survey.
2. The subtype of a person at diagnosis i.e. whether they present first with tremor, or with slowness and stiffness, is believed to have links with the cognitive ability, mood of the individual with Parkinson's (van Rooden *et al.* 2011), as is the length someone has been diagnosed (Selikhova *et al.* 2009). This was asked of the people who participated in the in-depth interviews to consider any difference in services they chose to access to help support any such issues.
3. The type of area of residence of our interviewees was ascertained to see if there was a difference in the services they could access to meet their needs.

Finally, in order to make a fair assessment of the economic impact of Parkinson's on people and society, the findings from the primary data were supplemented and collated with the findings from a literature review.

***Recruitment Strategy***

The research team utilised Parkinson's UK services to collect the data. Parkinson's UK has a large membership of PwP, their carers, and professionals. This network has facilitated the recruitment of a large number of participants in a short span of time. The study was granted an approval from the Sheffield Hallam University, Research Ethics Committee. At an early stage, the research established a project advisory group to develop and guide the various stages of the study. The advisory group suggested developing and piloting a sample questionnaire with PwP and their carers. A focus group meeting was arranged through one of the team members (Bhanu Ramaswamy) who works with PwP; the feedback from focus group was essential to ensure that questionnaire and information were fully understood by PwP and carers. Particular attention was paid to the structure of the questions, ensuring that as far as possible the questions were simple to answer, pre-coded with choices and offered in both electronic and paper format.

The time needed to complete the questionnaire was also factored in, so as not to overly burden the PwP and their carers. The sample questionnaire went through several iterations before the final version was approved by the advisory group. After approval, the sample of the questionnaire was piloted with PwP and carers. All the comments and changes were reflected in the final version. The advisory group received regular updates through monthly teleconference calls and quarterly meetings during the project lifespan.

To promote the research study and the online survey to PwP and their carers, an information sheet describing the aims and objectives of the study was developed and designed with input from health professionals including Parkinson's Nurses, as well as the PwP and carers. The study leaflet was developed as an A5 two-page flyer/tear-off postcard which was mailed out in the July 2015 edition of "The Parkinson" magazine. This was an important and timely strategy to access to the Parkinson's UK membership and obtain their interest and willingness to participate in the study. Those who showed interest were asked to fill in a short self-completion survey online or through a postcard. The tear-off postcard was returned to the Centre for Health and Social Care Research at Sheffield Hallam University, where a database was generated. In addition, the leaflets were also administered through the "Network News" publication sent to local groups. A copy of the information sheet and leaflet are provided in Appendix 4.

A link to the online survey which was hosted via the software, Survey Monkey, was emailed to potential participants with the Parkinson's monthly electronic newsletter. Forum members were also targeted as it was anticipated that as the forum is separate from the membership system there could potentially be additional unique users whose profile may be different. For those who requested a paper copy of the questionnaire, a copy with a prepaid envelope was mailed to their home address. In order to recruit potential participants who may not currently be known to Parkinson's UK, online forums such as http://www.mumsnet.com/Talk/nonmember_requests were approached. To further ensure participation from the black and minority ethnic (BME) community, contacts were sought via the Minority Ethnic Health Forum; Race Equality Foundation; REACH Community Health; and national charities working directly with the BME community e.g., http://www.mecopp.org.uk/home.php?section_id=1

***Recruitment of PwP from BME and Nursing/Care Homes (Booster Sample)***

Recruitment of ethnic minorities into research is a challenge, particularly with people in the older age groups who have several barriers to participation including language and communication, lack of cultural relevancy, mistrust of the health care system, and relatively low levels of education and socioeconomic status (Ismail *et al.* 2014).

Drawing on prior experiences of researching with people from ethnic minorities, the decision was made to partner with locally established community organisations that were able to identify potential participants from BME communities in Sheffield and Manchester. In the initial stage, the research team sought to make contact with Parkinson's healthcare professionals for help in recruiting PwP and carers from the local BME community. However, the response from healthcare professionals was poor due to Data Protection policies. One of the challenges of this task was that Parkinson's was either not acknowledged or discussed within the community (as is the case with other neurological and also mental health conditions). To help address this challenge, a member of the research team who specialises in

BME community engagement used various methods to recruit participants. The methods included: emails, telephone calls, and conversations with community leaders of BME groups, attending local community events and visiting places of worship to help publicise information and raise awareness about the Parkinson's research study. In Manchester, the research team contacted and visited a number of BME organisations in Longsight and Moss Side (BHA-Black Health Agency, SASCA – Somali Community group, Pakistani Resource Centre, MRSN, NEESA Group, Awaaz and Afro-Caribbean Carer Group). Similar types of organisations in Sheffield were also contacted (South Sheffield Community Empowerment Project, Pakistani Muslim Centre, Somali community Centre, Pakistani advice Centre, Yemeni community association and Afro-Caribbean centre SADDACA). Most of the participants from this group were recruited by word of mouth, and individual carers who were interviewed were asked to introduce other PwP and carers. Participants whose proficiency in the English language was limited were offered help from members of the research team who spoke their language and helped in filling the survey questionnaire.

Elderly nursing/care home residents have different health needs compared to those who are living in their own homes. Their mental and physical frailty makes it difficult for them to make choices as in the main their families make the decisions on their behalf. However, family carers are constrained by a lack of time and other family commitments, which in turn make them less likely to engage in other activities, particularly when visiting the PwP at their nursing home.

To identify nursing home residents with Parkinson's, the research team searched online databases for Registered Nursing Homes who provide care for PwP. The contact details of those nursing homes were extracted by a member of the research team who then made the initial contact with the nursing/care home staff to enquire as to whether there were any residents with Parkinson's. Nursing homes which confirmed the presence of PWP were invited to support the study. The identified nursing homes with PwP, were sent an information leaflet about the research study, participant information sheet, and copies of the research questionnaire consummate with the number of residents with Parkinson's in the nursing home. The research team were not allowed to speak directly to family members of residents with Parkinson's, so relied on the nursing home managers to identify potential participants. A member of the research team visited each of the nursing/care homes and discussed with the respective managers the details of the study and potential recruitment strategies. This helped to establish a relationship and to gain their confidence in the research team and to ascertain that the research topic was relevant to PwP and family carers. However, the research team had limited success partly due to the culture of nursing/care homes and inadequate time to establish the relationship. A study by McMurdo *et al.* (2011) reported that managers of nursing/care homes are often concerned about the level of disruption that research can cause in relation to other daily nursing/care home planned activities. Other factors which may have caused concern for nursing/care home managers include issues related to patient privacy, cognitive or communications difficulties, patients having complex health needs and the length of the questionnaire.

***Response Size***

In response to call made in the Parkinson's Newsletter, over 1000 people had expressed interest in participating in the study (including 220 who requested a printed copy of the questionnaire in post) during July-Sept 2015. Between October 2015 and February 2016 people were invited to fill online and/or postal questionnaires. In all together 853 people provided the information (485 filled the live online questionnaire and 368 who received an email invitation or hardcopy of questionnaires to complete the survey). The response was very low from PwP living in nursing/care homes and from BME community. In all, the research team was able to recruit 27 PwP and carers (10 from Sheffield and 17 from Manchester) from the BME community, a smaller sample than was originally planned. Other factors include the lack of any local statistics about the number of people from minority ethnic origin who have Parkinson's and the lack of response from Parkinson's health care professionals. Given the short time schedule of data collection, there was no response from local nursing homes in Manchester; however, eight people were recruited from nursing homes in Sheffield. All the PwP in Sheffield were recruited through community contact with nursing/home care staff who promoted the research with their family members and carers of PwP.

***Methods of recruitment for the in-depth case studies***

The online survey asked if respondents were willing to be contacted for further questioning if necessary. Of those who provided both an email and a telephone contact, four people were selected randomly according to the home country they lived in, to get a basic understanding whether a difference existed in access to services across the UK.

This method, however, resulted in a selection of four retired males, three diagnosed with Parkinson's, and one carer, so a female who was still in employment (the fifth interviewee), was chosen through purposive sampling methods from the survey respondents. Attempts were made to also investigate any differences in a person from a younger onset category; however, none of the people contacted responded as able to be interviewed further.

The five interviewees were contacted the week prior to their interview to obtain their permission, and to ascertain a time and date best for the telephone conversation. They were then emailed or posted the conceptual framework of the social model for Parkinson's to be used as a guide to the interview (Appendix 2). The conceptual framework had been trialled by a group of people with Parkinson's earlier in the project to help agree on the content of the survey questions.

The initial contact and in depth telephone interviews took place during the week of 22nd February 2016. Verbal consent was obtained to record the conversation on a voice recorder (for anonymised transcription purposes) (Appendix 3), and permission sought that should further clarification be required, the person was happy to be emailed a question, or to have a second, short [unrecorded] phone conversation.

## 1.5 Limitations of Current Study

Some of the limitations of this study are mentioned below.

The study sought responses from community-dwelling adults, excluding those currently at rehabilitation centres or hospitals for extended period.

Whilst the methods utilised to acquire responses covered people both living in their own homes, as well as specifically seeking information about people in institutional care facilities, there was a negligible response from those in nursing/care homes. This may have been due in part to the use of a household approach in order to understand the cost and impact of Parkinson's on household budgets and finances. These were less of an issue for people living in institutional places.

Of the eight people living in nursing homes in Sheffield who were specifically sought for the study, no information of cost of care was provided. Ironically, the family or care staff assisting with the form filling reported that the frequency of health service use during the last 12 months of the eight people was very high, but they did not have time to check nursing home records for usage of health services, especially hospitals.

As the request was extensively distributed through Parkinson's UK channels for online users, the profile of respondents' matches that of people previously described in research to engage or ascertain the opinions of people with Parkinson's i.e. highly educated, confident, and informed people (Deane *et al*. 2014). To reduce such bias, a postal survey method was offered with a limited response. The results of this study therefore apply most directly to people who are representative of the membership of Parkinson's UK.

There were greater numbers of respondents in the earlier, and mid stages of the condition (mean duration was around 9 years since diagnosis) as well as the younger age group, as opposed to the later stages (possibly due to difficulty accessing online information, or responding to a long survey) and older age group. Whilst the study has provided insight into costs hitherto unknown for this group of people, it allows little comparison to the normative data collected in UK literature, usually based on people in the later stage of Parkinson's from clinical or hospital data.

The main results from the study have been analysed from cross-sectional data providing a snapshot of a 12-month period of costs incurred by people with Parkinson's. Whilst the case study interviews provided a longitudinal view of this condition, it would have been valuable to capture changes in the health and wellbeing of more respondents over a longer period of time given the progressive nature and altering needs and impact on the wider support networks of people affected by Parkinson's.

Finally, the utilisation and cost of healthcare services information were limited to PwP and thus not collected for carers (spouses or other family members) who might have reported increased use of health services as a result of caring workload and resultant deterioration in their general health and quality of life (mainly due to depression and fatigue).

## 1.6 Structure of the Report

The report is divided into nine chapters. The study background, aims and objectives, conceptual framework for the cost of illness study, mixed methods approach for data collection (quantitative and qualitative) from PwP and carers are illustrated in Chapter 1. Chapter 2 synthesises the UK evidence from the published peer-reviewed journals and grey literature on prevalence, management and care of Parkinson's; impact on QoL and wellbeing of PwP, carers and family members; the cost of healthcare use; and societal (economic and financial) cost of Parkinson's. Chapter 3 describes items of information included in the questionnaire for the quantitative survey, response rate by parameters, socio-demographic profile of PwP and carers, their economic activities including employment, living environment of PwP and duration of Parkinson's. Chapter 4 presents current health status, quality of life and wellbeing of PwP and carers as well as the impact of Parkinson's on their quality of life. Chapter 5 describes the utilisation of primary care, hospital outpatient and inpatient, and emergency services by PwP for their Parkinson's care over the last 12 months as well as associated out-of-pocket (OOP) payments by them to use these services. The estimates of direct and indirect healthcare costs are also provided in this chapter. Chapter 6 gives the economic and financial costs of Parkinson's on PwP and their families, the changes in their financial situations and the estimates of societal costs of Parkinson's. Chapter 7 presents the extent of the financial impact of Parkinson's on PwP households. Chapter 8 illustrates financial costs to PwP and their families during the course of their journey with Parkinson's through in-depth case studies. Chapter 9 provides summary and conclusion and offers recommendations based on findings set out in earlier chapters.

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# 2. Literature Review

## 2.1 Methods

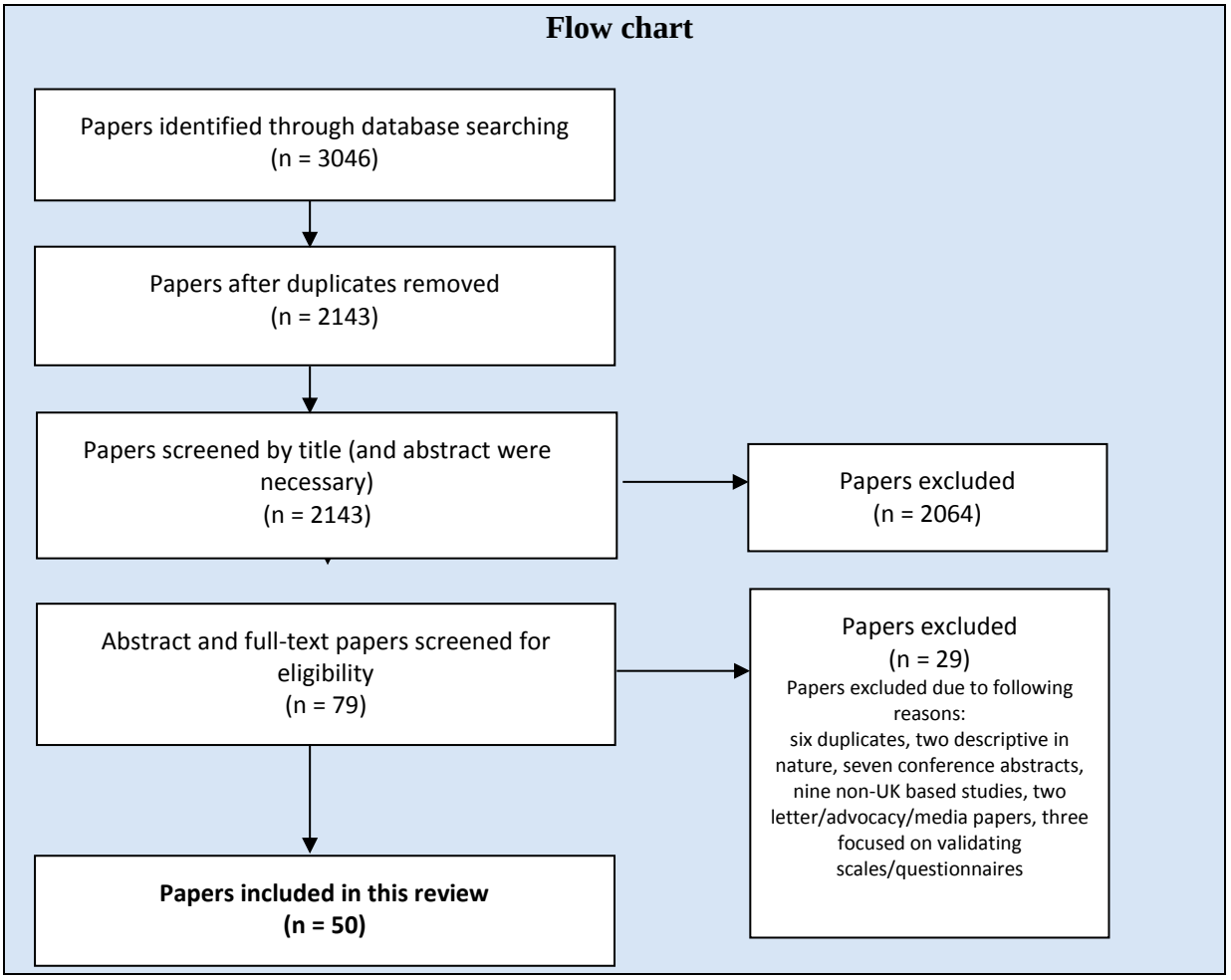
The literature review aimed to gather evidence on the impact of Parkinson's on the socio-economic life of individuals with the condition, their families and society based on prior research undertaken in the UK. The review also sought to enable a better understanding of the key medical and non-medical cost components directly associated with Parkinson's management and care, with an understanding of where public resources are currently directed. The literature has been synthesised using a comprehensive and transparent literature review process.

Inclusion criteria: The review searched for published, peer-reviewed papers and grey literature from the UK, which underpins and quantify the direct and indirect impact of Parkinson's on society. Articles published in the English language between January 1991 and August 2015 were eligible for inclusion. All quantitative and/or qualitative study types were included.

Search strategy: The literature search strategy was developed in consultation with the research team and comprised three facets: (1) terms for Parkinson's, (2) terms to describe the costs associated with the condition, such as financial, employment, pension, housing, healthcare costs, quality of life (QoL), and (3) terms to limit to studies situated in the UK. All terms included in facet one and facet two were searched for in the title and abstract fields and controlled vocabulary terms used where available. All terms included in facet three were searched for in the author address field and controlled vocabulary terms were used where available. The Boolean operators AND and OR were used, alongside truncation, phrase searching and proximity operators. The following databases were searched: ASSIA (ProQuest), CINAHL (EBSCO), Cochrane Library (Wiley), EMBASE (via NICE Evidence Search), MEDLINE (EBSCO) and Web of Science (Thomson Reuters). All search results were exported to RefWorks, a bibliographic management tool. A copy of the search strategy is provided in Appendix 5.

Quality appraisal and study selection: After removal of most duplicate records, the database searches retrieved 2143 papers. In the first instance, the titles of all retrieved papers were screened for relevancy, with abstracts read where necessary. This resulted in a shortlist of 79 papers. A second, thorough screening of the abstracts and full text of all shortlisted papers resulted in 50 papers deemed relevant to this review. The 29 papers excluded at this stage were eliminated for the following reasons: six were duplicates, two were descriptive in nature, seven were conference abstracts, nine were non-UK based studies, two were letter/advocacy/media papers, and three focused on validating scales/questionnaires. The scrutinising and selection of papers for inclusion were carried out by two members of the research team. The literature search screening process is summarised in the flow chart (adapted from Moher *et al.*, The PRISMA Group, 2009) in Figure 2.1.

**Figure 2.1: Flow chart of papers selection process from the database searches**




Data extraction and synthesis: Papers meeting the inclusion criteria were read and data extracted using a standardised extraction form encompassing: author / date, the focus of the study, research design and sample size. The evidence was grouped into six themes: (a) Parkinson's incidence differentials by socio-economic status, (b) Parkinson's management and care, (c) impact on QoL and wellbeing of PwP, (d) impact on quality of life and wellbeing of carers and family members, (e) cost of healthcare use, and (f) societal (economic, social and financial) cost of Parkinson's.

## 2.2 Studies Included for Review

Final inclusion of papers: A majority of the papers included in the literature review studied the impact on quality of life of PwP, carers and their family members (27 papers). Out of these, 10 papers examined the impact on the health and wellbeing of the caregivers (in the majority of cases, the papers focused on spouses) and other family members. A small number of studies (12) focused on estimating the healthcare costs of Parkinson's, costs to the families of PwP as well as on society. A brief summary of the topics covered by these studies as well as their detailed references is presented in Tables 2.3.1 to 2.3.4.

Grey Literature Search: In addition to the database searches, grey literature searches were undertaken on NICE Evidence Search and Google. Grey literature was considered essential to

this research and its inclusion is aligned to the comprehensive review methodology, as previously outlined. The inclusion of grey literature also helped minimise publication bias (Booth, Papaioannou and Sutton 2012, p.77). The grey literature searches used an abridged set of search terms; this was due to NICE Evidence Search and Google allowing a limited number of characters. The most salient search terms were identified through a scan of the literature yielded from the database searches. Most of the grey literature which was deemed to be relevant was also found to have been published elsewhere and thus duplicated with the previous searches. After screening for direct relevancy to costs of Parkinson's, the grey literature searches yielded eight additional resources which merited attention. The key findings from these resources are summarised below (Table 2.1).

**Table 2.2: Summary of key messages from grey literature studies**

| | |
|---|---|
| 1. | To detect and serve: DaTSCAN SPECT used to diagnose in cases of uncertainty. Although this approach is costly, it can differentiate a dopaminergic deficit in non-Parkinsonian condition. The new procedures were beneficial to the unnecessary treatment particularly anti-Parkinsonian drugs in people with no dopaminergic deficiency states and peoples 'quality of life. |
| 2. | Protect Parkinson's nurses in England and save the (NHS) money: Parkinson's nurses have played a significant role in the care and help of PwP. Their timely visits and interventions have helped to reduce: unnecessary consultant appointments, unplanned admissions, re-admissions, and lengths of stay in the hospital, thereby saving an additional NHS expenditure of £35.1 million per year. However, there was currently the budget constraint, as a result, Parkinson's nurse service may receive a cut in the investment. It meant that PwP were likely to omit delivering of vital care from Parkinson's nurses affecting on Parkinson's themselves and their carers. |
| 3. | Royal College of Nursing (RCN) Factsheet: Specialist nursing in the UK: Specialist nurses were significant for patients. They provided tailored care for the individual. The Parkinson's nurse can potentially save unnecessary costs in the healthcare system of almost £148,000 per year in bed days, £44,000 for avoiding consultant appointments, and £80,000 for unplanned admission. |
| 4. | Medical experts call for hospitals to ensure Parkinson's patients get the right treatment after report reveals they are twice as likely to die compared to other people following A&E admission: PwP were more likely to be admitted as an emergency admission than for planned medical procedures (72% v. 28% respectively). The cost of emergency admissions for PwP to the NHS was annually £200m (£3,338 per PwP as compared to £1,417 for a planned nonemergency hospital stay). The main causes for emergency admissions were pneumonia, physical deterioration, urinary tract infection and hip fractures, and PwP were up to twice as likely to be admitted for these conditions compared to the average patient. Further, PwP were almost twice as likely to stay in the hospital for more than 3 months and almost 2.5 times more likely to die in the hospital after an A&E admission. There is an urgency to ensure that PwP receives the correct, cost-effective interventions to reduce the burden of unplanned hospital admissions. |

| | |
|---|---|
| 5. | England hospital Episode Statistics Project: The results from a cross-sectional analysis of England Hospital Episodes database for 2009-2013 showed 324,055 hospital admissions by 182,859 PwP with the larger figure for non-elective than elective admissions. The share of emergency admission was 72% (costing £777 million). The main unplanned admissions were for pneumonia, motor deterioration, urinary tract infection, and hip fractures. PwP were more likely to stay longer (up to 7 days) at the hospital than their controls; there was also a two-fold share of PwP compared to controls for admission having a length of hospital stay exceeding more than 3 months. Therefore, people affected by Parkinson's should receive an accurate diagnosis of their condition to get timely treatment. |
| 6. | Parkinson's Fact Sheet: The number of PwP was approximately 120,000 in the UK in 2011. The manifestation of Parkinson's shows in three main symptoms, including bradykinesia, tremor and rigidity; a diagnosis of Parkinson's is based on having bradykinesia and one or two of the other three symptoms. An autopsy is an absolute approach for the diagnosis of Parkinson's. However, there are tools to help differential states namely PET scan, DaTSCAN, and CT and MRI. Parkinson's has a significant impact on quality of life of both PwP and their carers. This disorder directly affects ability to work thus forcing many PwP to withdraw from their jobs and occupation. There is also a tendency to a reduction in working hours for carers. PwPs are also likely to become isolated. The effect of Parkinson's on the socio-economic burden, therefore, affects both the PwP and carers. |
| 7. | Life with Parkinson's Non-motor symptoms: Parkinson's has an economic impact on both direct and indirect costs. The direct costs are presented in terms of medicine and medical care; the indirect costs are associated with loss of employment in person with the disease and also some carers. The major problem occurring in PwP is non-motor symptoms that these are not related to the movement difficulty in Parkinson's. |
| 8. | Parkinson's Change Attitudes: The PwP needed assistance for their daily living for instance support from someone (42.8% of PwP), transport (42.8%), motability (40.9%), health treatment (25.9%), and mobility aid (22.0%) and thus resulted in extra money spent per month. |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## 2.3 Main Findings from Studies

### 2.3.1 Incidence of Parkinson's by Socioeconomic Status and Geography

Using Primary Care practices data in North East Scotland, Caslake *et al.* (2013) estimated the crude annual incidence of Parkinson's at 28.7 per 100,000 persons with a higher incidence in men (21.1) as compared to women (14.7). The incidence of Parkinson's has risen exponentially with age particularly post 60 years in both men and women (incidence increased from 11.9 in 50-59 years to 149.3 in 80-89 age group). The overall age-adjusted male- female ratio for Parkinson's incidence was 2.18. However, the incidence didn't significantly vary by level of deprivation in Scotland. Caslake *et al*. (2013) also undertook a meta-analysis of 12 similar international studies (of which three were UK based). In other UK studies, the estimated Parkinson's incidence which varied between 13.3 and 18.3 was lower than estimated by Caslake *et al.* for North East Scotland. Dick *et al*. (2007) epidemiological study (conducted in four European countries: northern Scotland, south-eastern Sweden, northern Italy and eastern Romania) examined the association between occupational exposure and incidence of Parkinson's. Scottish data showed a non-significant increased risk for agriculture but significantly reduced the risk for 'transport and communication' for developing Parkinson's incidence. However, overall there was no significant relationship between lifetime toxic occupations exposure and incidence of developing Parkinson's.

**Table 2.3.1: UK Studies on Parkinson's incidence differentials by socio-economic status**

| ***Theme and Focus*** | ***Design / Sample Size*** | ***Reference*** |
|---|---|---|
| 1. Socio-economic status (SES) and deprivation (Scotland) | Epidemiological: 377 PwP, meta-analysis | Caslake *et al.* (2013) |
| 2. SES and occupational exposure | Epidemiological: 649 exposed and 1587 controls | Dick *et al.* (2007) |
| 3. SES and deprivation | Longitudinal: aged 50+ from 469 GP sites (6,813 men and 5,929 women) | Horsfall *et al.* (2013) |

**References**

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DICK, S., SEMPLE, S., DICK, F. and SEATON, A. (2007). Occupational titles as risk factors for Parkinson's disease. *Occupational Medicine*, 57(1), 50-56.

HORSFALL, L., PETERSEN, I., WALTERS, K. and SCHRAG, A. (2013). Time trends in incidence of Parkinson's disease diagnosis in UK primary care. *Journal of Neurology*, 260(5), 1351-1357.

Horsfall *et al*. (2013) examined time trends and the influence of socio-demographic and geographic factors on the incidence of Parkinson's diagnosis using the UK Primary Care database for patients aged over 50 years. The incidence of Parkinson's varied by age, gender, time period, social deprivation score and urban/rural status. The overall incidence of Parkinson's for people over 50 years was 84 per 100,000 person years. After accounting for socio-demographic factors, the adjusted incidence rates were 46 % higher in men than in women, 12% higher in urban than rural areas and marginally lower in less socially deprived areas. Over time, there was a downward trend in Parkinson's diagnosis with the adjusted incidence rate declining by around 6% every calendar year between 1999 and 2009 which may largely represent changes in diagnosis and/or coding rather than a true decline in incidence. The study concluded that the Parkinson's diagnosis rates in the primary care

setting were higher in men and greater in urban areas but not different between socio-economic groups.

### 2.3.2 Parkinson's Management and Care

Deane *et al*. (2014) undertook a study with stakeholders (PwP, caregivers, family and friends of PwP, healthcare and social care professionals) to identify and prioritise the top 10 evidential uncertainties that impact on everyday clinical practice for the management of Parkinson's in the UK. After surveying 1000 participants and in-depth discussions, stakeholders agreed on the following top 10 research priorities for Parkinson's management: the need to address motor symptoms (balance and falls, and fine motor control), non-motor symptoms (sleep and urinary dysfunction), mental health issues (stress and anxiety, dementia and mild cognitive impairments), side effects of medications (dyskinesia) and the need to develop interventions specific to the phenotypes of Parkinson's and better monitoring methods. Deane *et al*.'s study thus identified crucial gaps in the existing evidence to address everyday practicalities in the management of the complexities of Parkinson's.

Skelly *et al*. (2015) studied views of consultant geriatricians and neurologists and PDNS on the quality of in-hospital care provided to PwP. The study found wide variations in the standard of care and one-fifth of hospital professionals rated the overall standard of care as poor and three-fifths felt that medications were not given on time. The study suggested piloting out various interventions to improve the care of PwP in hospitals.

Walker *et al.* (2011) study aimed to assess the PwP health and social care living in North Northumberland (a mostly rural area), UK. About 13.3% of PwP were living in institutional care, and remaining 86.7% living in their own homes. Of those living in their own homes 27.7% had domestic home care services provided and 26.2% used personal home care, services. Five PwP had significant care input from a carer or a family member (7.7%) and 11 from a care worker (17%). Two patients were regularly visited by a district nurse, one by a social worker, and four by an occupational therapist and two patients regularly attended a local day care centre. The study concluded that living in a rural area appeared to be no hindrance to accessing care services when required.

Armitage *et al*. (2009) undertook in-depth interviews of PwP and their close relatives in care homes to explore the effectiveness of care specifically on the role of family members in implementing care pathways. Five primary themes included were: lack of information about PwP, functional variation, nature of relatives' involvement, care home environment and culture, and care provision. The study found an apparent shortfall in the knowledge and understanding of PwP among care home staff and there was a lack of involvement of PwP family in better management of care.

McLaughlin *et al*. (2011) explored the caring experience of relatives providing palliative care for PwP. All 26 caregivers were spouses, the majority female ($n = 17$) and all were responsible for providing physical, social and emotional care in the home. The majority (81%) were aged over 55 years of age and the length of their caring activities ranged between two and 20 plus years. Four themes emerged from the in-depth analysis: medical support for PwP, burden related to caregiving, information needs and economic implications. Although the relatives of PwP viewed caregiving as their role and duty, the results highlighted the widespread burden of providing care on the emotional and physical health of the caregivers.

The financial implications for providing care were outlined, with many reporting difficulties in accessing benefits. From the point of diagnosis, which had a huge emotional impact on relatives and caregivers, many felt that health professionals hadn't consulted them for the care pathway plan. Since diagnosis, caregivers commented on the lack of continued and coordinated care plans for relatives, resulting in symptoms being mismanaged and care opportunities for family and relatives being missed. Stereotypes of the meaning and timing of palliative care were common with many viewing it as being synonymous with cancer and not applicable to a PwP. As the wellbeing of the informal caregiver directly influences the care of the PwP, support interventions are required to relieve their burden, maximise outcomes and ensure targeting of services.

Waldron *et al*. (2013) examined the social worker's role in the delivery of palliative care to PwP. Differing perceptions of palliative care emerged: from a holistic approach to specialist care near the end of life. Negative associations of palliative care were identified. Other barriers also exist such as a lack of knowledge and experience of Parkinson's and a lack of resources that hinder the delivery of palliative care to clients with chronic conditions. Different interpretations of palliative care affect its delivery to clients with LTC. Very few PwP were referred to specialist palliative care specifically for management of their symptoms, which must prevent holistic care. Social workers have an important, yet underdeveloped, role in identifying and addressing palliative care needs. Participants stressed that palliative care provision should be extended to support family carers. They felt that the demanding role of a carer often goes unrecognised. Carers, who may have their own health problems, may have to adapt to their loss of independence, increased social isolation, physical exhaustion and psychological stress. They favoured a separate assessment of carers' needs and respite provision for carers that would depend on factors such as a client's level of mobility. Practical help, information, emotional support, referral to appropriate agencies that might be of benefit and respite opportunities were highlighted as carers' needs. Policies and procedures should be clarified regarding prioritisation and access for clients with chronic LTC to appropriate palliative care.

Higginson *et al*. (2012) examined changes in palliative care needs with Parkinson's in late stage, shown by H&Y stage 3-5. Over two-thirds of patients had a severe disability, of which over one-third were wheelchair-bound/bedridden. Over the year, half of the patients showed either an upward (worsening, 24/60) or fluctuant (8/60) trajectory on palliative care outcome scale and symptoms. The strongest predictors of higher levels of symptoms at the end of follow-up were initial scores on the palliative care outcome scale and being male, both were more predictive than initial H&Y scores. The quality of life of PwP in late stage (measured through EuroQuol-5 dimension [EQ5D] and Parkinson's Disease Quality of Life Questionnaire [PDQ]-8 tools) had deteriorated considerably over one year with one-third of PwP having died. The findings point to a profound and complex mix of non-motor and motor symptoms in PwP in late stage. Symptoms are not resolved and half of the patients deteriorate. Palliative problems are predictive of future symptoms, suggesting that an early palliative assessment might help screen for those in need of earlier intervention.

The results have been summarised below (Table 2.3.2).

**Table 2.3.2: UK Studies on Parkinson's management and care**

| *Theme and Focus* | *Design / Sample Size* | *Reference* |
|---|---|---|
| 1. Priority settings by clinicians, health professionals and families | Cross-sectional: 1000 people | Deane *et al.* (2014) |
| 2. In-hospitalisation care: clinicians and health professionals view | Cross-sectional: 93 staff | Skelly *et al.* (2015) |
| 3. Care services for rural PwP | Cross-sectional: 75 PwP | Walker, Sweeney and Gray (2011) |
| 4. Effectiveness of care in nursing home | Qualitative: carer's experience-51 relatives and 24 PwP | Armitage *et al.* (2009) |
| 5. Palliative care needs, QoL in Late stage | Longitudinal: 82 PwP | Higginson *et al.* (2012) |
| 6. Palliative care needs, QoL of carers | Qualitative: 26 carer's experience | McLaughlin *et al.* (2011) |
| 7. Social workers' role | Qualitative: 13 in-depth interviews of social workers | Waldron *et al.* (2013) |


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### 2.3.3 Quality of Life

### (A) Impact on quality of life and wellbeing of PwP

Parkinson's is a progressive condition and thus has a significant impact on QoL and wellbeing of PwP over time. A number of studies have documented the impact of the progression of Parkinson's into the gradual loss of both motor and non-motor functions, consequently impacting on QoL of PwP. To recognise and factorise specific aspects of impact on QoL and wellbeing on PwP, the eighteen studies identified could be classified into two broad groups: First, Parkinson's symptoms severity and diversity; second, self-help groups and social support and their interface with health and wellbeing.

1. *Differential effects of symptoms with* Parkinson's *stage*

Varied symptoms that emerge from the point of onset of Parkinson's will worsen, particularly in people who have been diagnosed for more than 6 years (Politis *et al*. 2010). Both the

experience of the motor (movement) and non-motor symptoms directly affects the QoL of PwP and worries/anxieties/depression associated with further deterioration in QoL in PwP with condition progression. The Parkinson's Disease Quality of Life Questionnaire (PDQ-39) which covers eight domains and comprises 39 items, is widely used as a disease-specific measure of health-related quality of life (HRQoL) in PwP. The eight domains are: mobility, activities of daily living (ADLs), emotional wellbeing, stigma, social support, cognition, communication, and bodily discomfort.

*Motor symptoms:* Bradykinesia, rigidity and tremor are the 'cardinal motor symptoms' affecting the everyday activities and life of PwP. Problematic mobility problems include: shuffling gait, start hesitation, freezing, festination, propulsion, and difficulty in turning. The most important consequence of the motor symptoms is falling, influencing costs related to injury, increased the length of hospital stay, and restricting participation in social activities. Motor symptoms were also shown to significantly impact on QoL scores and thus resulted in poorer HRQoL in PwP (Rahman *et al*. 2008). In comparing the QoL of PwP attending movement disorders clinic vs. general medical clinic in Scotland, it was found that the QoL of PwP attending the movement disorders clinic was significantly higher (Blackwell, Brown and Rochow 2005).

*Non-motor symptoms:* Non-motor symptoms manifest in a diverse range of symptoms comprising: mood, cognition, sensory disturbance, autonomic disturbance, and pain. The level and degree of non-motor symptoms are correlated to advancement in age and the severity of the disease. The evidence suggests that these symptoms have a significantly greater influence on HRQoL of PwP from early through to the advanced stages of Parkinson's. Depression, anxiety, impaired concentration, memory retrieval, sleep disturbance, and autonomic disturbance had shown significantly negative impacts on QoL (Findley *et al*. 2002; Politis *et al*. 2010; Rahman *et al*. 2008; Leroi *et al*. 2011; Duncan *et al*. 2014; Simpson, Lekwuwa and Crawford 2014). Depression develops in approximately 50% of PwP as the condition progresses, and although the most troublesome of the non-motor symptoms, it remains under-recognised and lacks effective treatment (Politis *et al.* 2010).

Shearer *et al*. (2012) evaluated health state utility value affecting motor and non-motor symptoms of patients with idiopathic Parkinson's using the EQ-5D. Findings indicated pain, depression, motor impairment and insomnia as the main declining factors in utility value of PwP. Depression had the greatest impact during the early stage of the condition. Thus an improvement of the main factors influencing utility value could contribute to an increase in QoL among PwP.

In a survey of PwP, the most troublesome symptoms, the pain (in particular musculoskeletal and visceral pain) was ranked the highest amongst non-motor symptoms in an early stage Parkinson's group, thus affecting directly their QoL (Politis *et al*. 2010). These symptoms resulted in a direct increase in medical and other health care costs, and should therefore be recognised as a key factor of this disorder, and taken into account for developing better management of the condition.

2. *Self-help groups and social support in PwP*

The literature highlighted that as Parkinson's progresses, PwP experience three main alterations in their perception and adaptation of living with the condition: (1) change, (2)

addressing changes, and (3) reflections on living with Parkinson's (Benharoch and Wiseman 2004).

First, the most common symptom changes in PwP included tremors, changes in movement quality, dribbling, difficulties in swallowing and speech, tiredness, problems with digestion, and deterioration of memory. Other changes included a decline in mobility, loss of employment, but gains in new skills due to being diagnosed with Parkinson's. Second, the need to address changes identified medications management over time, reactions to other people's involvement, occupations undertaken to maintain wellbeing, and finding new ways of doing things. Third, reflections on living with Parkinson have included thoughts on problems encountered, acceptance of the disease, self-consciousness, the importance of a positive attitude and maintaining normality. PwP who were participating in self-help groups were more likely to accept their condition and also adapt their usual lifestyle. However, they also expected that self-help groups should be more supportive. Conversely, PwP who were not supported socially reported higher scores/levels of distress, anxiety, stress, and less satisfaction (Simpson *et al*. 2006). Further, those PwP who had stronger social support in terms of the number of close relationships, reported better psychological outcomes (Simpson *et al*. 2006). Therefore, further research should explore the social support and services that might mitigate deterioration in QoL of PwP.

Barrow and Charlton (2002) explored how progression of the condition had affected the lives of eight PwP and whether self-help group membership was related to coping methods (four of the participants were members of the Parkinson's UK Society and four were not). It was found that all participants had experienced losses of physical and mental functioning and independence, self-identity and future quality of life and were afraid of further losses as the Parkinson's progressed. Although all participants used a range of coping methods, it was found that there were differences between members and non-members in the prominence of certain methods and overall coping style. For non-members, coping centred upon maintaining a normal life and denying they had the condition; for group members, the condition and its likely consequences were accepted and incorporated into everyday life. The discourse of non-members contained many references to a self-help group as a source of distress, while discourse of members identified it as a supportive resource. This exploratory study enhances our understanding of differences between people in their willingness to use a self-help group, and in turn, raises questions about the provision of psychological services in a chronic progressive disorder.

To sum up, the QoL of PwP is mainly affected by non-motor and motor symptoms. Non-motor symptoms include psychological wellbeing, particularly depression and anxiety. Depression is a significant problem affecting PwP, it is not well treated and leads to direct medical and healthcare costs. On the other hand, common motor symptoms derived from bradykinesia, rigidity, and tremors are associated with the physical wellbeing of PwP. These symptoms can provoke a fall associated with injury, treatment in hospital, and additional social care needs. These factors accelerate a reduction in QoL in PwP.

Some studies focused on the impact of Parkinson's on wellbeing. Two studies found poorer QoL and emotional wellbeing in early onset groups than late-onset of PwP (Knipe *et al*. 2011; Lawson *et al*. 2014). Another study showed that the subjective wellbeing scores of PwP living in a care home were lower than in people living alone in their own home (Cubi-Molla

and Devlin 2014). Moreover, people with advanced Parkinson's experienced a decline in their ability to perform their occupation well due to lower physical, psychological, social and spiritual wellbeing, leading to the difficulties with their employment. These caused distress and disappointment of PwP, as well as impacting on their QoL and wellbeing (Murdock, Cousins and Kernohan 2014).

**(B) Impact on quality of life and wellbeing of carers and family members**

Parkinson's not only impacted on people who are living with the condition, but it also affects the QoL of caregivers, as assessed using PDQ-carer, questionnaire and Short form (SF)-12 questionnaire and self-reported wellbeing questions. Studies have found a number of factors influencing QoL in carers, including: age, gender, health status, duration of caregiving role, the level of mobility in PwP, and impaired cognitive function in PwP. Most caregivers were female and were the spouse or partner of the PwP. The caregivers were younger, with mean age lower than those of PwP. An increase in morbidity, particularly psychiatric symptoms, was found almost five-times higher in caregivers compared to the general population of similar age group. In addition, the QoL of caregivers over the long-term duration of caregiving was inferior as compared to the general population particularly in the four dimensions of social, anxiety and depression, stress, and self-care. It has been reported that Parkinson's has a widespread impact on caregivers' social, psychosocial, and physical wellbeing (Davey *et al*. 2004; O'Reilly *et al*. 1996; Kudlicka, Clare and Hindle 2014; Peters *et al*. 2011; Peters *et al*. 2013; Morley *et al*. 2012; Drutyte *et al*. 2014). Morley *et al*. (2012) indicated that a carer's age, gender, health status, caregiving duration, mobility and cognitive impairment were significant factors influencing QoL of caregivers.

Schrag *et al*. (2004) explored the impact of Parkinson's on the offspring of PwP. The activities of daily living help and the loss of social life were main burdens where the children were still in adolescence. In some of the adult children, the aspect of caring for their own family was a significant influence. Morley *et al*. (2011) examined the QoL and wellbeing affecting younger children and older children of parents with Parkinson's and multiple sclerosis (MS). A comparison found that there was no difference in QoL and wellbeing in either group. The clinical guideline was important for offspring who were looking after their parents with PD and MS. The NICE guidelines for Parkinson's disease published in 2006 made no reference to the children of PWP; many children who were providing informal care to PwP expressed that they did not have enough information about their parent's Parkinson's (Schrag *et al*. 2004; Morley *et al.* 2011). Future guidelines should include information for adult children to help ensure better communications and interactions with health professionals.

Falls in PwP were identified as the most important factor that significantly impacted on informal care, with carers experiencing anxiety, worry, fear, anger, frustration, and shock due to falls in PwP. Increased occurrence of falling in PwP lessened the chances for carers to go out for their normal activities, decreased contact with their friends and neighbours. Furthermore, falling also increased health care costs of PwP and caregivers (Davey *et al*. 2004). Education courses and support for informal caregivers was limited and there is a need for them to be supported by health professionals, particularly Parkinson's Disease Specialist Nurses (PDNS).

The results have been summarised below (Table 2.3.3).

**Table 2.3.3: UK Studies on Parkinson's impact on quality of life**

| *Theme and Focus* | *Design / Sample Size* | *Reference* |
|---|---|---|
| **(A) Impact on QoL - PwP only** | | |
| 1. Physical and mental functioning, independence and self-identity | Qualitative: 8 in-depth interviews of PwP | Barrow and Charlton (2002) |
| 2. Positive impact by participation in different daily activities | Qualitative: 7 in-depth interviews of PwP | Benharoch and Wiseman (2004) |
| 3. QoL differentials: attending general vs. movement disorder clinic | Cross-sectional: 42 PwP | Blackwell, Brown, Rochow (2005) |
| 4. QoL and Wellbeing differentials | Cross-sectional: 199 PwP | Cubi-Molla and Devlin (2014) |
| 5. Condition progression (Advanced stage) and treatment | RCT:280 PwP, Sumanirole vs. placebo | Duchane and Jenkinson (2003) |
| 6. Non-Motor symptoms at Early stage | Epidemiological: 58 PwP and 99 healthy controls | Duncan *et al.* (2014) |
| 7. QoL differential factors after controlling for disease severity and medication | Cross-sectional (UK, Italy, Spain, USA, Canada, Japan): 203 clinicians, 1020 PwP, 687 carers | Findley *et al.* (2002) |
| 8. Differentials by young vs older | Cross-sectional: 426 PwP | Knipe *et al.* (2011) |
| 9. Early stage cognitive impairment | Epidemiological: 219 PwP and 99 healthy controls | Lawson *et al.* (2014) |
| 10. Differentials by Parkinson's stages | Cross-sectional: 123 PwP | Lee *et al.* (2006) |
| 11. Differentials and predictors | Cross-sectional: 81 PwP | Lekuwa and Crawford (2014) |
| 12. Early stage - apathy and impulse controls | Cross-sectional: 99 PwP | Leroi *et al.* (2011) |
| 13. Parkinson's progression | Qualitative: 10 in-depth interviews of PwP | Murdock,Cousins and Kernohan (2014) |
| 14. Daily activity and most severe health complaints by Parkinson's progression | Cross-sectional: 130 PwP | Politis *et al.* (2010) |
| 15. Daily activity and management of symptoms/complaints by Parkinson's progression | Cross-sectional: 265 PwP | Rahman *et al.* (2008) |
| 16. Motor and Non-Motor symptoms by Parkinson's progression | Cross-sectional: 162 PwP | Shearer *et al.* (2012) |
| 17. Wellbeing and social support | Cross-sectional: 34 PwP | Simpson *et al.* (2006) |
| **(B) Impact on QoL - Carers and Family members** | | |
| 1. Fall management by carers | Qualitative: 14 in-depth interviews of carers | Davey *et al.* (2004) |
| 2. Stress and financial impact on carers | Cross-sectional: 1881 carers | Drutyte *et al.* (2014) |
| 3. Stress on carers | Cross-sectional: 123 carers | Schrag *et al.* (2006) |
| 4. PwP and Carers by Parkinson's severity | Cross-sectional: 65 PwP, 50 carers | Kudlicka, Clare and Hindle (2014) |

| | | |
|---|---|---|
| 5. PwP and Carers by Parkinson's severity | Cross-sectional: 238 PwP-carers | Morley *et al.* (2012) |
| 6. Health and wellbeing differentials Carer spouse vs. non-carer spouse | Epidemiological: 154 carer spouses, 124 non-carer spouses as control | O'Rielly *et al.* (1996) |
| 7. Health and wellbeing differentials of PwP and Carers | Cross-sectional: 901 PwP, 734 carers | Peters *et al.* (2011) |
| 8. QoL and health and social services experience of Carers of Parkinson's vs. Other neurological conditions | Cross-sectional: 1910 carers (434-motor neuron disease, 721-multiple sclerosis and 755-Parkinson's disease) | Peters *et al.* (2013) |
| 9. QoL of Offspring | Cross-sectional: 143 offspring | Morley *et al.* (2011) |
| 10. QoL of Offspring | Cross-sectional: 89 offspring | Schrag *et al.* (2004) |

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### 2.3.4 Cost of Healthcare Use

The greatest impact of Parkinson's is on the deterioration of QoL of both PwPs and caregivers. There is also a tremendous economic and financial burden on society in terms of social care and health care delivery costs. The overall economic burden of Parkinson's could be assessed by measuring the direct medical and non-medical costs as well as indirect costs.

The annual total costs of a Parkinson's case varied markedly between £13,800 (McCrone, Allcock and Burn 2007) and £29,000 (Findley *et al.* 2011). The direct medical costs were estimated to be £1,881 per patient per annum which comprised hospitalisation (£1,378), professional visits (£385), and tests (£117). Direct non-medical costs (professional care costs) were £13,364 per person per annum, and indirect costs (informal care costs by families, productivity losses, and sick-leave) ranged between £11,000 and £12,500 per person per

annum (McCrone, Allcock and Burn 2007; Findley *et al*. 2011). The proportion of direct medical costs, direct non-medical costs, and indirect costs were 7%, 50% and 43% respectively (Findley, *et al*. 2011). As seen in the previous figure, the overwhelming costs of Parkinson's were attributed to direct non-medical costs and indirect costs. In addition, McCrone, Allcock and Burn (2007) demonstrated that the burden of informal care cost was the greatest, contributing to 80.3% of the total cost of £13804, whilst direct social cost was just 5%. Further, the data from the studies which focused on the impact on caregivers' QoL showed that most carers were retired, female and also the spouse or partner of the PwP. McCrone *et al*. further argued that as most PwP were male, there was an underestimation of the costs of time put in by female caregivers.

Total costs of care varied by QoL of PwP in relation to medication cycles and the severity of the condition. The severe health states resulted in an increase in the time spent in OFF state (when medication to improve the dopaminergic system and movement was not at its optimal, and people experienced tremor, stiffness, slowness of movement, and/or mobility problems), with increasing H&Y scores, and thus resulted in rising costs. Also the longer duration of Parkinson's, depression, gait disturbance, and community/neighbourhood related problems resulted in a further increase in costs (Findley *et al*. 2011). Findley (2007) estimated that the total cost of PD was between £450 million and £3 billion per year; the underlying variation was mainly due to the indirect costs and prevalence rate for Parkinson's used in the model.

Hospitalisations cost the NHS more, as compared to ambulatory care. According to hospital admissions data for PwP, 28% were a consequence of elective admission and 72% non-elective admission as compared to age and sex-matched individuals admitted to hospital for who the respective proportions were 60% and 40% (Low *et al*. 2015). Almost double the rate of non-elective admission was found in PwP, with the highest rate (45.3%) recorded in those in the age range between 75-84 years (Low *et al*. 2015). The cost of excess bed days (EBD) accounted for 12% of the total costs (Low *et al.* 2015). Pneumonia, Parkinson's itself, urinary tract infections, cardiac-related and hip fractures were the most causes of non-elective admissions. The proportion of falls and fractures, particularly hip fractures contributed much more in the total costs (comparison frequencies and costs) (Low *et al*. 2015). These were consistent with motor symptoms in which falls were the significant troublesome complaint affecting QoL and informal care costs. Furthermore, PwP who had co-morbidities associated with urinary tract infections, pneumonia and hip fractures were likely to stay longer in the hospital, and in those over 85 years, the likelihood of mortality was higher as compared to the younger age cohorts (Low et al. 2015). Similarly, Xin *et al*. (2014) found that pneumonia, urinary tract infections, falls and fractures, cardiovascular and circulatory disorders, central nervous system disorders and disorders of sense organs, gastrointestinal disorders, and mental disorders were the main causes for emergency admissions and hospitalisations in PwP with disease progression.

The PDNS can reduce number of doctors and specialist consultations about Parkinson's care. According to Hobson, Roberts and Meara's (2003) study, the PDNS assessed 321 patients and made 881 interventions during one year. The estimated cost saving by employing a PDNS was £54,992. Community visits by PDNS potentially saved £8,296 on outpatient and £1203 on inpatient visits. Jerman *et al*. (2002) and Hurwitz *et al*. (2005) examined PDNS intervention and found the nurse specialists had little impact on the clinical conditions of PwP

but that they were able to improve the overall wellbeing of the PwP without adding healthcare costs.

A cost-effectiveness and QoL review of Parkinson's undertaken by Dowding, Shenton and Salek (2006) found that the carers' burden was the major source of economic costs which so far had not been factored into cost-effectiveness analysis studies. They further stated that Parkinson's cost of social care as well as healthcare could significantly be decreased by improving HRQoL of carers.

The summary results from reviewed papers are shown below (Table 2.3.4).

**Table 2.3.4: UK Studies on healthcare and societal costs related to Parkinson's**

| ***Theme and Focus*** | ***Design / Sample Size*** | ***Reference*** |
|---|---|---|
| 1.Cost- effectiveness/ QoL reviews | Literature review: International | Dowding, Shenton and Salek (2006) |
| 2. Medication costs differentials by Parkinson's progression | Cross-sectional: 409 PwP, movement disorder clinic | Dodel *et al.* (1998) |
| 3. Economic and healthcare impact | Cross-sectional: 432 PwP | Findley *et al.* (2007) |
| 4. Healthcare costs: home vs. residential care | Cross-sectional: 302 PwP by severity | Findley *et al.* (2011) |
| 5. Healthcare costs by Parkinson's progression | Cross-sectional: 444 PwP | Findley *et al.* (2003) |
| 6. Specialist Nurse service cost | Cross-sectional: 321 PwP | Hobson, Roberts & Meara (2003) |
| 7. Specialist Nurse Intervention on health care costs and QoL | RCT: 1859 PwP | Jarman *et al.* (2002); Hurwitz *et al.* (2005) |
| 8. Hospitalisation costs and incidence | Routine Hospital Episode Statistics data for 4 years | Low *et al*. (2015) |
| 9. Hospitalisation costs, incidence by Parkinson's progression | RCT: 2074 PwP, followed over 10 years | Xin *et al.* (2014) |
| 10. Healthcare and societal costs by severity | Longitudinal: 174 PwP | McCrone, Allcock and Burn (2007) |
| 11. Societal costs - loss of employment | Quantitative: two datasets: 151 and 308 PwP | Schrag and Banks (2006) |
| 12. Employment loss and financial burden | Cross-sectional: 72 PwP | Clarke, Zobkiw and Gullaksen (1995) |

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HOBSON, P., ROBERTS, S. & MEARA, J. (2003). What is the economic utility of introducing a Parkinson's disease nurse specialist service? *The Clinician*, 3, 1-3.

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JARMAN, B., HURWITZ, B., COOK, A., BAJEKAL, M. and LEE, A., 2002. Effects of community based nurses specialising in Parkinson's disease on health outcome and costs: randomised controlled trial. BMJ (Clinical research ed.), 324(7345), pp. 1072-1075.

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MCCRONE, P., ALLCOCK, LM. and BURN, DJ. (2007). Predicting the cost of Parkinson's disease. *Movement Disorders*, 22(6), 804-812.

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### 2.3.5 Societal (Economic, Social and Financial) Cost of Parkinson's

Only a few studies revealed the societal costs of Parkinson's. In terms of (loss of) employment for PwP, the duration since diagnosis of the condition had a direct impact on full-time and part-time work status. The more advanced the condition, the less employment was noted in those populations. Schrag and Banks (2006) found that in PwP with Parkinson's duration of more than 5 years, only 6-10% of them were working full-time and 7% held part-time jobs. 46 % of PwP were unable to work after having Parkinson's for more than 5 years and this figure increased to 82% for those having Parkinson's for more than 10 years. Additionally, the average time loss of employment due to Parkinson's was 4.9 years. Gender, type of work, and living circumstances had the least influence on average years of employment lost (Schrag and Banks 2006). McLaughlin *et al*. (2011) through in-depth interviews with caregivers outlined the financial implications for providing care to PwP by family members and underlined the difficulties in accessing benefits and the loss of income.

Clarke, Zobkiw and Gullaksen (1995) studied the QoL and care of PwP attending movement disorders clinics in England and found that the main problems were related to their housing/ accommodation, travel, holidays and pursuing hobbies. They also found financial difficulties arose amongst PwP due to involuntary early retirement and delays in receiving welfare benefits. PwP were satisfied with their hospital care, specialised clinic and PDNS input. It has been suggested that there is a need to strengthen the roles of physiotherapists, speech therapists, specialist nurses and social workers in the management of Parkinson's, as well as place more value on the support needs of carers, which includes providing respite care. Drutyte *et al*. (2014) found an important stressor amongst carers was a reduced household income which was due to caring for the PwP; 25% of carers were found to have reduced their employment and 30% also experienced a reduction in their financial conditions.

There was a significant correlation between the H&Y score for Parkinson's and the direct economic costs of health and social care with the more advanced stage of the condition

leading to increased direct costs, particularly that of social care. These costs by stages varied as follows: stage 0 and I, II, III, IV, and V (£2,971, £3,065, £6,183, £10,134, and 18,358 respectively) (Findley *et al*. 2003). Those PwP who were in later stages of Parkinson's were likely to become non-responsive to medication (or develop drug resistance) and thus aggravate the condition, leading to increased expenditure on health and social care. Furthermore, the difference in the type of accommodation was a significant variant of the cost of care. People who were living in their own home (compared to those in a nursing home) had the lowest total of annual direct costs (£4,189). Costs for PwP living full-time in institutional care were almost fivefold higher than PwP living in their own home (Findley *et al*. 2003).

## 2.4 Conclusion

Parkinson's is an incurable, long-term, neuro-degenerative condition with movement, cognitive, psychological and physiological symptoms that have a substantial impact on QoL, especially as the condition progresses and particularly as an individual becomes less able to look after him or herself. In many cases, Parkinson's care is informal, as family members and friends take on a carer role assisting the PwP. Indeed, the vast majority of the cost of managing Parkinson's has been attributed to informal care and social care, rather than direct medical costs. The literature clearly highlights that not only does the QoL of PwP deteriorate over time, but the QoL of their family members and carers are also severely affected – both in economic and social contexts. Family members gave up their time, employment and resources, plus watched the deterioration of the QoL of people they cared for; thus accentuating the total societal costs. Grey and published literature has also highlighted the critical role played by Parkinson's nurses in the management and care of Parkinson's, and reiterates that additional funding by the NHS should be allocated for strengthening and extending outreach services of Parkinson's nurse specialists (and possibly other health and social care specialists) to PwP and their families.

## References

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# 3 Survey Response Profile

## 3.1 Items Included in the Questionnaire

***Resource use and items for financial costings***

The collection of 'resource use' information is crucial for any cost of illness study. However, this would have involved filling out a lot of quantitative numbers and values for type, frequency and specific reference/recall period. Therefore, information on key cost drivers collected through online survey questionnaire were simplified and pre-coded for the ease of participants. The following table (Table 3.1) presents key items/indicators considered for this study.

**Table 3.1: Key items and indicators included in the questionnaire**

| | |
|---|---|
| 1. Socio-demographic profile (PwP and Carer) | Gender, age, marital status, education, economic activity, current/recent occupation, ethnicity, country of residence, postcode, duration of stay at current address, housing status, living with whom, household size and composition |
| | Changes in work status, employment conditions and working hours due to Parkinson's; annual workdays off related to Parkinson's |
| 2. Parkinson's / Long-term condition | Year of diagnosis of Parkinson's, any other LTC and its treatment. |
| 3. Health and Wellbeing (PwP and Carer) | General health status, change in general health over 12 months, health-related quality of life (mobility, self-care, usual activities, pain/discomfort, anxiety/depression), health state scale, life satisfaction, life worthwhile, happiness, anxiousness |
| 4. Use of Healthcare Services (last 12 months) | Outpatient Care: Number of contacts to GP, Practice Nurse, Hospital Nurse, Hospital Doctor, Neurologist, Psychiatrist, Geriatrician/Care of the Elderly Consultant, Parkinson's Nurse, Speech and Language Therapist, Physiotherapist, Occupational Therapist, Mental Health Professional, Psychologist/Counsellor, Optometrist, Dietician, Chiropodist, Podiatrist, Chiropractor, Pharmacist; Funding source (NHS, Self-funded, Private health scheme, Reimbursement health scheme, Combination of funding, Other); Cost to you |
| | Diagnostic tests: Number of Blood test, MRI scan, EEG, CT scan, DAT scan, PET scan, X-ray, Other tests; Funding source (NHS, Self-funded, Private health scheme, Reimbursement health scheme, Combination of funding, Other); Cost to you |
| | Inpatient Care: Incidence, Total hospitalisation days; Planned inpatient stays, Unplanned inpatient stays under 3 days/more than 3 days; Funding source (NHS, Self-funded, Private health scheme, Reimbursement health scheme, Combination of funding, Other); Cost to you |
| | A&E Visits: number of times called 999 or 111; used ambulance service, visited A&E; funding source (NHS, self-funded, private health scheme, reimbursement health scheme, combination of funding, other); Cost to you |
| | Medication: Number of medications/prescriptions; Funding source (Free prescription, Privately funded, 3 month pre-payment certificate, 12 month pre-payment certificate, MedEx, HC2 certificate, HC3 certificate, Exempt from charges, MatEx); Cost to you; Number of non-prescription medicines and Cost to you; Side effects of Parkinson's medications and Cost to you |

| | |
|---|---|
| 5. Access and Mode of Travel to Healthcare Services | Problems in accessing GP, Practice Nurse, Hospital Nurse, Hospital Doctor, Neurologist, Psychiatrist, Geriatrician/Care of the Elderly Consultant, Parkinson's Nurse, Speech and Language Therapist, Physiotherapist, Occupational Therapist, Mental Health Professional, Psychologist/ Counsellor, Optometrist, Dietician, Chiropodist, Podiatrist, Chiropractor, Pharmacist; Main transport use to access; Who accompanied you; Funding source (NHS, Self-funded, Private health scheme, Reimbursement health scheme, Combination of funding, Other); Cost to you |
| 6. Equipment Purchased | Number and type of equipment purchased; Funding source (NHS, Self-funded, Local council grant, Charity support, Other); Cost to you |
| 7. Alterations to Accommodation | Number, type, and date of alterations; Funding source (NHS, Self-funded, Local council grant, Charity support, Private health scheme, Reimbursement health scheme, Combination of funding, Other); Cost to you |
| 8. Access and Alterations to Vehicle | Type of driving license, Access to any vehicle, mobility vehicle, Alterations to vehicle; Funding source (NHS, Self-funded, Local council grant, Charity support, Private health scheme, Reimbursement health scheme, Combination of funding, Other); Cost to you |
| 9. Utility and other expenses | Problem in home indoor temperature (Central heating, Electric blanket, Fan heater, Air conditioning, Cooling fan, Other); Additional monthly cost to you; purchasing takeaway and convenience food and additional monthly cost to you |
| 10. Access to Daily Living Support | Whether needed assistance for Cleaning, Shopping, Personal care, Bathing, Cooking, Gardening, Ironing, Decorating, Transport, Attending medical appointments, Exercise/physiotherapy classes; How often; Who helps; Cost to you |
| 11. Receipt of Income/Benefits by Household Members | Receipt and Changes in finances related to Regular income from employment, Working Tax Credit, Income Support, Jobseekers Allowance, State Pension, Occupational Pension, Pension Credit, NHS Continuing Care, Attendance Allowance £55.10 a week/£82.30 a week, Mobility Allowance, Carers Allowance, Employment and Support Allowance work-related activity group (£102.15/ week), Employment and Support Allowance support group (£109.30/week), Disability Living Allowance lower rate care component (£21.80/week), DLA middle rate care component (£55.10/week), DLA higher rate care component (£82.30/week), DLA lower rate mobility component (£21.80/week), DLA higher rate mobility component (£57.45/week), Personal Independent Payment lower rate daily living component (£55.10/week), PIP higher rate daily living component (£82.30/week), Personal Independent Payment lower rate mobility living component (£21.80/week), PIP higher rate mobility living component (£57.45/week), Child Benefit, Child Tax Credit, Housing Benefit, Council Tax Benefit, Other benefit, Other income |
| 12. Household Income | Gross annual income (Under £10,000, £10,000 - £19,999, £20,000 - £29,999, £30,000 - £39,999, £40,000 - 49,999, £50,000 or more, Don't know); Reduction in monthly income, how much and why; |
| 13. Impact of Parkinson's on Household Finances | Not affected; Affected (Savings have been reduced, Borrowing has increased to meet basic needs, Re-mortgage to release equity, Reduced holidays, Changed priorities for spending, Reduced social activities e.g. eating out, Level of income to use on gifts for birthdays/Christmas has reduced, Other) |

### *Health economic evaluation framework*

A basic framework of health economics evaluation has been used, with both NHS and societal perspectives in mind. The cost of illness (here with Parkinson's) study included individual's (PwP) level costs and their reported outcomes. The costs covered direct medical

and non-medical costs, indirect costs, and tangible costs associated with physical and psychological experiences as well as other costs associated with the management and care of PwP. As listed in Table 3.1, the use of health care services (resource use) by PwP included primary and outpatient care, diagnostic tests, ambulance and A&E services, inpatient care and medications. Any out-of-pocket (OOP) payments made by PwP and their family to use health care services were also recorded. Non-medical costs included OOP towards travel to attend medical appointments and equipment purchased in order to improve mobility both within and outside of the home as well as for better management of conditions (e.g. medication dispenser with timer). Non-healthcare costs included alterations to accommodation, mobility or other vehicle, living environment in terms of regulation of hot or cold temperature, regular purchasing of takeaway and convenience food, and payments towards daily living assistance such as personal care, bathing, cooking, gardening, ironing, cleaning, decorating, shopping, transport, attending medical appointments, and exercise/physiotherapy classes. The individuals' level outcomes/consequences/effects as a result of Parkinson's were stated in both monetary and non-monetary indicators. These included health-related quality of life using the EQ5D-5L instrument to convert into quality-adjusted life years (QALYs), wellbeing and loss of income/wages as a result of PD. Further, if using a longer timeframe (usually more than two years), then appropriate discounting to both costs and effects needed to be applied.

All physical resource use items including time-related to health and social care services were monetised using the published unit costs (reference costs) from the Department of Health and reports from the PSSRU http://www.pssru.ac.uk/project-pages/unit-costs/. The societal cost, in terms of productivity loss (workdays off due to sickness, reduction in weekly hours, and early retirement), as well as other non-monetised costs including state benefits were computed and monetised using the published sources. However, in the total societal cost, the research team did not account for premature mortality due to Parkinson's during the working life. The total annual financial burden on the PwP household was computed by adding all OOP expenses and loss of income of both PwP and caregivers incurred during the last 12 months.

## 3.2 Survey Response Rate

Filling in of the questionnaire, either online or through the post, was a challenge for the PwP and their caregivers. The survey sought varied quantitative and qualitative information through 112 detailed questions spread over 30 A4 size pages. Due to the volume and quality of the information needed from relatively older people, it was reported by some to be a daunting task. To achieve an acceptable response rate, various forms of reminders and appeals were made by the Parkinson's UK charity. Table 3.2.1 shows the number of people who responded to the survey between October 2015 and the end of February 2016.

**Table 3.2.1: Responses by invitation type and respondent type, Nov 2015-Feb 2016**

| Date of Count | Invitation type | | | Who Filled The Questionnaire First | | | |
|---|---|---|---|---|---|---|---|
| | Email Invitation/ Leaflet response | Parkinson's 2015 LIVE | Total | PwP | Carer | Other | Missing |
| 03/11/2015 | 274 | 315 | 589 | 379 | 169 | 31 | 10 |
| 18/11/2015 | 321 | 353 | 674 | 438 | 185 | 39 | 12 |
| 10/12/2015 | 323 | 425 | 748 | 475 | 201 | 51 | 21 |
| 14/01/2016 | 361 | 442 | 803 | 510 | 219 | 54 | 20 |
| 04/02/2016 | 367 | 448 | 815 | 517 | 223 | 53 | 22 |
| 23/02/2016 | 367 | 459 | 826 | 521 | 230 | 53 | 22 |
| 02/03/2016 | 368 (43%) | 485 (57%) | 853 (100%) | 533 (62.5%) | 245 (28.7%) | 53 (6.2%) | 22 (2.6%) |

After scrutiny of the returned questionnaires section by section, it became clear that of the responses received, many were only partially completed, resulting in missing information and data gaps. People who clicked on the online survey hyperlink, 51 people, read just one-page, the **Patient Information Sheet** and didn't continue further to fill-in the detailed questionnaire. Further, in 26 cases no information was provided about the PwP; these were excluded from the database. Out of the remaining 776, there was also missing information for the key cost of illness variables. 126 respondents managed to fill in demographic information, with another 6 not providing the date (month/year) of diagnosis of Parkinson's. The detailed data analysis to examine the extent of economic and financial costs to PwP and their families is therefore based on 644 cases (Table 3.2.2). However, within these 644 individual records, there was missing information for some variables. For instance, various sections of healthcare use information (listed as item 4 in Table 3.1) was provided by 610 respondents only (644-34=610), thus, the estimates of direct medical costs of Parkinson's are based on these 610 PwP. Similarly, the impact on household financial condition was based on the 580 (644-64=580) responses received, although the caregiver's information was missing in 42 cases.

**Table 3.2.2: Main missing information by type of respondent**

| Response Type | | Respondent Type | | | | Total |
|---|---|---|---|---|---|---|
| | | 0 | PwP | Carers | Other | |
| **Total** | | **16** | **560** | **234** | **43** | **853** |
| | 1. No Response (to be deleted) | 16 | 17 | 10 | 8 | 51 |
| | 2. No PwP Information | 0 | 0 | 13 | 13 | 26 |
| | **Remaining cases after deletion 1 and 2** | **0** | **543** | **211** | **22** | **776** |
| | Demographics Only | 0 | 56 | 59 | 11 | 126 |
| | No Parkinson's Diagnosed date | 0 | 6 | 0 | 0 | 6 |
| **Net Cases** | | **0** | **481** | **152** | **11** | **644** |
| | No Healthcare Use | 0 | 30 | 3 | 1 | 34 |
| | No HH Impact | 0 | 53 | 10 | 1 | 64 |
| | No Carer information | 0 | 42 | 0 | 0 | 42 |

## 3.3 Socio-demographic Profile of Respondents (PwP and Carers)

This section is based on analysis of 776 respondents. Epidemiological studies show that Parkinson's is higher among men; in our study also, the percentage of men amongst PwP was 61%, as compared to 39% for women. A majority of PwP (65%) were aged 65 years and over with a mean age 67.1 years. Most of the PwP had some education and more than two-thirds had further or higher education qualifications (beyond GCSE level). Only 11% of PwP (n=85) had no qualification. The majority of PwP 78.6% (n=610) were married, 7.6% were widowed (n=59) and 7.1% were divorced or separated.

In contrast to PwP demographics, the majority of the carers were female, 67% (n=364), with a mean age of 62.6 years (significantly lower than those of PwP). As the majority of caregivers were spouses of the PwP (of which a majority were men), this was reflected in the carers' demographics (i.e. a dominance women and over-representation in younger age groups of under 55 years than men). Only 11.2% (n=61) of carers had no qualification and the majority 63% had similar higher and further education qualification as compared to PwP. The majority of the carers were married or living as married 85% (n=465), and only 2.6% were widowed. The demographic profile reveals that the majority of PwP were men and of an older age, as compared to their caregivers who were their spouses and younger in age.

In terms of ethnicity, a large majority of people who participated in the survey belonged to the white ethnic group. As mentioned earlier about the participants' recruitment in Section 1.4, a booster sample of ethnic minorities (BME) was added from Manchester and Sheffield. As a result 41 (5.3%) PwP and 37 (4.7%) carers belonged to non-White ethnic groups.

The results have been summarised below (Table 3.3).

**Table 3.3: Demographic and social attributes of PwP and Carers**

| Profile | PwP | | Carers | |
|---|---|---|---|---|
| | N | % | N | % |
| Total | 776 | 100 | 546 | 100 |
| **Gender** | | | | |
| Male | 472 | 60.8 | 174 | 31.9 |
| Female | 298 | 38.4 | 364 | 66.7 |
| Other | | | 2 | 0.4 |
| prefer not to say | 1 | 0.1 | 6 | 1.1 |
| NR | 5 | 0.6 | | |
| **Age Group** | | | | |
| Up to 44 | 10 | 1.3 | 40 | 7.3 |
| 45-54 | 57 | 7.3 | 72 | 13.2 |
| 55-64 | 198 | 25.5 | 121 | 22.2 |
| 65-74 | 325 | 41.9 | 223 | 40.8 |
| 75-84 | 149 | 19.2 | 76 | 13.9 |
| 85 & above | 28 | 3.6 | 5 | 0.9 |
| NR | 9 | 1.2 | 9 | 1.6 |
| Mean Age (years) | 67.1 | | 62.6 | |

| | | | | |
|---|---|---|---|---|
| **Education** | | | | |
| No formal education | 14 | 1.8 | 11 | 2.0 |
| Went to school but did not finish | 17 | 2.2 | 6 | 1.1 |
| Completed school no qualifications | 85 | 11.0 | 61 | 11.2 |
| Completed school with qualifications | 138 | 17.8 | 108 | 19.8 |
| Further education qualification | 163 | 21.0 | 107 | 19.6 |
| Higher education qualification | 345 | 44.5 | 237 | 43.4 |
| Other | 3 | 0.4 | 3 | 0.5 |
| NR | 11 | 1.4 | 13 | 2.4 |
| **Marital Status** | | | | |
| Single | 39 | 5.0 | 31 | 5.7 |
| Married or living as married/civil partnership | 610 | 78.6 | 465 | 85.2 |
| Widowed | 59 | 7.6 | 14 | 2.6 |
| Divorced or separated | 55 | 7.1 | 23 | 4.2 |
| Other | 3 | 0 .4 | 4 | 0.7 |
| NR | 10 | 1.3 | 9 | 1.6 |
| **Ethnic group** | | | | |
| White | 714 | 92.0 | 504 | 92.3 |
| Mixed/Multiple ethnic groups | 1 | 0.1 | 1 | 0.1 |
| Asian/Asian British | 30 | 3.9 | 29 | 3.7 |
| Black/African/Caribbean/Black British | 6 | 0.8 | 6 | 0.8 |
| Other ethnic group | 4 | 0.5 | 1 | 0.1 |
| NR | 21 | 2.7 | 5 | 0.9 |

## 3.4 Economic Activity (Employment) Status of PwP and Carers

The majority of the PwP were retired/pensioners (74.1%, n=568), of which 182 PwP (23.7%) took early retirement due to ill health. Further, 87 (11.3%) PwP were not able to work due to illness or incapacity. Therefore, Parkinson's had a direct impact on the employment of 269 (35%) PwP as it meant they forcefully withdrew themselves from the workforce. Only 95 (12.4%) PwP were currently working of which 34 (4.4%) PwP were still in full-time employment, 29 (3.8%) in part-time employment and 32 (4.2%) were self-employed. About 1.3% (n=10) PwPs were looking for work (i.e. unemployed).

Among carers, more than a half of them (56%) had retired (pensioners) and 6% were caring for children/relatives and/or homemakers. Compared to PwP, a higher proportion of carers were working (31.2%, n=169), of which 62 (11.4%) carers were in paid full-time employment, 54 (10%) in part-time paid employment and 53 (9.8%) were self-employed. A notable number of carers either took early retirement to shoulder caring responsibilities or were unable to work due to illness were few (11.8%, n=64); another 16 (3%) carers were full-time caring for their relatives. It appears that caregivers held the responsibility for not only looking after the PwP, but also the responsibility for having to work in order to lessen the financial difficulties which arose because of having Parkinson's in the family.

The results as follows are summarised in Table 3.4. Further breakdown of main economic activity by home countries is presented in Appendix 6: Table A2.

**Table 3.4: Economic activity of PwPs and Carers**

| Main Economic Activity | PwP | | Carers | |
|---|---|---|---|---|
| | N | % | N | % |
| **Employment Status** | | | | |
| Paid employment - full time | 34 | 4.43 | 62 | 11.46 |
| Paid employment - part time | 29 | 3.78 | 54 | 9.98 |
| Self-employed with employees | 5 | 0.65 | 14 | 2.59 |
| Self-employed (working alone without employees) | 27 | 3.52 | 39 | 7.21 |
| **Sub-total of Workers** | **95** | **12.39** | **169** | **31.24** |
| Unemployed (looking for work) | 10 | 1.30 | 9 | 1.66 |
| Not working due to illness or incapacity | 87 | 11.34 | 8 | 1.48 |
| Caring for relatives | 3 | 0.39 | 16 | 2.96 |
| Early retired due to ill health/caring responsibilities | 182 | 23.73 | 56 | 10.35 |
| Retired/pensioner | 386 | 50.33 | 249 | 46.03 |
| **Sub-total of Retired/pensioners + Early retired** | **568** | **74.05** | **305** | **56.38** |
| Homemaker | 1 | 0.13 | 17 | 3.14 |
| Volunteer | 0 | 0.00 | 2 | 0.37 |
| In education or training | 0 | 0.00 | 1 | 0.18 |
| Others | 3 | 0.39 | 14 | 2.59 |
| Total | 767 | 100.00 | 541 | 100.00 |
| NR | 9 | | 5 | |

## 3.5 Living Environment of PwP

Of all PwPs who participated in the survey, most of them (over 80.3%) were living in England, 11.2 % in Scotland, 5.5% in Wales and 1.2% in Northern Ireland (Table 3.5). The lower representation from Northern Ireland was due to a lack of response from PwP and their carers. 14 (1.8%) PwP did not report which country they lived in.

Regarding their housing status, the majority of PwP were owner occupiers with no mortgage 60.6% (n=470), owner occupied - with a mortgage were 11.3% (n=88), 3.6% rented privately (n=28) and a small percentage (5.3%) reported living in sheltered and non-sheltered social housing. The proportion of PwP living with parents, family members and friends was 11.4%.

For current living arrangements most PwP were living with their spouse or partner, nearly 63% (n=488), 13.4 % (n=104) were living alone, 12.6% (n=98) were living with children and grandchildren and 4.8% lived in shared accommodation or care home. There were very few individuals who lived with other family members, friends/carers, and 11 PwP did not report where they were living.

The majority of the PwP (78%, n=602) were living with just their partner or spouse, thus their household size was 2. 14% (n=106) lived alone, therefore their household size was 1. The proportion of PwP who were living in households of 3 people or more was 5% (n=53), and

there were 15 PwP who did not report their household size. The overall mean household size was 1.99.

The results have been summarised below (Table 3.5).

**Table 3.5: Geographical and social profile of PwP**

| **Country of Residence** | N | % |
|---|---|---|
| England | 623 | 80.3 |
| Northern Ireland | 9 | 1.2 |
| Scotland | 87 | 11.2 |
| Wales | 43 | 5.5 |
| Not Reported | 14 | 1.8 |
| **Housing Status** | | |
| Owner occupied - no mortgage | 470 | 60.6 |
| Owner occupied - with mortgage | 88 | 11.3 |
| Shared ownership | 11 | 1.4 |
| Housing Association Non-Sheltered tenant | 16 | 2.1 |
| Housing Association Sheltered tenant | 11 | 1.4 |
| Local Authority Non-Sheltered tenant | 7 | 0.9 |
| Local Authority Sheltered tenant | 7 | 0.9 |
| Rent privately | 28 | 3.6 |
| Living with parents/partner/children/friends | 11 | 1.4 |
| Resident in a residential /nursing home | 17 | 2.2 |
| Of no fixed abode | 1 | 0.1 |
| Other | 4 | 0.5 |
| NR | 105 | 13.5 |
| **Current living arrangement** | | |
| Alone | 104 | 13.4 |
| Spouse/partner | 488 | 62.9 |
| Children/grandchildren | 98 | 12.6 |
| Parents/grandparents | 10 | 1.3 |
| Other family members | 13 | 1.7 |
| Friends/Carers | 15 | 1.9 |
| Shared accommodation/care home | 37 | 4.8 |
| NR | 11 | 1.4 |
| **Household size** | | |
| 1 | 106 | 13.7 |
| 2 | 602 | 77.6 |
| 3 | 29 | 3.7 |
| 4+ | 24 | 3.1 |
| NR | 15 | 1.9 |
| Mean Adults | 1.88 | |
| Mean Children | 0.11 | |
| Mean All | 1.99 | |

## 3.6 Duration of Parkinson's

Out of 776 PwP, 52 (6.7%) did not provide information about the date of diagnosis of their Parkinson's. Amongst one-thirds of PwPs, Parkinson's was diagnosed less than 5 years ago, for another one-third it was between 5 and 10 years ago, and for the remainder, it was more than 15 years ago. The mean duration since diagnosis of Parkinson's was 8.37 years and this figure was significantly higher for men (8.77 years) as compared to women (7.76 years).

The results have been summarised below (Table 3.6.1).

**Table 3.6.1: Distribution of PwP by duration since diagnosis of Parkinson's**

| Duration of Parkinson's | N | % | % of 724 |
|---|---|---|---|
| Up to 2 years | 84 | 10.82 | 11.60 |
| 2.1-5 | 155 | 19.97 | 21.41 |
| 5.1-10 | 253 | 32.60 | 34.94 |
| 10.1-15 | 130 | 16.75 | 17.96 |
| 15.1-20 | 65 | 8.38 | 8.98 |
| 20+ | 37 | 4.77 | 5.11 |
| Total | 724 | 93.30 | 100.00 |
| Not Recorded | 52 | 6.70 | |
| All | 776 | 100.00 | |
| Mean duration | **8.37** | | |

Out of 581 PwP who provided information about medication, 9 (1.5%) were not on any medication and 38% were on one or two prescribed medications. At the other extreme, 4% were taking more than 10 prescribed medications to manage the condition and the side effects of the anti-Parkinsonian medications. Further, 253 (42%) PwP had no other LTC beside Parkinson's, and of the remainder, 307 PwP were also currently being treated for other conditions including diabetes, angina, blood pressure, and other cardiovascular diseases (Table 3.6.2). The number of medications taken for the Parkinson's as well as for other LTC with a possible detrimental effect on daily routine activities, physical mobility and quality of life are discussed in the next section.

**Table 3.6.2: PwP receiving treatment for LTC in addition to Parkinson's**

| Long-term Condition | N | % | % of 608 |
|---|---|---|---|
| Yes - not on medication | 48 | 6.19 | 7.89 |
| Yes – treated with medication | 307 | 39.56 | 50.49 |
| No other LTC | 253 | 32.60 | 41.61 |
| Total | 608 | 78.35 | 100.00 |
| Not Recorded | 168 | 21.65 | |
| All | 776 | 100.00 | |

# 4. Quality of Life and Wellbeing

## 4.1 Health Status of PwP and Carers

With respect to general health status, 253 (38.5%) PwP reported that their health was fair, 194 (29.5%) reported it was good and 39 (5.9%) that it was very good. Overall, 26% of PwP reported their general health status to be poor or very poor. The majority of PwP (72%) reported a worsening of their health status over the last 12 months, 24% stated that it stayed the same and the remaining 4% felt that their health had got better (Table 4.1).

Among carers, 13.3% reported their health status as very good, 42.4% as good and 29.8% as fair. Relatively fewer carers (14.6%) reported their health status to be poor or very poor. More than 46% of carers reported that their health status has worsened over the last 12 month period (Table 4.1). From this, it is possible to state that the increased burden of care over time has coincided with deterioration in the health of many of the caregivers.

**Table 4.1: General health status and its change over 12 months for PwP and Carers**

| Health Status | PwP | | Carers | |
|---|---|---|---|---|
| | N | % | N | % |
| **In general your health status** | | | | |
| Very Good | 39 | 5.9 | 41 | 13.3 |
| Good | 194 | 29.5 | 131 | 42.4 |
| Fair | 253 | 38.5 | 92 | 29.8 |
| Poor | 129 | 19.6 | 34 | 11.0 |
| Very Poor | 42 | 6.4 | 11 | 3.6 |
| Total Reported | 657 | 100.0 | 309 | 100.0 |
| **Change in health status over 12 month** | | | | |
| Got better | 29 | 4.5 | 10 | 3.4 |
| Stayed the same | 153 | 23.8 | 149 | 50.3 |
| Got worse | 460 | 71.7 | 137 | 46.3 |
| Total Reported | 642 | 100.0 | 296 | 100.0 |

## 4.2 Daily Living Assistance of PwP

Health status and QoL dimensions may be better understood by examining the dependence of PwP on other people to undertake daily routine activities. Out of 776 PwP, 529 provided information about a need for help with daily or routine activities within and outside the house. Between 32% and 60% of PwP needed help in one or more of their usual daily activities. More than one-third of PwP needed help with personal care and bathing, and about a half needed assistance to cook a meal. 62% of PwP needed help with cleaning their house and between 41% and 49% of PwP needed help with ironing, decorating and gardening. Similarly, outside of the house, 52% of PwP needed help with daily/weekly shopping. About half of the PwP also needed help with transport to attend medical appointments as and when they were scheduled. The PwP needing help with their routine daily activities varied by gender, age and living arrangement. For instance, except cleaning and shopping, higher percentages of men compared to women with Parkinson's needed help with their daily living. Similarly, a majority of PwP who were aged 75 years and over were dependent on others for

their daily activities; in contrast, those who were living alone were able to manage better on their own (Table 4.2).

**Table 4.2: PwP needed help in daily living/routine activities**

| DLA | Yes | No | NR | Yes as % of 529 | If Man | If Aged 75+ | If Living Alone |
|---|---|---|---|---|---|---|---|
| ***In Home*** | | | | | | | |
| Cleaning | 316 | 210 | 3 | 59.7 | 59.5 | 75.4 | 56.9 |
| Personal care | 199 | 316 | 14 | 37.6 | 39.5 | 57.6 | 15.3 |
| Bathing | 167 | 345 | 17 | 31.6 | 33.7 | 51.3 | 15.3 |
| Cooking | 243 | 268 | 18 | 45.9 | 47.2 | 58.1 | 23.6 |
| Gardening | 252 | 177 | 100 | 47.6 | 55.0 | 73.9 | 60.0 |
| Ironing | 211 | 217 | 101 | 39.9 | 52.2 | 64.8 | 22.8 |
| Decorating | 242 | 167 | 120 | 45.8 | 57.2 | 67.8 | 52.7 |
| ***Outside Home*** | | | | | | | |
| Shopping | 260 | 258 | 11 | 49.2 | 49.8 | 59.5 | 33.3 |
| Transport | 232 | 192 | 105 | 43.9 | 53.8 | 73.4 | 47.5 |
| Medical appointments | 257 | 186 | 86 | 48.6 | 56.2 | 78.8 | 42.4 |
| Exercise/physiotherapy | 171 | 217 | 141 | 32.3 | 45.8 | 62.2 | 34.5 |

## 4.3 Quality of Life of PwP and Carers

PwP and carers were asked to complete the health-related quality of life (EQ-5D-5L) questionnaire; these were filled by 650 PwP and 301 carers. Table 4.3 provides the distribution of responses of the five health-related dimensions by the level of problems. In the majority of PwP, QoL was at sub-optimal level as only about 11.9% reported having no problem with mobility, 28% no problem with self-care, 10.5% no problem with usual activities, 9.6% no problem with pain/discomfort and 26.2% no problem with anxiety/depression. A very high percentage of PwP reported between moderate and extreme problems for mobility (63%), usual activities (58%), and pain/discomfort (59%); thus reflecting their low quality of life. The responses for the five dimensions were combined by using weight suggested by Devlin *et al*. (2016) to arrive at individual level Quality Adjusted Life Year (QALY). The average QALY score for PwP was 0.576; a health person could expect to achieve a QALY score of 1. The Mean Visual Analogue Scale (VAS) score which varies between 0 (worst health state) and 100 (worst health state) was 57.9 for PwP.

Amongst carers, HRQoL was relatively better than PwP. However, between 70% (anxiety/depression) and 30% (self-care) of carers reported a sub-optimal level of QoL. About 1 in 4 carers reported moderate to extreme problems with mobility, usual activities, pain/discomfort, as well as anxiety/depression. This could be a reflection of their fatigue and the burden of day to day caring for their PwP. The mean QALY score was 0.764 and the VAS score was 70.1 (much lower than the general adult population). The QoL of PwP and carers varied by their demographics as well as by the duration since diagnosis of Parkinson's. Interestingly, the mean QALY score of PwP didn't differ between men (0.5758) and women (0.5757); however it was significantly lower for PwP aged 75 and over (0.5289 vs. 0.5876 those aged under 65, and higher for those living alone (0.6127). Figure 4.1 shows the QALY score was lowest for PwP aged over 85 (almost half compared with those aged less than 45).

**Table 4.3: Quality of life among PwP and Carers**

| Health Related Quality of Life | PwP | | Carers | |
|---|---|---|---|---|
| | **N** | **%** | **N** | **%** |
| Mobility | | | | |
| **I have no problems in walking about** | **77** | **11.9** | **169** | **56.1** |
| I have slight problems in walking about | 163 | 25.2 | 65 | 21.6 |
| I have moderate problems in walking about | 228 | 35.2 | 33 | 11.0 |
| I have severe problems in walking about | 143 | 22.1 | 27 | 9.0 |
| I am unable to walk about | 36 | 5.6 | 7 | 2.3 |
| | 647 | 100.0 | 301 | 100.0 |
| Self-care | | | | |
| **I have no problems washing or dressing myself** | **182** | **28.0** | **239** | **79.7** |
| I have slight problems washing or dressing myself | 210 | 32.4 | 30 | 10.0 |
| I have moderate problems washing or dressing myself | 167 | 25.7 | 12 | 4.0 |
| I have severe problems washing or dressing myself | 45 | 6.9 | 8 | 2.7 |
| I am unable to wash or dress myself | 45 | 6.9 | 11 | 3.7 |
| | 649 | 100.0 | 300 | 100.0 |
| Usual activities | | | | |
| **I have no problems doing my usual activities** | **68** | **10.5** | **160** | **53.3** |
| I have slight problems doing my usual activities | 202 | 31.2 | 76 | 25.3 |
| I have moderate problems doing my usual activities | 208 | 32.1 | 28 | 9.3 |
| I have severe problems doing my usual activities | 105 | 16.2 | 20 | 6.7 |
| I am unable to do my usual activities | 64 | 9.9 | 16 | 5.3 |
| | 647 | 100.0 | 300 | 100.0 |
| Pain/Discomfort | | | | |
| **I have no pain or discomfort** | **62** | **9.6** | **108** | **36.2** |
| I have slight pain or discomfort | 205 | 31.7 | 109 | 36.6 |
| I have moderate pain or discomfort | 261 | 40.3 | 56 | 18.8 |
| I have severe pain or discomfort | 91 | 14.1 | 21 | 7.0 |
| I have extreme pain or discomfort | 28 | 4.3 | 4 | 1.3 |
| | 647 | 100.0 | 298 | 100.0 |
| Anxiety/Depression | | | | |
| **I am not anxious or depressed** | **170** | **26.2** | **91** | **30.4** |
| I am slightly anxious or depressed | 243 | 37.4 | 116 | 38.8 |
| I am moderately anxious or depressed | 174 | 26.8 | 68 | 22.7 |
| I am severely anxious or depressed | 40 | 6.2 | 16 | 5.4 |
| I am extremely anxious or depressed | 23 | 3.5 | 8 | 2.7 |
| | 650 | 100.0 | 299 | 100.0 |
| **Mean QALY*** | **0.576** | | **0.764** | |
| **Mean VAS Score** | **57.9** | | **70.1** | |

*To compute QALYs, level specific weights in each domain are taken from Devlin *et al.* (2016): Table 2.

Further, the QALY score was much lower for PwP belonging to BME group compared to those of white ethnicity. Figure 4.2 shows that the QoL of PwP fell steeply with the duration since diagnosis of Parkinson's but stabilised in later years. Thus, QoL of PwP deteriorated significantly with age and progression of Parkinson's. Amongst carers, the mean QALY score was significantly lower for women carers (0.7465) than men carers (0.7902); the score was significantly lower for carers aged 75 and over (0.7163 vs. 0.7722 for aged under 65). Interestingly the QALY score was much higher for carers from BME group when compared to white ethnic group (Figure 4.1). The QoL of carers also fell sharply with the duration since diagnosis of Parkinson's, thus reflecting on the longer they were caring for the PwP lower were their QoL (Figure 4.2).

**Figure 4.1: QALY scores for PwP and Carers by age and ethnicity**

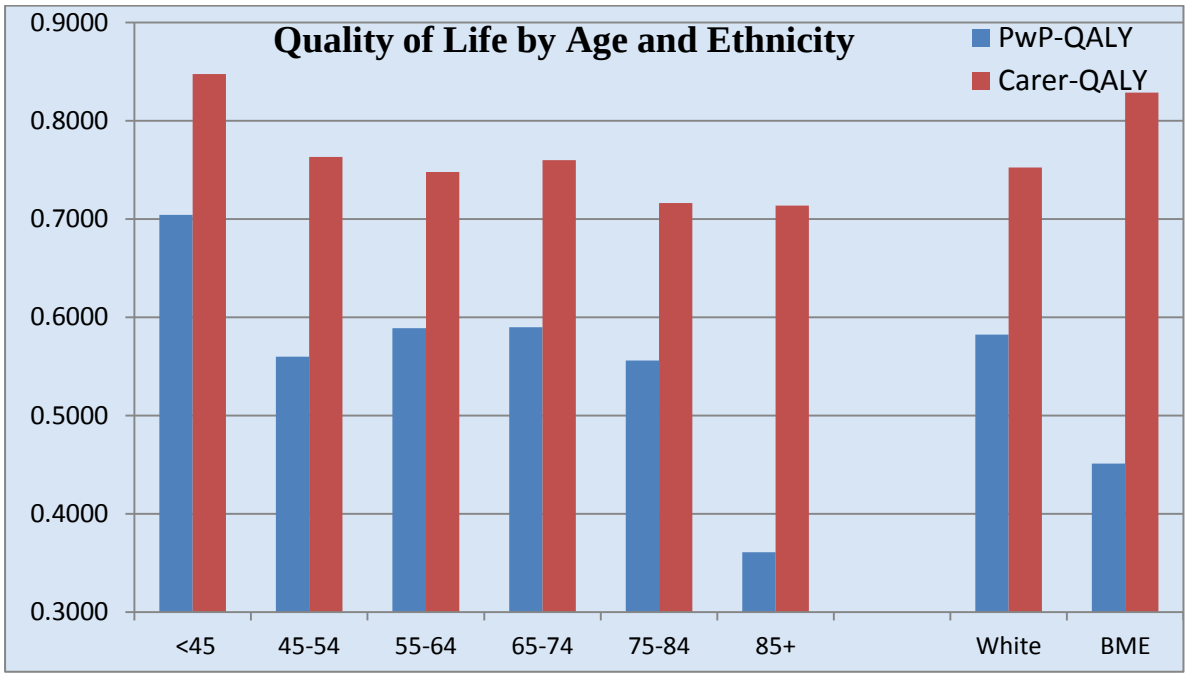
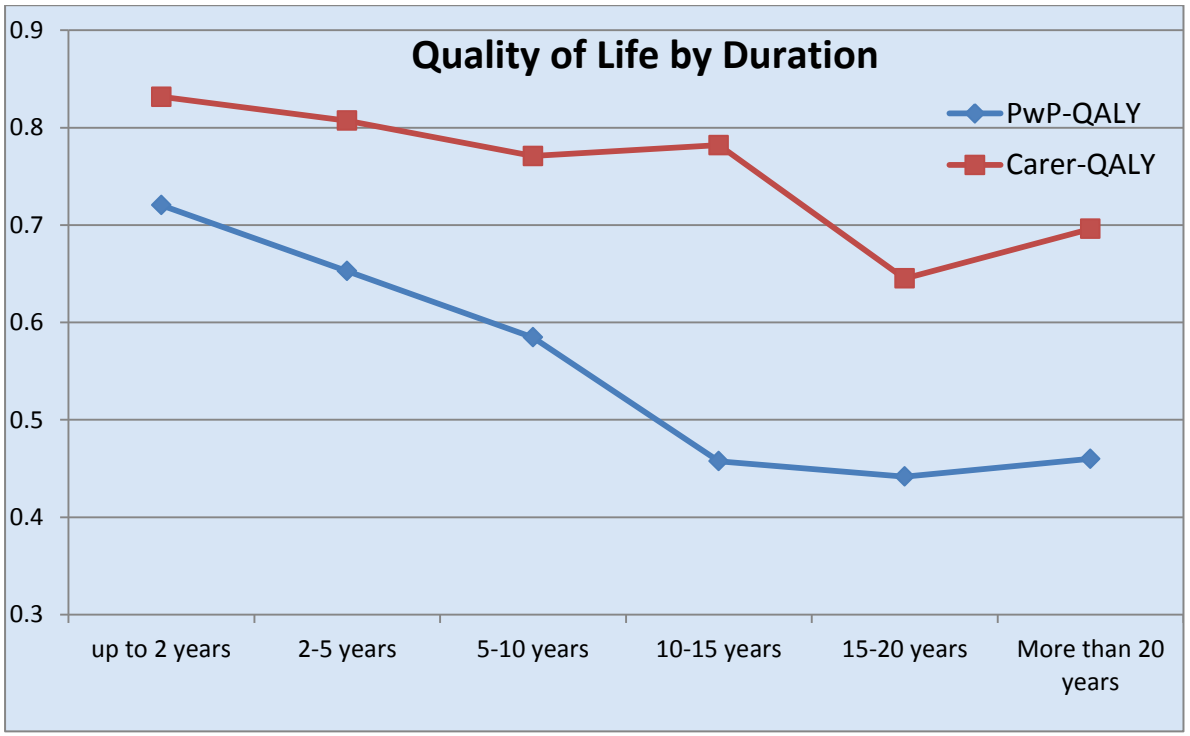



**Figure 4.2: QALY scores for PwP and Carers by duration of Parkinson's**



## 4.4 Wellbeing of PwP and Carers

In the survey, people were asked to rate their wellbeing on a scale of 0 to 10. The four questions regarding life satisfaction, life worthwhile, happiness and anxiousness were adapted from the Office for National Statistics (ONS) framework for measuring personal wellbeing (ONS 2012). The wellbeing information was completed by 638 PwP and 294 carers (Table 4.4). The mean wellbeing score for PwP was 5.3 for satisfaction with life, 5.8 for feelings about doing things in life that are worthwhile, 5.5 for how happy they felt yesterday and 3.9 for feeling anxious yesterday. The majority of PwP reported low scores of wellbeing for all four questions. The ONS categorised 0-4 scores as "very low" and 5-6 as "low" wellbeing for life satisfaction, worthwhile and happiness questions. Similarly, high scores on anxiousness reflect low wellbeing as well (6-10 scores categorised as "very high" and 4-5 as "high" on anxiousness). Compared to the general population aged 65 years and over, the wellbeing scores for PwP were much lower (Gumber and Owen 2014).

Amongst carers, the mean wellbeing scores were 5.7 for satisfaction with life, 6.6 for doing things in life that are worthwhile, 5.8 for how happy they felt yesterday and 4.3 for how anxious they felt yesterday. These scores were marginally better than those of PwP. However, a large percentage of carers had reported low scores on their wellbeing too, which ranged from 39.4% for worthwhile to 59% for anxiousness.

**Table 4.4: PwP and Carers reporting low scores on wellbeing**

| | PwP | | Carers | |
|---|---|---|---|---|
| Wellbeing (Mean score / % ) | Mean score | % having low wellbeing* | Mean score | % having low wellbeing* |
| How satisfied are you with your life nowadays? | 5.3 | 61.9 | 5.7 | 55.8 |
| To what extent do you feel the things you do in your life are worthwhile? | 5.8 | 53.1 | 6.6 | 39.4 |
| How happy did you feel yesterday? | 5.5 | 60.1 | 5.8 | 57.9 |
| How anxious did you feel yesterday? | 3.9 | 52.9 | 4.3 | 59.0 |

* Low wellbeing refers to people reporting scores between 0 and 6 for life satisfaction, worthwhile and happiness and between 4 and 10 for anxiousness (ONS 2012).

**Figure 4.3: Wellbeing scores for PwP by duration since diagnosis of Parkinson's**

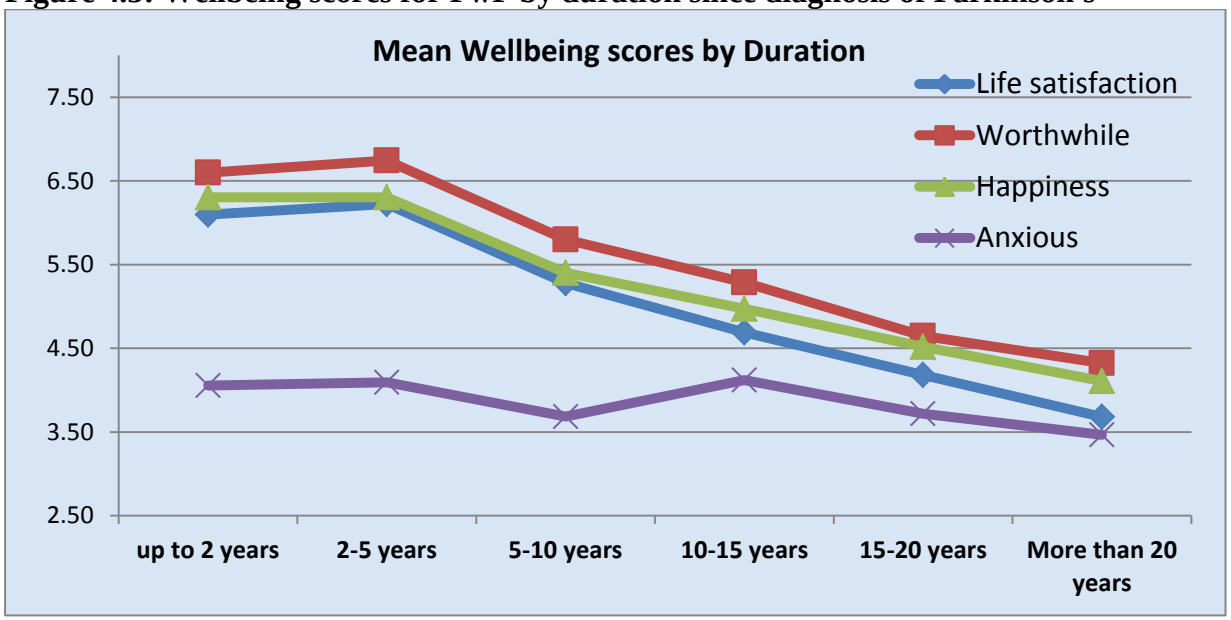
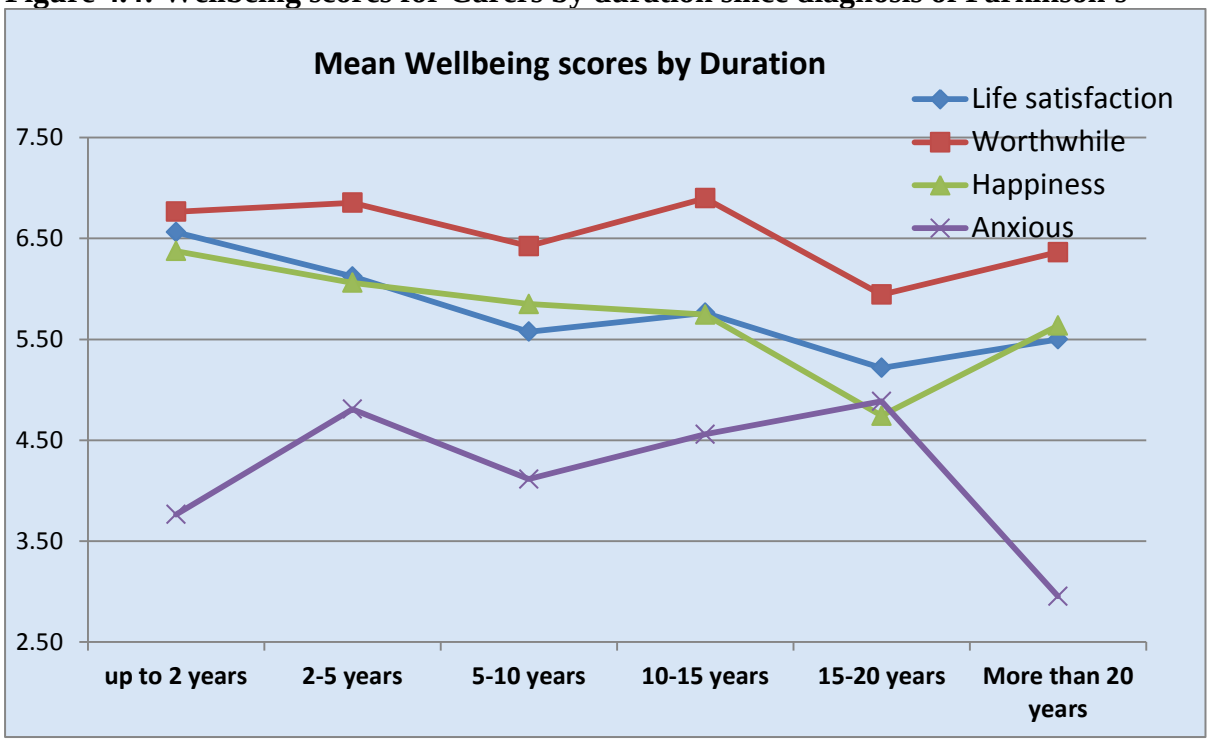


**Figure 4.4: Wellbeing scores for Carers by duration since diagnosis of Parkinson's**




Figures 4.3 and 4.4 show the variations in mean wellbeing scores of PwP and carers by the duration since diagnosis of Parkinson's. The mean wellbeing scores of PwP for life satisfaction, worthwhile, and happiness declined with the duration since diagnosis of Parkinson's (and reached the lowest levels in those diagnosed with Parkinson's for more than 20 years). The score on anxiousness for PwP had also gone down with the duration since diagnosis of Parkinson's; this suggests that they stopped worrying too much about their current situation vis-à-vis that in the past. Mean wellbeing scores of carers didn't decline sharply (as was the case for PwP) with the duration since diagnosis of Parkinson's. Their anxiety level among them also subsided with the passage of time.

## References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Gumber A and Owen D (2014). *Ethnicity, neighbourhood deprivation and quality of life: An exploratory analysis of Annual Population Survey data*. Paper presented at the Labour Force Survey/Annual Population Survey User Conference 2014, Organised by UK Data Service, London, 28th November, 2014. Accessed at: http://www.better-health.org.uk/resources/presentations/ethnicity-neighbourhood-deprivation-and-quality-life-exploratory-analysis-an.

Office for National Statistics (2012). *First Annual ONS Experimental Subjective Well-being Results*. London, ONS. Accessed at: http://webarchive.nationalarchives.gov.uk/20160105160709/http://www.ons.gov.uk/ons/rel/wellbeing/measuring-subjective-wellbeing-in-the-uk/first-annual-ons-experimental-subjective-well-being-results/first-ons-annual-experimental-subjective-well-being-results.html.

# 5. Healthcare Use and Cost

## 5.1 Primary Care and Outpatient Services

### 5.1.1 Utilisation

Out of 776 PwP, 610 had provided information about the use of primary care (GP or Clinic) and hospital outpatient services. The use of services is presented in Table 5.1.1 by type of healthcare professionals. About three-fourths (73.4%) of PwP consulted a GP for their Parkinson's treatment; the next to follow were a neurologist (67.5%) and a hospital doctor (27.4%). Other specialists consulted were the Psychiatrist (8.4%) and Geriatrician/Elderly Care Consultant (12.3%). Amongst nurses, a Parkinson's nurse was most consulted (75.9%), followed by Practice nurse (31%) and hospital nurse (16.4%). The other key health professionals contacted were: Physiotherapist (43.3%), Speech and Language Therapist (26.9%), Occupational Therapist (24.8%), Optometrist (25.4%), Chiropodist/Podiatrist (33.4%) and Pharmacist (32.3%). The average annual number of consultations was highest for the GP (3.7) followed by Physiotherapist (2.9), Pharmacist (2.8), Parkinson's nurse (2.2), Chiropodist/Podiatrist (1.6) and Neurologist (1.4). On average PwP made 21.8 consultations with various health professionals in a year; this reflected a very high usage of healthcare services (which turned out to be nearly having consultation every two to three weeks). However, some PwP reported the problem in accessing healthcare services. The accessing problem was higher for the three most sought healthcare professionals by PwP for their Parkinson's (i.e. GP, neurologist and Parkinson's nurse); varied between 17.4% and 12.8% of PwP reported the problem.

**Table 5.1.1: Consultations with healthcare professionals during last 12 month**

| Healthcare Consultations | % Contacted | Total consultations | Mean consultations | % Reported access problem |
|---|---|---|---|---|
| GP | 73.44 | 2241 | 3.67 | 12.79 |
| Practice Nurse | 30.98 | 881 | 1.44 | 3.11 |
| Hospital Nurse | 16.39 | 528 | 0.87 | 2.62 |
| Hospital Doctor | 27.38 | 661 | 1.08 | 4.10 |
| Neurologist | 67.54 | 830 | 1.36 | 12.95 |
| Psychiatrist | 8.36 | 104 | 0.17 | 2.46 |
| Geriatrician/Elderly Care Consultant | 12.30 | 194 | 0.32 | 1.31 |
| Parkinson's Nurse | 75.90 | 1333 | 2.19 | 17.38 |
| Speech and Language Therapist | 26.89 | 619 | 1.01 | 4.10 |
| Physiotherapist | 43.28 | 1793 | 2.94 | 9.02 |
| Occupational Therapist | 24.75 | 488 | 0.80 | 3.77 |
| Mental Health Professional | 7.05 | 157 | 0.26 | 2.30 |
| Psychologist/ Counsellor | 5.90 | 241 | 0.40 | 2.13 |
| Optometrist | 25.41 | 251 | 0.41 | 1.97 |
| Dietician | 7.70 | 106 | 0.17 | 1.64 |
| Chiropodist, Podiatrist | 33.44 | 958 | 1.57 | 3.44 |
| Chiropractor | 5.57 | 206 | 0.34 | 0.82 |
| Pharmacist | 32.30 | 1696 | 2.78 | 1.97 |
| **Total Consultations** | | **13287** | **21.78** | |

### 5.1.2 Consultations Cost

Although most of the healthcare services were provided by the NHS free at the point of contact, a significant number of PwP have consulted further utilising private services with OOP payments. In more than 50% Chiropodist, Podiatrist and Chiropractor consultations, PwP incurred OOP expenses; 29% saw an Optometrist privately, and 19.3% consulted a Physiotherapist privately. On average, PwP incurred £180.90 OOP expenditure annually on healthcare consultations (Table 5.1.2). After applying a unit cost per contact time of NHS healthcare professionals, an average of £443.04 per PwP per annum turned out to be the cost to the NHS. Both together, the total annual healthcare consultations cost worked out to be £623.94 per PwP for the treatment of Parkinson's utilising conventional professionally provided health services.

**Table 5.1.2: Mean consultations costs and OOP expenditure during last 12 month**

| Healthcare Consultations | OOP Expenses (£) | | Funding source (% distribution) | | | Cost to NHS (£) | | | Total Cost (NHS+ OOP) |
|---|---|---|---|---|---|---|---|---|---|
| | Total | Mean | NHS | SF | Other | Unit cost | Total | Mean | |
| GP | 2175 | 3.57 | 96.43 | 2.90 | 0.67 | 44 | 94688 | 155.23 | 158.80 |
| Practice Nurse | 575 | 0.94 | 97.44 | 1.54 | 1.03 | 12 | 10188 | 16.70 | 17.64 |
| Hospital Nurse | 875 | 1.43 | 89.91 | 6.42 | 3.67 | 12 | 6132 | 10.05 | 11.48 |
| Hospital Doctor | 7725 | 12.66 | 91.76 | 3.30 | 4.95 | 14 | 8596 | 14.09 | 26.75 |
| Neurologist | 11450 | 18.77 | 88.84 | 6.65 | 4.51 | 58 | 41702 | 68.36 | 87.13 |
| Psychiatrist | 1175 | 1.93 | 90.14 | 2.82 | 7.04 | 59 | 5428 | 8.90 | 10.83 |
| Geriatrician/Elderly Care Consultant | 1025 | 1.68 | 96.67 | 3.33 | 0.00 | 58 | 10846 | 17.78 | 19.46 |
| Parkinson's Nurse | 1850 | 3.03 | 96.36 | 2.14 | 1.50 | 22 | 28512 | 46.74 | 49.77 |
| Speech & Language Therapist | 500 | 0.82 | 96.09 | 1.12 | 2.79 | 17 | 10030 | 16.44 | 17.26 |
| Physiotherapist | 29975 | 49.14 | 72.63 | 19.34 | 8.03 | 17 | 15079 | 24.72 | 73.86 |
| Occupational Therapist | 6825 | 11.19 | 90.91 | 2.42 | 6.67 | 17 | 7548 | 12.37 | 23.56 |
| Mental Health Professional | 425 | 0.70 | 95.31 | 1.56 | 3.13 | 19 | 2907 | 4.77 | 5.47 |
| Psychologist/ Counsellor | 1125 | 1.84 | 87.27 | 5.45 | 7.27 | 32 | 5216 | 8.55 | 10.39 |
| Optometrist | 15375 | 25.20 | 57.41 | 29.01 | 13.58 | 31 | 4185 | 6.86 | 32.06 |
| Dietician | 1275 | 2.09 | 87.30 | 7.94 | 4.76 | 17 | 1479 | 2.42 | 4.51 |
| Chiropodist, Podiatrist | 16875 | 27.66 | 39.15 | 53.77 | 7.08 | 17 | 4556 | 7.47 | 35.13 |
| Chiropractor | 7475 | 12.25 | 41.67 | 50.00 | 8.33 | 31 | 434 | 0.71 | 12.96 |
| Pharmacist | 3650 | 5.98 | 86.27 | 7.84 | 5.88 | 9 | 12726 | 20.86 | 26.84 |
| **Total Consultations** | **110350** | **180.90** | | | | | **270252** | **443.04** | **623.94** |

* Unit cost per contact time was derived from Curtis and Burns (2015). SF- Self-financed

### 5.1.3 Diagnostic Cost

Various consultations in the primary care and outpatient care also involved diagnostic/clinical tests during the course of management of the condition. These included a blood test, MRI scan, EEG, CT scan, DAT scan, PET scan, X-ray and other test/procedure. Several PwP reported having blood test(s) (43.3%), an MRI scan (18.2%), X-ray (15.9%) and CT scan (13.3%) during the last 12 months (Table 5.1.3). On an average 2.65 diagnostic tests were carried out annually, most of which were undertaken via NHS provision. After applying a unit cost per diagnostic procedure, on average £165.11 per PwP per annum was turned out to

be the cost to the NHS. Including OOP expenses, the total annual diagnostic tests cost worked out to £183.47 per PwP.

## 5.2 Emergency (A&E) Services

Two out of thirteen PwP used emergency healthcare services during the last 12 months (Table 5.2). About 16% of PwP called 999 or 111 for medical help, 15% visited A&E and 13% used ambulance services. The mean usage of emergency services during the last 12 months was a little over 0.3 contacts. After applying a unit cost for emergency service episode, on an average £95.37 per PwP per annum was the cost to the NHS. Including OOP expenses, the total annual cost of emergency service use worked out to be £96.56 per PwP.

## 5.3 Inpatient Services

Over the past 12 months, 121 PwP (19.8%) were admitted to the hospital because of their Parkinson's and related complications. Considering all multiple episodes together, on an average, they reported 12.56 days of hospital stay in a year. Table 5.3 breaks down hospital admissions into 'day case', 'planned', 'unplanned short stay (up to 3 days)', and 'unplanned longer stay (>3 days)'. This distinction was important to capture cost differentials due to variability in the unit cost by type of hospital admission. About 9% of PwP were admitted to a hospital as a day case and 6.2% had a planned inpatient admission. However, unplanned admissions (13.2%) were higher than planned ones (4.8% and 8.4% of PwP reported unplanned admission for up to 3 days and more than 3 days respectively). The mean inpatient admission during last 12 months was a little over 0.6 episodes, with most admissions were into the NHS hospitals. After applying a unit cost by types of hospital admissions, on average £1241.49 per PwP per annum was the cost to the NHS. Including OOP expenses, the total annual cost for inpatient admission worked out to be £1250.96 per PwP.

## 5.4 Mode of Travel and Travel Cost

A majority of PwP didn't travel alone to attend for various healthcare appointments. The percentage of PwPs who travelled alone varied between as low as 21.2% when consulting a specialist such as Neurologist/ Geriatrician/ Elderly Care Consultant or 28.8% for a Parkinson's nurse to as high as 48.1% in the case of a Pharmacist. Significant contribution and support were provided by family members to attend these appointments. A relatively small number of PwP walked to attend medical appointments, the proportion of which was relatively higher when using community-based services such as GP services and Pharmacy. The most frequent mode of travel to medical appointments was by car (either self-driving or as a passenger). Use of public transport and the taxi was minimal unless the visit was to the Mental Health Professional (including a psychologist, psychiatrist, and counsellor) when a higher number of PwP (11.5%) used a taxi (Table 5.4.1). The mode of travel (public vs. private transport) reflects on the extent of OOP expenses on travel. The percentage of PwP reporting travel expenses varied between 2.5% for visiting a Dietician to 62.6% for visiting their GP. Those who incurred OOP expenses, on an average a visit to their GP or Practice nurse cost them £8.82 or £5.95 whereas for the Optometrist £39.81 and the Mental Health Professional £35.24.

**Table 5.1.3: Mean diagnostic tests and out-of-pocket expenditure during last 12 month**

| Diagnostic Test/ Procedure | % Screened | Number of Episodes | | OOP Expenses (£) | | Funding source (% distribution) | | | Cost to NHS (£) | | | Total Cost (NHS+OOP) |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Total | Mean | Total | Mean | NHS | SF | Other | Unit cost | Total | Mean | |
| Blood test | 43.28 | 870 | 1.43 | 700 | 1.15 | 95.94 | 1.11 | 2.95 | 6 | 4782 | 7.84 | 8.99 |
| MRI scan | 18.2 | 167 | 0.27 | 4625 | 7.58 | 87.2 | 4 | 8.8 | 395 | 56485 | 92.6 | 100.18 |
| EEG | 8.52 | 92 | 0.15 | 225 | 0.37 | 92.42 | 4.55 | 3.03 | 116 | 9860 | 16.16 | 16.53 |
| CT scan | 13.28 | 101 | 0.17 | 1225 | 2.01 | 92.39 | 1.09 | 6.52 | 151 | 13892 | 22.77 | 24.78 |
| DAT scan | 5.25 | 35 | 0.06 | 1425 | 2.34 | 86.05 | 0 | 13.95 | 151 | 4077 | 6.68 | 9.02 |
| PET scan | 1.31 | 12 | 0.02 | 0 | 0.00 | 88.89 | 0 | 11.11 | 151 | 1057 | 1.73 | 1.73 |
| X-ray | 15.9 | 269 | 0.44 | 1350 | 2.21 | 93.64 | 0.91 | 5.45 | 14 | 3458 | 5.67 | 7.88 |
| Other test | 4.26 | 71 | 0.12 | 1650 | 2.70 | 84.62 | 5.13 | 10.26 | 145* | 7105 | 11.65 | 14.35 |
| **Total Test** | | **1617** | **2.65** | **11200** | **18.36** | | | | | **100716** | **165.11** | **183.47** |

* Weighted mean costs of the non-blood test procedures. Unit cost derived from Curtis and Burns (2015).

**Table 5.2: Mean ambulance and A&E services and OOP expenditure during last 12 month**

| A&E services | % Used | Number of Episodes | | OOP expenses (£) | | Funding source (% distribution) | | | Cost to NHS (£) | | | Total Cost (NHS+OOP) |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Total | Mean | Total | Mean | NHS | SF | Other | Unit cost | Total | Mean | |
| Called 999 or 111 | 15.9 | 201 | 0.33 | 100 | 0.16 | 94.5 | 4.59 | 0.92 | 12 | 2160 | 3.54 | 3.7 |
| Used an ambulance | 13.11 | 191 | 0.31 | 50 | 0.08 | 98.88 | 0 | 1.12 | 99 | 18909 | 31 | 31.08 |
| Visited A & E | 15.41 | 190 | 0.31 | 575 | 0.94 | 94.95 | 4.04 | 1.01 | 205 | 37105 | 60.83 | 61.77 |
| **Total** | | | | 725 | **1.19** | | | | | 58174 | **95.37** | **96.56** |

* Unit cost per contact derived from Curtis and Burns (2015).

**Table 5.3: Mean inpatient admissions and OOP expenditure during last 12 month**

| Inpatient services | % Admitted | Number of Episodes | | OOP expenses (£) | | Funding source (% distribution) | | | Cost to NHS (£) | | | Total Cost (NHS+OOP) |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Total | Mean | Total | Mean | NHS | SF | Other | Unit cost | Total | Mean | |
| Day case | 9.02 | 89 | 0.15 | 2300 | 3.77 | 97.73 | 1.14 | 1.14 | 704 | 59840 | 98.10 | 101.87 |
| Planned inpatient stay | 6.23 | 64 | 0.1 | 950 | 1.56 | 94 | 2 | 4 | 3405 | 207705 | 340.50 | 342.06 |
| Unplanned-stay up to 3 days | 4.75 | 47 | 0.08 | 650 | 1.07 | 94.29 | 0 | 5.71 | 608 | 26752 | 43.86 | 44.92 |
| Unplanned-stay 3+ days | 8.36 | 160 | 0.26 | 675 | 1.11 | 98.36 | 0 | 1.64 | 2863 | 458080 | 750.95 | 752.06 |
| Other | 0.82 | 11 | 0.02 | 1200 | 1.97 | 80 | 10 | 10 | 1233* | 4932 | 8.09 | 10.05 |
| **Total** | | **371** | **0.61** | **5775** | **9.47** | | | | | **757309** | **1241.49** | **1250.96** |

* Weighted mean of all planned and unplanned hospitalisation cost. Unit cost derived from Curtis and Burns (2015).

In a very small number of cases, the NHS provided transport, but in the majority of cases travel was self-funded OOP. The total travel expenses incurred by 610 PwP amounted to £21875. The travel cost here was underestimated for those who drove their own car and forgot to mention petrol expenses under travel cost; however several of PwP had reported paid for parking charges at the hospital if using their own/family car (Table 5.4.2).

**Table 5.4.1: Mode of travel and travelled with whom by healthcare services**

| Mode of Travel to Healthcare Services | Mode of transport | | | | | | Travelled with | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | Walk | Car driver | Car passenger | Bus/ train | Taxi | Cycle/ Motor cycle | Alone | Family member | Carer | Friend /Other |
| GP | 18.2 | 37.0 | 35.3 | 3.5 | 4.6 | 1.5 | 42.3 | 38.3 | 18.1 | 1.4 |
| Practice nurse | 17.0 | 33.9 | 42.2 | 2.2 | 4.8 | 0.0 | 37.4 | 44.1 | 18.0 | 0.5 |
| Neurologist/ Geriatrician, Elderly Care Consultant | 2.0 | 36.7 | 47.2 | 10.1 | 4.0 | 0.0 | 21.2 | 55.4 | 19.0 | 4.4 |
| Parkinson's Nurse | 4.2 | 41.5 | 44.2 | 6.9 | 3.0 | 0.3 | 28.8 | 50.7 | 18.0 | 2.6 |
| Speech/Language Therapist | 4.3 | 34.5 | 42.2 | 12.1 | 6.0 | 0.9 | 42.2 | 42.2 | 13.7 | 2.0 |
| Physiotherapist | 1.8 | 49.1 | 38.7 | 4.9 | 4.9 | 0.6 | 46.3 | 34.7 | 14.3 | 4.8 |
| Occupational Therapist | 9.1 | 34.5 | 47.3 | 7.3 | 1.8 | 0.0 | 40.4 | 46.8 | 8.5 | 4.3 |
| Mental Health Professional* | 6.6 | 37.7 | 41.0 | 1.6 | 11.5 | 1.6 | 42.9 | 39.3 | 14.3 | 3.6 |
| Optometrist | 9.8 | 28.7 | 45.1 | 10.7 | 4.9 | 0.8 | 33.0 | 48.2 | 16.1 | 2.7 |
| Dietician | 12.0 | 40.0 | 48.0 | 0.0 | 0.0 | 0.0 | 43.5 | 43.5 | 8.7 | 4.3 |
| Pharmacist | 28.6 | 38.4 | 29.7 | 0.0 | 1.6 | 1.6 | 48.1 | 33.5 | 17.1 | 1.3 |

* including a psychologist, psychiatrist, and counsellor.

**Table 5.4.2: Mean travel cost (per incurred case) by healthcare services**

| Healthcare Services | PwP reported | | Total OOP expenses (£) | Mean OOP cost per incurred case (£) | Funding source (% distribution) | | |
|---|---|---|---|---|---|---|---|
| | N | % | | | NHS | SF | Other |
| GP | 382 | 62.6 | 3370 | 8.82 | 6.9 | 86.7 | 6.4 |
| Practice nurse | 153 | 25.1 | 910 | 5.95 | 6.5 | 86.6 | 7.0 |
| Neurologist/Geriatrician/ Elderly Care Consultant | 251 | 41.1 | 4755 | 18.94 | 5.6 | 86.6 | 7.8 |
| Parkinson's Nurse | 206 | 33.8 | 2310 | 11.21 | 6.8 | 87.2 | 6.1 |
| Speech and Language Therapist | 69 | 11.3 | 1045 | 15.14 | 8.2 | 81.6 | 10.2 |
| Physiotherapist | 100 | 16.4 | 2530 | 25.30 | 6.1 | 86.4 | 7.5 |
| Occupational Therapist | 32 | 5.2 | 800 | 25.00 | 18.8 | 68.8 | 12.5 |
| Mental Health Professional * | 41 | 6.7 | 1445 | 35.24 | 10.9 | 83.6 | 5.5 |
| Optometrist | 79 | 13.0 | 3145 | 39.81 | 3.8 | 86.7 | 9.5 |
| Dietician | 15 | 2.5 | 140 | 9.33 | 16.0 | 80.0 | 4.0 |
| Pharmacist | 100 | 16.4 | 1425 | 14.25 | 12.9 | 84.2 | 2.9 |

* including a psychologist, psychiatrist, and counsellor.

## 5.5 Medication and Prescription Cost

581 PwP provided information about their medication related to Parkinson's. Only 9 (1.5%) PwP have not been prescribed medication to manage their Parkinson's. On an average PwP were taking 4 medications; however some of them (4%) were taking 10 or more medications for Parkinson's (Table 5.5). A majority of PwP were over aged 65 and thus exempt from prescription charges. 84 PwP (14.7%) had paid for prescriptions with mean annual payments ranged between £25 and £108.85. Overall mean annual OOP cost of prescriptions was £14.53.

**Table 5.5: Number of prescribed medication, source of funding and OOP expenditure**

| Prescribed Medications | | | Sources of Funding | | | Mean OOP (£) |
|---|---|---|---|---|---|---|
| No. of medications | No. of PwP | Percent | Prescription type | No. of PwP | Percent | |
| 0 | 9 | 1.5 | Free prescriptions in my area | 277 | 48.4 | 0 |
| 1 | 86 | 14.8 | Privately funded | 18 | 3.1 | 74.44 |
| 2 | 133 | 22.9 | 3 month pre-payment certificate | 3 | 0.5 | 93.33 |
| 3 | 103 | 17.7 | 12 month pre-payment certificate | 61 | 10.7 | 108.85 |
| 4 | 86 | 14.8 | Exempt from charges | 211 | 36.9 | 0 |
| 5 | 68 | 11.7 | Other | 2 | 0.3 | 25 |
| 6 to 9 | 73 | 12.6 | Total | 572 | 100 | 14.53 |
| 10+ | 23 | 4 | Mean annual no. of prescriptions | **13.8** | | |
| Total | 581 | 100 | Total/Mean no. of medications | **2175 / 3.80** | | |

Over time PwP experience side effects of Parkinson's medication, which adds costs to their daily living. For instance, some PwP on dopamine agonists to manage their Parkinson's may develop impulsive and compulsive behaviours, which can range from compulsive gambling to binge eating and hypersexuality, as a result of the medication. In our survey out of 572 PwP on medications 194 (34%) reported such side effects that resulted in heavy out-of-pocket expenditure on binge eating, shopping, and gambling; some of them even reported over £10,000 expenses on these activities. To control for impulsive and compulsive behaviours, PwP had purchased over the counter medications or supplements. Out of 558 PwP, 146 (26.2%) bought such medications and on average spent £14.59 per month. The overall mean OOP expenditure for all respondents was £3.82 per month which amounting to £45.81 a year.

## 5.6 Direct and Indirect Healthcare Cost

Putting all together the use of healthcare services by 610 PwP over the last 12 months, the total direct medical cost of consultations, diagnostics, call and ambulance, A&E, inpatient services and medication was £1,285,354 to the NHS and £161,920 to PwP as OOP expenses. The total direct annual medical cost estimated was £2388 per PwP (Table 5.6) of which the share of NHS was 88.7% in the total direct medical costs. Figure 5.1 shows the breakdown of annual costs of Parkinson's to the NHS by type of service. Taking into account travel (£36) equipment (£1923) expenses, the total annual healthcare cost per PwP added up to £4347. Importantly the share of the non-medical cost component, usually an oversight by health policy makers, was 45% in the total healthcare cost. Where appropriate, a breakdown of various types of healthcare costs by individual Home Countries has been provided in Appendix 6.

**Figure 5.1: Distribution of direct medical costs to the NHS by type of service (£, %)**

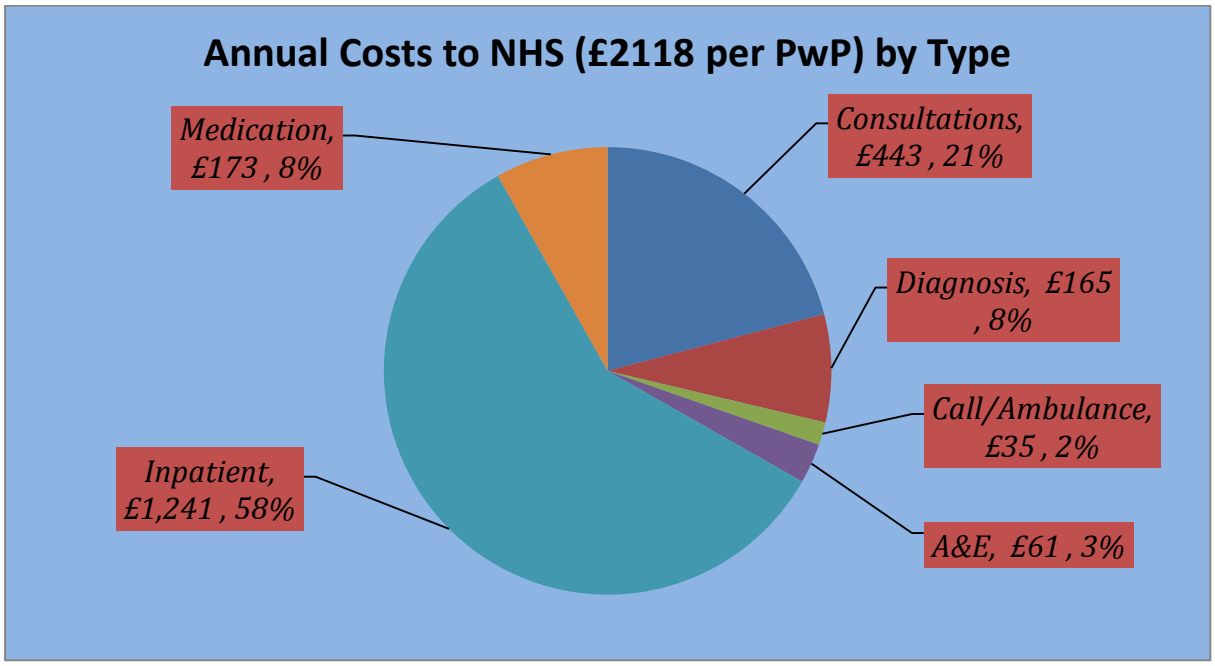



**Table 5.6: Total annual healthcare cost to the NHS and PwP**

| Direct and Indirect Cost | Type | N | Total Utilisation | Cost to NHS (£) | | Cost to PwP (OOP in £) | | Mean Cost (NHS+ OOP) |
|---|---|---|---|---|---|---|---|---|
| | | | | Total | Mean | Total | Mean | |
| Direct - Medical | Consultations | 610 | 13287 | 270252 | 443.04 | 110350 | 180.90 | 623.94 |
| | Diagnosis | 610 | 1617 | 100716 | 165.11 | 11200 | 18.36 | 183.47 |
| | Call/Ambulance | 610 | 392 | 21069 | 34.54 | 150 | 0.25 | 34.79 |
| | A&E | 610 | 190 | 37105 | 60.83 | 575 | 0.94 | 61.77 |
| | Inpatient | 610 | 371 | 757309 | 1241.49 | 5775 | 9.47 | 1250.96 |
| | **Sub-total** | | | 1,186,451 | 1945.00 | 128050 | 209.92 | 2154.92 |
| | Medication | 572 | 7827 | 98903* | 172.91 | 8310 | 14.53 | 187.44 |
| | Non-prescription medication | 558 | 146 | | | 25560 | 45.81 | 45.81 |
| | **Total Medical** | | | **1,285,354** | **2117.91** | **161920** | **270.25** | **2388.16** |
| Indirect (Non-Medical) | Travel | 610 | | ** | | 21875 | 35.86 | 35.86 |
| | Equipment | 594 | 1013 | ** | | 1142275 | 1923.02 | 1923.02 |
| **Total Healthcare cost** | | | | | | 1,326,070 | 2229.13 | 4347.04 |
| * Number of Annual Free prescription multiplied by £8.20 (3.80 medications per PwP assuming repeat prescription every 8 weeks= 3.80*13/2=24.72. About 85.3% received a free prescription, therefore, the cost to NHS worked out to be 24.71 x 0.853 x 8.20 x 572. | | | | | | | | |
| ** Few PwP received free travel/subsidised equipment under the NHS Continuing Care scheme whose costs to the provider were not estimated. | | | | | | | | |

# References

Curtis L and Burns A (2015).*Unit Costs of Health and Social Care 2015*. Kent: Personal Social Services Research Unit (PSSRU), University of Kent.

# 6. Economic and Financial Cost

## 6.1 Impact on Employment of PwP and Carers

More than 50% (n=391) of PwP reported that Parkinson's had a direct effect on their employment. One-third (n=171) of carers also reported an impact of Parkinson's on their employment and working conditions. Three-fourths of PwP (71 out of 95) who were working had reported workdays lost during the last 12 months due to Parkinson's and on average they lost 62.1 workdays in a year. 61 (64.2%) of PwP were forced to reduce their weekly working hours due to Parkinson's, and on an average, they reduced weekly hours by 12.4. Similar types of impact on workdays lost and working conditions were noticed for the caregivers; however, the reduction was relatively lower when compared with PwP. Less than one-thirds of working carers (49 out of 169) had reported workdays lost as a result of caring for PwP and on average they lost 18.9 annual workdays. 54 (32%) caregivers reduced their weekly working hours and on an average they cut their weekly hours by 10.7 (Table 6.1.1).

### 6.1.1 Current Direct Employment Income Loss

There were productivity losses both for PwP and those providing care to them. A conservative magnitude of these losses in monetary terms could be estimated by using the average hourly, daily or weekly earnings of workers. According to the ONS, the average weekly earnings in December 2015 was £496 for 37.6 weekly hours (ONS 2016). This amounts to a total annual productivity loss (workdays lost plus a reduction in weekly hours) of £956,643 for working PwP and £487,656 for caregivers (Table 6.1.1). The total loss of annual income from employment to working PwP and carers was £1,444,299. Overall for 729 families affected by Parkinson's, this loss worked out to be £1981.21 per household.

**Table 6.1.1: Impact on employment and annual productivity loss**

| | **PwP** | | **Carers** | |
|---|---|---|---|---|
| **Impact on employment of Parkinson's** | **N** | **%** | **N** | **%** |
| Yes | 391 | 50.4 | 171 | 31.3 |
| No | 338 | 43.6 | 345 | 63.2 |
| NR | 47 | 6.1 | 30 | 5.5 |
| All | 776 | 100.0 | 546 | 100.0 |
| **Currently Working** | **95** | **12.4** | **169** | **31.2** |
| **Workdays lost** | | | | |
| Reported workdays lost in last 12 months | 71 | 74.7 | 49 | 29.0 |
| Total number of sick days taken | 4409 | | 926 | |
| Mean workdays lost per reported person | 62.1 | | 18.9 | |
| Total Annual Monetary Loss (@ £496 weekly earnings*) | £437,373 | | £91,859 | |
| **Reduction in working hours** | | | | |
| Reported reduction in work hours in last 12 months | 61 | 64.2 | 54 | 32.0 |
| Number of weekly hours reduced | 757 | | 577 | |
| Mean weekly hours reduced per reported person | 12.4 | | 10.7 | |
| Total Weekly Monetary Loss (@ £496 for 37.6 weekly hours) | £9986 | | £7612 | |
| Total Annual weekly hours reduction loss | £519,270 | | £395,797 | |
| **Total Annual Productivity Loss** | **£956,643** | | **£487,656** | |

* ONS (2016): p.17.

### 6.1.2 Current Indirect Employment Earnings Loss

Here indirect earnings losses due to early retirement or inability to work during the current year are estimated. In Chapter 3, Table 3.4 it was reported that 182 PwP took early retirement; 87 were unable to work (incapacity) due to their Parkinson's whilst 10 PwP were looking for work (i.e. unemployed). These figures for carers for shouldering caring responsibilities for their PwP were 56 took early retirement, 8 unable to work and 9 unemployed. The unemployed people on average were losing annual earnings of £25792 (£496 x 52). Therefore, for 19 unemployed people (10 PwP and 9 carers), the total annual earning loss amounted to £490,048 (£25792 x 19). In terms of people who were unable to work (incapacity), if we assuming all 95 people (87 PwP and 8 carers) were claiming incapacity benefits (which is £105.35 per week for 2015/16 - Department for Work and Pensions [DWP] 2015: p.7), the net weekly earnings loss estimated to be £390.65 (£496 minus £105.35) per person. The annual earnings loss worked out to be £20313.8 per person, and the total loss for 95 people amounted to £1,929,811. In terms of loss of earnings due to early retirement, 238 people (182 PwP and 56 carers) took involuntarily retirement early due to Parkinson's. Of these, 85 people (66 PwP and 19 carers) were currently under the age of 65 and thus there was an indirect loss of annual earnings of £25792 (£496 x 52) per person, which aggregated to £2,192,320 (£496 x 52 x 85). Altogether these annual earnings losses to both PwP and carers (unemployed, unable to work and took early retirement as a result of Parkinson's) added up to £4,612,179 (£490,048 + £1,929,811 + £2,192,320), with an overall average of £6013.3 for the 767 PwP households (Table 6.1.2).

**Table 6.1.2: Indirect annual employment earnings loss due to Parkinson's**

| Indirect Employment Earnings Loss Description | PwP | Carers | All |
|---|---|---|---|
| 1. Unemployed (looking for work) | 10 | 9 | 19 |
| Annual employment earnings loss (@£496 x 52 per person) | 257920 | 232128 | 490048 |
| 2. Not working due to illness or incapacity | 87 | 8 | 95 |
| Annual employment earnings loss [net weekly earnings loss (£496 minus £105.35 as incapacity benefits=£390.65) x 52] | 1767300.6 | 162510.4 | 1929811.0 |
| 3. Early retired due to ill health/caring responsibilities | 182 | 56 | 238 |
| Of which currently under aged 65 | 66 | 19 | 85 |
| Annual employment earnings loss (@£496 x 52 per person) | 1702272 | 490048 | 2192320 |
| **Total indirect annual earnings loss due to Parkinson's** | **3727492.6** | **884686.4** | **4612179.0** |
| **Average loss per PwP household (n=767)** | **4859.8** | **1153.4** | **6013.3** |

### 6.1.3 Unpaid Care (Earnings Loss) to Caregivers

The DWP recently provided estimates of 200,000 people[4] who are caring for their family members for 20 or more weekly hours but have not been registered for carer allowance and

[4] According to the 2012/13 Family Resource Survey, 330,000 working-age people were providing informal care for 20-35 hours per week. About 40% of the 330,000 were in full-time employment, so would already be paying National Insurance contributions, which leaves 200,000 potential beneficiaries of Carer's Credit (DWP 2016). Out of 200,000 (about 70,000 would be male and 130,000 female) around two-thirds would be aged 50 or over.

loosing on their pension credit years for national insurance (DWP 2016). Inclusive of missing age reporting, 242 (44.3%) carers were aged under 65 of which 141 were working, 6 unemployed, 7 not working due to ill-health and 19 retired early to undertake caring responsibilities of PwP. The remaining 69 carers had devoted fully to looking after their PwP. Assuming all of them are caring for 20 hours or more per week and not taking any social benefits, then we can estimate their unpaid caring contribution in monetary term. According to the ONS, the weekly earnings was £496 for 37.6 weekly hours, then for at least 20 hours of care their weekly earnings loss would be £264 or £13728 in a year. The total unpaid caring for 69 carers equated to £947,232 earnings loss per year and overall mean earnings loss (of 767 PwP household) was on average £1235 per household. A very similar approach (opportunity cost of time) was used to estimate unpaid caring for people with Dementia by Knapp *et al.* (2007).

### 6.1.4 Total Employment Earnings Loss during Working Life

To calculate working lifetime earnings loss of all 182 PwP who took early retirement at different ages in their working life, one needs to estimate the mean years of early retirement before the stipulated age of 65 for men and 60 for women. Although more recently, the retirement age has been moving upwards for women, in our survey almost all women respondents took early retirement prior to 2015. In the survey, however, we didn't ask in which year the respondents took early retirement, although 67 PwP and 54 carers provided detailed notes about how Parkinson's had affected their employment and decision to retire early (select quotes regarding their involuntary early retirement decisions are shown in Appendix 7). We had worked out through their notes that the average working years lost was 5.96 years (male 6.41 and female 5.07 years) for PwP which worked out to be 1078 man-years. Thus, a total lifetime earnings loss as a result of premature retirement for PwP worked out to be £27,808,419. Similarly, 56 carers took early retirement. The average working years lost was 3.60 years (male 3.38 and female 3.86 years) and thus accounted for the loss of 206 man-years, equivalent to £ 5,302,835. Thus, a total lifetime earnings loss as a result of premature retirement for PwP households added to £ 33,111,254 and overall mean earnings loss (of 767 PwP) was £43,170 per household. These accumulated losses during working life are estimated at current earnings level and not have been adjusted for inflation.

## 6.2 Financial Cost Related to Changes in Living Arrangements

### 6.2.1 Equipment Purchased

Out of 776 PwP, 594 provided information on equipment purchased during the past 12 months. Two-thirds of PwP (376 out of 594) purchased a total of 1013 pieces of equipment. These were purchased mainly to improve mobility within the house (bedroom, bath/shower room, kitchen) and garden, and outside the home so as to improve balance and reduce falls due to tremor. The most common items purchased were walking sticks, walkers, medicine dispenser/timer, reclining chairs, raised toilet seats, wheelchairs, special cutlery, furniture, stair-lift chair, grip handles in shower, bedrooms, entrance and walkways, special hospital type beds and mobility scooters or even automatic cars or Wheelchair Accessible Vehicle (WAVs). About 82% of equipment were fully self-financed, with the NHS equipment

provided mainly through the Continuing Care programme by either supplying equipment for free or at a subsidised rate. The support from the local council and a charity was minimal. The average OOP expenditure for equipment was £1128, and per incurring PwP was £3038. The overall average for 594 PwP was £1923 (Table 6.2.1).

**Table 6.2.1: Equipment purchased in the past 12 months by funding source and cost**

| How funded | Equipment | | |
|---|---|---|---|
| | N | % | Mean (£) |
| NHS | 135 | 13.33 | 27.41 |
| Self-financed | 826 | 81.54 | 1343.70 |
| Local Council grant | 20 | 1.97 | 761.25 |
| Charity support | 17 | 1.68 | 204.41 |
| Other | 15 | 1.48 | 665.00 |
| Total | 1013 | 100.00 | 1127.62 |
| Per incurring PwP (376) | | | 3037.97 |
| Overall (for 594 PwP) | | | 1923.02 |
| **Number (%) of PwP purchased equipment** | **376** | **63.3** | |

### 6.2.2 Alterations to Accommodation

Out of 776 PwP, 585 provided information about alterations to accommodation carried out as a consequence of having Parkinson's. Of these 278 (47.4%) PwP had made changes to their accommodation in the past. The type and extent of the alterations depended on the condition (severity) of Parkinson's. For example, some had changed toilets, converted bathrooms to wet-room or walk-in shower, broadened main-doors, and had a ramp built. If they were no longer able to access the bedroom upstairs via a stair-lift, gradually they moved downstairs by converting the living room, reception room or garage into a bedroom. Some of the PwP moved to a bungalow thus involving a heavy capital expenditure even after retirement from work. Thus with the progression of Parkinson's the accommodation was altered in line with changes in needs. About a half of PwP households had made alterations since the diagnosis of Parkinson's. More than 70% of alterations were self-financed; 13.5% were through NHS assistance and 12.6% through local council grants. On an average, OOP expenses for accommodation alterations were £2070; and per reporting PwP this was £3894. The overall average for 585 PwP was £1857 since their diagnosis of Parkinson's. As two-thirds of PwP had been diagnosed for more than 5 years, they may not have been able to recall expenses they had made on earlier accommodation alterations. Therefore, we have also looked into these expenses over the last two years (158 out of 224 PwP had incurred OOP expenses over the last two years). On an average, OOP expenses for accommodation alterations in the last two years was £3888 per reporting PwP, with an overall average of £1050 for 585 PwP (Table 6.2.2).

**Table 6.2.2: Accommodation alterations undertaken by source of funding and cost**

| How funded | Alterations in House | | |
|---|---|---|---|
| | N | % | Mean (£) |
| NHS | 71 | 13.52 | 104.58 |
| Self- funded | 369 | 70.29 | 2737.67 |
| Local Council grant | 66 | 12.57 | 558.33 |
| Charity support | 2 | 0.38 | 2500.00 |
| Combination of funding | 8 | 1.52 | 1643.75 |
| Other | 9 | 1.71 | 1541.67 |
| Total | 525 | 100.00 | 2069.52 |
| Per reporting PwP (279) | | | 3894.27 |
| Overall (for 585 PwP) | | | 1857.26 |
| **Number, % of PwP made alterations** | **278** | **47.4** | |
| **During last two years** | | | |
| Per reporting PwP (158) | 224 | 42.67 | 3888.13 |
| Overall (for 585 PwP) | | | 1050.13 |

### 6.2.3 Driving and Vehicle Modification

568 PwP and carers provided information about driving licenses and access to a motor vehicle. 71% of PwP and 45% of carers or other members of the household had full-driving license. A couple of PwP reported that their driving license was revoked by DVLA due to their diagnosis of Parkinson's. 487 PwP out of 568 (85.7%) said that they had access to a motor vehicle and 122 (24.4%) reported that was a mobility vehicle. 49 PwPs either modified their vehicle or purchased a WAV or an automatic car to improve motor-ability as a result of Parkinson's. Most of PwP (88%) had to meet such expenses through their own pocket. During last two years 31 PwP did modification of vehicle with on average of £4278 OOP expenses per motor-ability vehicle. One PwP who bought a new automatic car had paid £14,500.

## 6.3 Out-of-Pocket Expenses on Daily Living and Energy Cost

Out of 776 PwP, 582 provided information about their spending on takeaways and on convenience foods as a consequence of having Parkinson's. 199 (34.2%) PwP were spending more on takeaways and convenience food every month on a regular basis (Table 6.3.1). Overall mean expenditure per month on takeaways food (for 582 respondents) was £25.44 and £74.40 per incurring case.

**Table 6.3.1: PwP increasing spend on takeaways/convenience food due to Parkinson's**

| Takeaway food | N | Percent | Valid Percent |
|---|---|---|---|
| Yes | 199 | 25.6 | 34.2 |
| No | 355 | 45.7 | 61.0 |
| Don't know | 28 | 3.6 | 4.8 |
| Total | 582 | 75.0 | 100.0 |
| Missing | 194 | 25.0 | |
| Total | 776 | 100.0 | |

Information on the extra use of energy for the home as a result of Parkinson's was provided by 466 PwP. The majority of them (55%) reported an increase in expenses related to central heating bills and on average reported additional monthly expenses of £56.70 per case, with an overall average of £31.15. Some PwP reported additional expenses towards increasing usage of an electric blanket (2%), fan heater (4%), air conditioning (3%), and cooling fan (6%). In all, 299 PwP (64%) reported some extra energy cost per month (all together £22195), with an average of £74.23 increased expenditure as a consequence of having Parkinson's (Table 6.3.2).

**Table 6.3.2: PwP reporting problems with temperature regulation due to Parkinson's**

| Energy Cost | PwP Reported | | | Mean Expenses (£) | |
|---|---|---|---|---|---|
| | No | Yes | % of 466 | Overall (of 466) | Per incurring case |
| Central heating | 210 | 256 | 54.94 | 31.15 | 56.70 |
| Electric blanket | 412 | 54 | 11.59 | 2.36 | 20.37 |
| Fan heater | 410 | 56 | 12.02 | 3.64 | 30.27 |
| Air conditioning | 455 | 11 | 2.36 | 3.36 | 141.82 |
| Cooling fan | 387 | 79 | 16.95 | 5.52 | 32.47 |
| Other | 445 | 21 | 4.51 | 1.63 | 36.19 |
| **PwP reporting extra energy cost per month** | **167** | **299** | **64.16** | **47.63** | **74.23** |

As described in Section 4.2, several PwP needed help for their daily or routine activities within and outside the house. More than one-third of PwP needed help with personal care and bathing and about a half for cooking a meal. For cleaning their house, 62% of PwP needed help on a daily or weekly basis. As and when required, between 41% and 49% of PwP needed help for ironing, decorating and gardening. Similarly, for activities outside the house, 52% of PwP needed help for daily or weekly shopping. About a half of them needed help for transport and attend to medical appointments as and when these were scheduled. Several PwP had reported attending weekly or bi-weekly physiotherapy/exercise classes and 35% of them needed help to attend these classes (Table 6.3.3). A family member, particularly a spouse, played a critical role in shouldering most of the in-house and outside house activities. PwP who were living alone, received help from their children or grandchildren. However, some of the tasks like house cleaning, gardening and decorating were done by a privately hired person. In those in a more advanced stage of the condition, when the spouse was unable to provide adequate support, private agency carers performed some of the personal care and bathing tasks. If required, the private carers also shouldered the responsibility of ironing clothes and shopping for them. Most of the formal carers were hired through agencies on the weekly or monthly basis. A few had reported a payment to a private agency around £2200 per month.

The total OOP expenses incurred for various daily, weekly, or 'as and when required' activities from £830 for cooking to £13990 for decorating. Using a weighting procedure to add-up weekly costs, a total annual expense incurred to meet such requirement has been calculated. The reported weekly expenses for undertaking tasks of house cleaning, personal care, bathing, cooking, ironing, shopping and transport which were mostly performed on a daily or weekly basis were multiplied by 52; gardening, attending to medical appointments

and physiotherapy/ exercise classes usually performed every two-weeks were multiplied by 26; and decorating which was infrequently performed, was multiplied by 2.

**Table 6.3.3: PwP needing help for daily living activities and weekly OOP expenditure**

| Type of Help and Cost | *In Home* | | | | | | |
|---|---|---|---|---|---|---|---|
| | Cleaning | Personal care | Bathing | Cooking | Gardening | Ironing | Decorating |
| No. of PwP needing help | 326 | 207 | 178 | 251 | 259 | 217 | 250 |
| % of 529 | 61.63 | 39.13 | 33.65 | 47.45 | 48.96 | 41.02 | 47.26 |
| **Help provided by (% distribution)** | | | | | | | |
| Spouse | 36.1 | 54.0 | 51.7 | 69.5 | 38.2 | 57.1 | 29.4 |
| Child/grandchild | 7.8 | 8.6 | 11.9 | 10.3 | 7.9 | 8.1 | 8.3 |
| Sibling | 1.0 | 1.1 | 0.7 | 1.4 | 1.2 | 1.0 | .9 |
| Carer | 5.4 | 28.7 | 30.0 | 12.7 | 1.7 | 12.6 | 2.2 |
| Friend | 3.4 | 1.1 | 1.4 | 2.8 | 7.1 | 3.5 | 3.1 |
| Neighbour | 0.7 | | | | 1.7 | | 0.9 |
| Social Worker | | 1.1 | .7 | | | | |
| Home help | 2.0 | 2.9 | 2.1 | 1.9 | | 2.5 | |
| Cleaner | 39.9 | | | | | 6.6 | |
| Gardener | 0.7 | | | | 41.1 | | |
| Decorator | | | | | 0.4 | | 52.6 |
| Taxi | | | | | | | |
| Other | 3.0 | 2.3 | 1.4 | 1.4 | .8 | 8.6 | 2.6 |
| All | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |
| % needed help on daily/weekly basis | 77.1 | 77.4 | 67.6 | 85.0 | 34.5 | 57.0 | 2.7 |
| **Total OOP expenses (£)** | **4670** | **4120** | **1150** | **830** | **3370** | **1090** | **13990** |
| **Mean OOP per incurring case** | **14.33** | **19.90** | **6.46** | **3.31** | **13.01** | **5.02** | **55.96** |
| **Mean OOP (£) of 529** | **8.83** | **7.79** | **2.17** | **1.57** | **6.37** | **2.06** | **26.45** |
| **Total estimated annual OOP expenses* (£)** | 242840 | 214240 | 59800 | 43160 | 87620 | 56680 | 27980 |

| Type of Help and Cost | *Outside Home* | | | |
|---|---|---|---|---|
| | Shopping | Transport | Medical appointment | Exercise/ physiotherapy |
| Number of PwP needing help | 274 | 246 | 267 | 184 |
| % of 529 provided information | 51.80 | 46.50 | 50.47 | 34.78 |
| **Help provided by (% distribution)** | | | | |
| Spouse | 55.1 | 58.0 | 63.1 | 36.4 |
| Child/grandchild | 19.6 | 15.0 | 12.9 | 6.4 |
| Sibling | 2.4 | 1.8 | 1.2 | |
| Carer | 9.4 | 4.0 | 6.2 | 6.4 |
| Friend | 3.3 | 4.4 | 5.8 | 1.7 |
| Neighbour | 0.4 | | | 0.6 |
| Social Worker | | | | |
| Home help | 1.2 | | 0.4 | |
| Cleaner | 1.6 | | | |
| Gardener | | | | |
| Decorator | | 0.4 | | |
| Taxi | 1.2 | 10.6 | 5.0 | 0.6 |
| Other | 5.7 | 5.8 | 5.4 | 48.0 |
| All | 100.0 | 100.0 | 100.0 | 100.0 |
| % needed help on daily/weekly basis | 75.1 | 28.7 | 6.7 | 62.5 |
| **Total OOP expenses (£)** | **2590** | **2230** | **1680** | **2990** |
| **Mean OOP per incurring case** | **9.45** | **9.07** | **6.29** | **16.25** |
| **Overall Mean OOP (£) of 529** | **4.90** | **4.22** | **3.18** | **5.65** |
| **Total estimated annual OOP expenses* (£)** | 134680 | 115960 | 43680 | 77740 |

The resultant total annual OOP expenses for in-house activities worked out to be £732320, for outside of house £372060, and the aggregated cost was £1,104,380. These were reported by 529 PwP, therefore, the annual mean OOP expenses estimated as £2087.70 per PwP household.

## 6.4 Changes in Income and Social Benefits

Out of 776 PwP, 583 reported on the sources of income and benefits they had received and the change in these over the last 12 months. The results are presented in summary and detailed sources of income/benefits in Tables 6.4.1 and 6.4.2. Nearly a half of PwP received income as state pension and a similar proportion of them received as an occupational pension; this is followed by 13% who received income from employment and 9% from other sources. In terms of benefits 83% received incomes from various state allowances and credits; however, about 8% received Local Council for housing and other benefits. Carers reported a similar pattern in sources of income and benefits; however, the magnitude was relatively smaller compared to those for PwP. Further, just under a half of carers received incomes from various state allowances and credits.

Over the last year some PwP had reported discontinuance of income from employment (3%), state pension and occupational pensions (5%), and state allowances and credits (12%). The respective discontinuance rates for carers were 4%, 3%, and 6%. An estimated discontinuance of pensions and state benefits for PwP and carers amounts to a loss of £10,773.75 and £6060.75 per week respectively, which worked out at £875,394 per year. The overall mean annual loss per PwP household of pensions and benefits due to a diagnosis of Parkinson's worked out to be £1502.

**Table 6.4.1: Summary of sources of income/benefits for PwP and Carers**

| Summary of Income/Benefits* | Currently Receiving | | | | Received in past 12 months but no longer getting | | | |
|---|---|---|---|---|---|---|---|---|
| | PwP | | Carers | | PwP | | Carers | |
| | N | % of 583 | N | % of 583 | N | % of 583 | N | % of 583 |
| Reported income from employment (1) | 74 | 12.69 | 75 | 12.86 | 18 | 3.09 | 22 | 3.77 |
| Reported income from other sources (29) | 55 | 9.43 | 30 | 5.15 | 0 | 0.00 | 1 | 0.17 |
| Reported income as State Pension (5) | 279 | 47.86 | 238 | 40.82 | 27 | 4.63 | 20 | 3.43 |
| Reported income as Occupational Pension (6) | 263 | 45.11 | 177 | 30.36 | 26 | 4.46 | 13 | 2.23 |
| Reported income from Allowances/Credits (2, 3, 4, 7, 9 to 25) | 482 | 82.68 | 276 | 47.34 | 68 | 11.66 | 35 | 6.00 |
| Reported benefits from Housing/Council/Other Benefits (8, 26, 27, 28) | 44 | 7.55 | 42 | 7.20 | 9 | 1.54 | 4 | 0.69 |
| All | 1197 | | 838 | | 148 | | 95 | |

*Item number details against sources are shown in Table 6.4.2

## Table 6.4.2: Detailed sources of income/benefits for PwP and Carers

| Source no. | Sources of Income/Benefits | Currently Receiving | | | | Received in past 12 months but no longer getting | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | PwP | | Carer | | PwP | | Carer | |
| | | N | % | N | % | N | % | N | % |
| 1 | Regular income from employment | 74 | 6.18 | 75 | 8.98 | 18 | 12.16 | 22 | 23.16 |
| 2 | Working Tax Credit | 9 | 0.75 | 11 | 1.32 | 1 | 0.68 | 4 | 4.21 |
| 3 | Income Support | 4 | 0.33 | 2 | 0.24 | 1 | 0.68 | 0 | 0.00 |
| 4 | Jobseekers Allowance | 7 | 0.58 | 1 | 0.12 | 1 | 0.68 | 1 | 1.05 |
| 5 | State Pension | 279 | 23.31 | 238 | 28.14 | 27 | 18.24 | 20 | 21.05 |
| 6 | Occupational Pension | 263 | 21.97 | 177 | 21.20 | 26 | 17.57 | 13 | 13.68 |
| 7 | Pension Credit | 14 | 1.17 | 11 | 1.32 | 3 | 2.03 | 0 | 0.00 |
| 8 | NHS Continuing Care | 6 | 0.50 | 9 | 1.08 | 1 | 0.68 | 3 | 3.16 |
| 9 | Attendance Allowance £55.10 a week | 22 | 1.84 | 17 | 2.04 | 2 | 1.35 | 3 | 3.16 |
| 10 | Attendance Allowance £82.30 a week | 35 | 2.92 | 53 | 6.35 | 3 | 2.03 | 7 | 7.37 |
| 11 | Mobility Allowance | 26 | 2.17 | 20 | 2.40 | 4 | 2.70 | 1 | 1.05 |
| 12 | Carers Allowance | 23 | 1.92 | 19 | 2.28 | 5 | 3.38 | 2 | 2.11 |
| 13 | Employment and Support Allowance work-related activity group (£102.15/ week) | 7 | 0.58 | 1 | 0.12 | 7 | 4.73 | 5 | 5.26 |
| 14 | Employment and Support Allowance support group ( £109.30/week) | 32 | 2.67 | 14 | 1.68 | 8 | 5.41 | 2 | 2.11 |
| 15 | Disability Living Allowance lower rate care component (£21.80/week) | 39 | 3.26 | 11 | 1.32 | 9 | 6.08 | 1 | 1.05 |
| 16 | Disability Living Allowance middle rate care component (£55.10/week) | 40 | 3.34 | 22 | 2.63 | 2 | 1.35 | 2 | 2.11 |
| 17 | Disability Living Allowance higher rate care component (£82.30/week) | 61 | 5.10 | 27 | 3.23 | 6 | 4.05 | 1 | 1.05 |
| 18 | Disability Living Allowance lower rate mobility component (£21.80/week) | 10 | 0.84 | 9 | 1.08 | 2 | 1.35 | 1 | 1.05 |
| 19 | Disability Living Allowance higher rate mobility component (£57.45/week) | 94 | 7.85 | 31 | 3.71 | 9 | 6.08 | 2 | 2.11 |
| 20 | Personal Independent Payment lower rate daily living component (£55.10/week) | 17 | 1.42 | 1 | 0.12 | 0 | 0.00 | 0 | 0.00 |
| 21 | Personal Independent Payment higher rate daily living component (£82.30/week) | 13 | 1.09 | 6 | 0.72 | 2 | 1.35 | 1 | 1.05 |
| 22 | Personal Independent Payment lower rate mobility living component (£21.80/week) | 5 | 0.42 | 1 | 0.12 | 0 | 0.00 | 1 | 1.05 |
| 23 | Personal Independent Payment higher rate mobility living component (£57.45/week) | 9 | 0.75 | 5 | 0.60 | 0 | 0.00 | 0 | 0.00 |
| 24 | Child Benefit | 10 | 0.84 | 11 | 1.32 | 0 | 0.00 | 0 | 0.00 |
| 25 | Child Tax Credit | 5 | 0.42 | 3 | 0.36 | 3 | 2.03 | 1 | 1.05 |
| 26 | Housing Benefit | 10 | 0.84 | 10 | 1.20 | 1 | 0.68 | 0 | 0.00 |
| 27 | Council Tax Benefit | 26 | 2.17 | 21 | 2.51 | 2 | 1.35 | 1 | 1.05 |
| 28 | Other benefit | 2 | 0.17 | 2 | 0.24 | 5 | 3.38 | 0 | 0.00 |
| 29 | Other income | 55 | 4.59 | 30 | 3.59 | 0 | 0.00 | 1 | 1.05 |
| | Total sources of income/benefits | 1197 | 100.00 | 838 | 100.00 | 148 | 100.00 | 95 | 100.00 |

## 6.5 Resultant Societal Cost

The combined magnitude of both health and social care cost of Parkinson's to society is summarised in Table 6.5. The direct healthcare cost was mainly borne by the NHS; when these are combined with OOP payments, the average annual cost per PwP was £2388. The indirect annual healthcare cost, mainly borne by the PwP, was £1959. Thus, the total annual healthcare cost per PwP worked out to be £4347. There were other non-healthcare expenses related to changes in living arrangements and environment that were directly borne by PwP households. The annual non-healthcare cost was £3622 per PwP household. The total annual healthcare and non-healthcare cost per household added up to £7969. Where appropriate, a breakdown of these health and social care costs by individual Home Countries has been provided in Appendix 6.

**Table 6.5: Aggregated annual health and social care cost of Parkinson's on society**

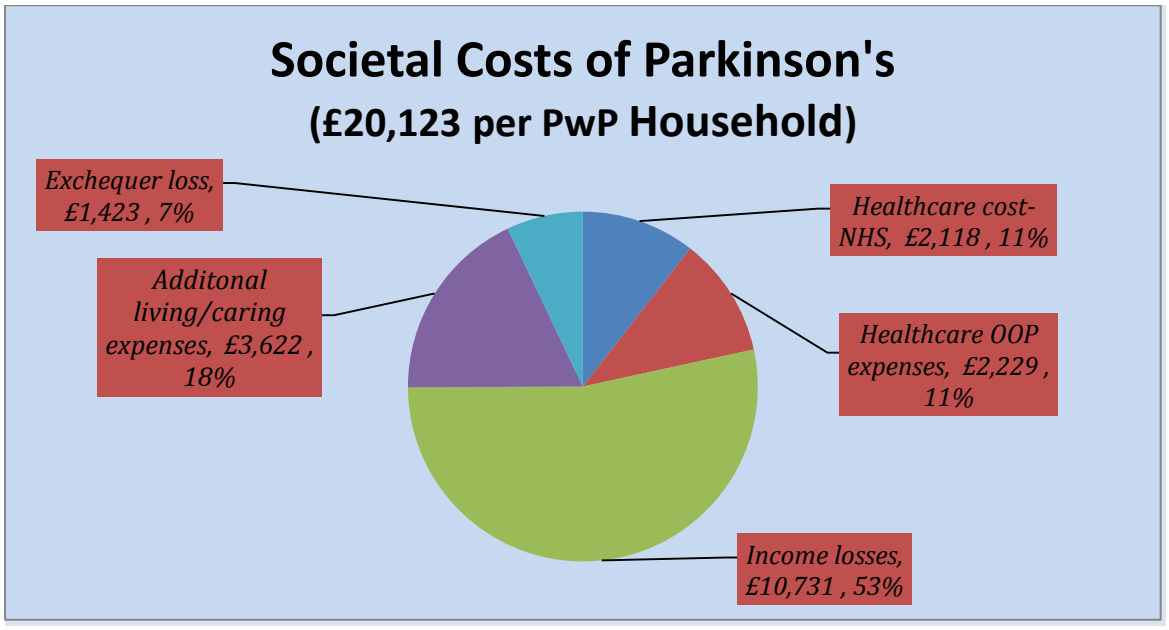
| Annual Direct and Indirect Cost | Cost/Income Loss Description | | Total Cost (£) | Mean Cost per family |
|---|---|---|---|---|
| Direct Healthcare | 1. Health services by the NHS | NHS | 1,285,354 | 2,118 |
| | 2. Healthcare OOP (n=610) | PwP | 161,920 | 270 |
| | **Sub-total (1 to 2)** | | 1,447,274 | 2,388 |
| Indirect Healthcare | 3. Travel (n=610) | | | |
| | 4. Equipment (n=594) | PwP | 1,164,150 | 1,959 |
| **Total Healthcare (1 to 4)** | | | **2,611,424** | **4,347** |
| Non-healthcare | 5. Alterations in accommodation (n=585) | PwP | 307,163 | 525 |
| | 6. Living environment - energy cost (n=466) | PwP | 266,340 | 572 |
| | 7. Takeaways (n=582) | PwP | 177,660 | 305 |
| | 8. Mobility vehicle/car (n=501) | PwP | 66,313 | 132 |
| | 9. Daily living assistance (n=529) | PwP | 1,104,380 | 2,088 |
| **Total Non-healthcare (5 to 9)** | | | **1,921,855** | **3,622** |
| Income Loss (Direct and Indirect) | 10. Current Workdays lost and reduction in weekly hours (n=729) | PwP & Carers | 1,444,299 | 1,981 |
| | 11. Current Indirect employment earnings forgone due to early retirement or inability to work or unemployed (n=767) | PwP & Carers | 4,612,179 | 6,013 |
| | 12. Unpaid caring (earnings loss) | Carers | 947,232 | 1,235 |
| | 13. State pension and benefit loss (n=583) | PwP & Carers | 875,394 | 1,502 |
| | **Sub-total (10 to 13)** | | **7,879,104** | **10,731** |
| | Current productivity loss (10 ) per worker (workers=264) | | | 5,471 |
| | 14. Exchequer loss related to reduced productivity (10 and 11) | | | 1,423 |
| **Annual Financial Burden of Parkinson's** | On Household | | | 16,582 |
| | Adding NHS costs | | | 18,700 |
| | Adding Exchequer loss | | | 20,123 |

To arrive at the total societal cost, we calculated current income loss due to Parkinson's in terms of annual sick days off and reduced weekly working hours for both working PwP and carers. This was valued at an annual income loss of £5471 per worker and the overall mean per household calculated as £1984. Several PwP and carers were forced to take early retirement or inability to work or became unemployed due to Parkinson's; using the opportunity cost of time approach we estimated earnings foregone for those who are still in their working-age. The overall mean per PwP household for such annual earnings forgone worked out to be £6013. Many carers are not enrolled with DWP for caring allowance and thus providing unpaid care to their family members. The unpaid caring per household worked out to be £1235. Further, many PwP and carers had reported a loss of certain benefits and cut in pension since registering with DWP as an elderly disabled person or carer. This amounted to an annual loss of £1502 per household. Thus, total annual income loss per household amounted to £10,731.

Further, the direct and indirect earnings loss to the working-age PwP and carers also reflect on reduced income tax and national insurance contributions to the Government exchequer. According to Knapp et al. (2007), excluding national insurance contribution, the effective rate of income tax loss was 17.8% of income forgone. In our survey annual earnings forgone per PwP household was £7994 (£1981+£6013); thus after application of the effective income tax rate, the resultant exchequer loss worked out to be £1423 per household per year.

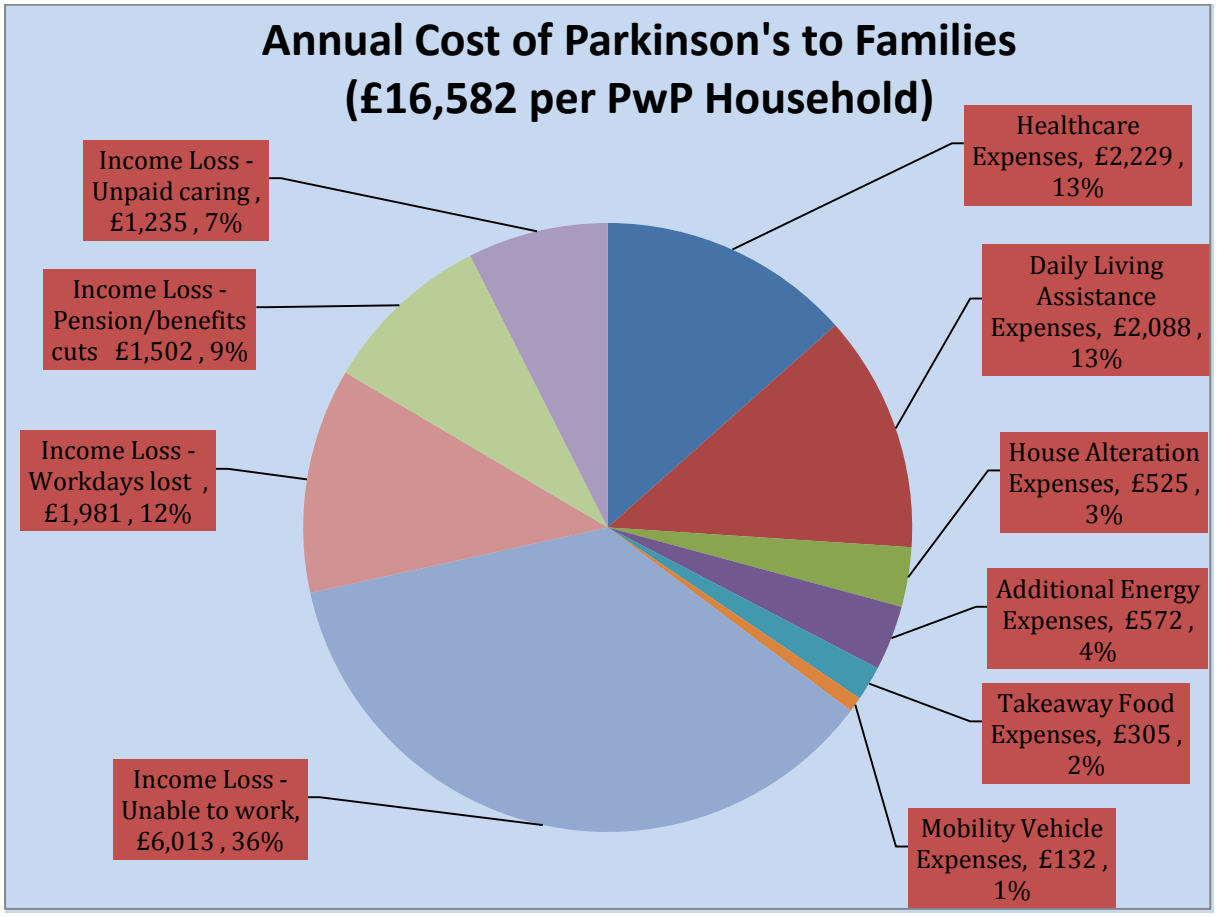
Aggregating all direct and indirect costs, the annual financial burden of Parkinson's on society was £20,123 per PwP household. This included the annual financial cost to the NHS of £2118 per PwP for their treatment and exchequer loss of £1423 per household. Figure 6.1 shows the broad breakdown of societal costs per PwP household - the share of income losses 53% followed by total OOP expenses 29%, and the remaining 11% by the NHS and 7% as exchequer loss.

**Figure 6.1: Distribution of societal costs per PwP household by major categories (£, %)**



The annual direct financial burden on Parkinson's household was £16,582 or £1382 per month. These cost estimates exclude PwP who were transferred from family care in their own home to a nursing home care (the financial burden on families transferring to care home was very large, with a couple of families reporting of paying between £2700 and £3200 per month for such care). Figure 6.2 shows the breakdown of annual costs of Parkinson's to PwP household by type of costs (i.e. income losses and additional expenses).

**Figure 6.2: Distribution of annual cost to PwP households by type of cost (£)**

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# 7. Financial Impact on Households

## 7.1 Impact on Household Income

Out of 776 PwP, the gross annual household income range category was reported by 527 (67.9%) household. The majority of PwP (56%) or carers (60%) reported their annual income to be under £20,000 (Table 7.1.1). The majority of households (60%) reported the combined household income of under £30,000. It was considered that this might reflect on their financial capability to manage and provide the best care for Parkinson's. It also suggests the financial impact of Parkinson's to be very large for a majority of households receiving gross annual income under £30,000.

**Table 7.1.1: Annual income of PwP and Carers**

| Gross Annual Household Income | PwP | | Carer/Other | | Total* | |
|---|---|---|---|---|---|---|
| | N | % | N | % | N | % |
| Under £10,000 | 114 | 21.8 | 116 | 29.0 | 58 | 11.0 |
| £10,000 - £19,999 | 180 | 34.4 | 124 | 31.0 | 149 | 28.3 |
| £20,000 - £29,999 | 100 | 19.1 | 59 | 14.7 | 110 | 20.9 |
| £30,000 - £39,999 | 47 | 9.0 | 37 | 9.3 | 74 | 14.0 |
| £40,000 - 49,999 | 31 | 5.9 | 15 | 3.8 | 43 | 8.2 |
| £50,000 or more | 25 | 4.8 | 23 | 5.7 | 67 | 12.7 |
| Don't know | 26 | 5.0 | 26 | 6.5 | 26 | 4.9 |
| Total Reported | 523 | 100.0 | 400 | 100.0 | 527 | 100.0 |

* The missing values for the total income category are replaced by the highest income category reported for PwP or carer in the household.

About one in four households (25%) reported a reduction in their monthly income as a consequence of Parkinson's (Table 7.1.2). This was reported earlier as mainly due to a loss in annual working days and forced a reduction in weekly working hours for both PwP and carers, and similar concerns are reflected below. The underlying reasons reported for a decreased monthly income included a reduction in work hours (31%), given-up work completely (28%), moved to less demanding jobs (12%) and the rest (29%) mentioned no specific reasons for the reduction in monthly income.

**Table 7.1.2: Impact on monthly income of PwP households by underlying reasons**

| **Household experienced a reduction in income due to Parkinson's over the last 12 months** | N | % | Valid Percent |
|---|---|---|---|
| Yes reduced income by £0-£200 monthly | 49 | 8.4 | 9.5 |
| Yes reduced income by £201 - £500 monthly | 30 | 5.1 | 5.8 |
| Yes reduced income by £501+ monthly | 50 | 8.6 | 9.7 |
| No reduction in monthly income | 388 | 66.6 | 75.0 |
| Total Reporting impact | 517 | 88.7 | 100.0 |
| Not Reported | 66 | 11.3 | |
| Total Respondents | 583 | 100.0 | |

| **Reason for household monthly income reduction** | | | |
|---|---|---|---|
| I have had to reduce my hours at work | 33 | 5.7 | 23.4 |
| I have had to move to a less demanding job | 13 | 2.2 | 9.2 |
| My job does not pay sick leave and I have had to take an increasing number of days off | 2 | 0.3 | 1.4 |
| I have had to give up work and am now claiming benefits | 23 | 3.9 | 16.3 |
| My partner/relative had to reduce their hours at work | 11 | 1.9 | 7.8 |
| My partner/relative had to move to a less demanding job | 4 | 0.7 | 2.8 |
| My partner/relative has had to give up work to care for me | 16 | 2.7 | 11.3 |
| Others | 39 | 6.7 | 27.7 |
| All reasons | 141 | 24.2 | 100.0 |
| Not Reported/Applicable | 442 | 75.8 | |
| Total Respondents | 583 | 100.0 | |

## 7.2 Impact on Household Budget

Overall the financial impact of Parkinson's on a family was widespread; only 168 (28.8%) of the respondents stated that they have not seen the impact at the time they completed the survey, although it seems likely this may change as the condition progresses (Table 7.2). The remaining 415 (71.2%) PwP and carers had expressed on average three types of impact (1217/415 = 2.9), which having Parkinson's exerted on their financial situation. The share of direct monetary impact in terms of reduced savings and increased borrowings including mortgage equity release was the highest (26%); followed by the changed priorities for spending (20%), reduced social activities (19%), reduced holidays (18%) and reduced spending on festive gifts (11%).

**Table 7.2: Financial effect on household budget by type of impact**

| Overall Financial Impact of Parkinson's on Family | N | % |
|---|---|---|
| Not affected at the moment | 168 | 28.8 |
| Had affected | 415 | 71.2 |
| All | 583 | 100.0 |
| **Impact type** | | |
| 1. Savings have been reduced | 263 | 21.6 |
| 2. Borrowing has increased to meet basic needs | 37 | 3.1 |
| 3. Re-mortgage to release equity | 15 | 1.2 |
| 4. Reduced holidays | 214 | 17.6 |
| 5. Changed priorities for spending | 248 | 20.4 |
| 6. Reduced social activities e.g. eating out | 235 | 19.3 |
| 7. Level of income on gifts for birthdays/Christmas has reduced | 139 | 11.4 |
| 8. Other | 66 | 5.4 |
| All | 1217 | 100.0 |

# 8. Lifetime Costs of Parkinson's

## 8.1 Findings Emerged from In-depth Interviews

Of the five people interviewed, none lived in a city; all fell into the category of late onset (over 40 years at diagnosis), and ranged from being diagnosed from 3 up to 11 years. This places CC in the early stages of Parkinson's, AL, MA and LA in the mid stages, and AC's wife in the late stages of the condition (Table 8.1).

**Table 8.1: Basic coding for interviewees**

| Identification | Person 1 | Person 2 | Person 3 | Person 4 | Person 5 |
|---|---|---|---|---|---|
| Gender | Male: AL | Male: MA | Male: CC | Male: AC | Female: LA |
| Role | Diagnosed with Parkinson's + wife joined conversation | Diagnosed with Parkinson's | Diagnosed with Parkinson's | Carer for someone diagnosed with Parkinson's | Diagnosed with Parkinson's |
| Age at diagnosis | 68 | 52 | 65 | Spouse aged 51 at diagnosis | 52 |
| Years with Parkinson's | Into his 5th year | Into his 9th year | Into his 3rd year | Into spouse's 11th year | Into her 5th year |
| First symptom | Wife noted right-hand tremor; AL noted slowness | Both slowness and tremor | Both slowness and tremor | Stiffness and slowness | Stiffness and slowness |
| Country | England | Wales | Northern Ireland | Scotland | Scotland |
| Residential area | Rural | Town | Town | Rural | Town |

In terms of gaining information, it proved difficult for people who had Parkinson's for more than a couple to years to pin-point when specific changes that necessitated spending (direct or indirect) occurred or might occur.

AL reported what he had noted from reflecting on the past few years:

> *'It is difficult to break down into years one to four. I believe the deterioration due to Parkinson's was a slow and gradual one, I guess the decline is small and the same percentage each year. This applies to both the physical side and the emotional/ psychological one'.* AL by email

The conceptual social framework (Appendix 2) has been used to chart an overview of the costs (financial, social, and psychological) the five interviewees discussed over the course of their years with Parkinson's (Appendix 3). The results have been subdivided into the following four subsections: a pre-diagnostic stage: diagnostic experience, elapsing years and future years.

**Pre-diagnostic stage**

Whilst each person with Parkinson's interviewed could state the year they were diagnosed, for some, it took further probing to ascertain how many years prior to this they had been experiencing motor symptoms (problems experienced with aspects of movement, usually a slowness or stiffness, affecting daily life), and what impact this actually had on their lives.

As they were all near to retirement, or retired, it was easiest to consider pre-diagnostic changes in terms of how it affected their work. For example, AL initially noticed changes in his working life during the 5 years prior to diagnosis of finger stiffness affecting his use on the computer, and taking longer to recall names and contact numbers for work, something AL had prided himself as working well. As he was already retired at this point, he stated the changes did not affect his decision to retire. This is different to MA and LA whose decision to retire early was based on the Parkinson's.

CC initially believed the diagnosis of Parkinson's had no impact on retirement decision as it was made 4 years after retirement. On further questioning however, he noted increased issues when covering his 8 – 10 mile round route at work at an outdoor museum that probably led him to take an option to retire at 61.

> *'I quite enjoy walking, but I noticed then I was becoming a bit slower, a bit more clumsy, tripping over things that really weren't there, tripping over my own feet.'*
>
> *'…Other things as well. The loss of concentration came quite easily and a lot of what I did and what I still do is talk to groups of people and you get lost for the correct word. I know what I want to say, but I can't find the word.'*

Whilst over the 60-year retirement option offered employees of his Local Authority, his retirement came four years prior to the age of 65 years at which time CC had planned retirement:

> *'…but as this* [symptoms pre-diagnosis of Parkinson's] *developed I thought, I don't really want to spend the early years in retirement feeling under the weather and miserable, so I went at 61.*

MA's symptoms caused him to look for alternative employment:

> MA: '*Well initially when I first started noticing symptoms I was self-employed at the time. I used to install and service, well I used to do installation of the hands-free kits in cars for mobile phones and also install and service two-way radio systems…Well I noticed when I was doing installations that I was having problems sort of feeding cables through small gaps whereas previously I would've done it say in a matter of a few seconds. It would take me several minutes to do the same thing. Because I didn't seem to be able to, I didn't have the dexterity in my hands. Using tools was becoming more difficult…I would have to give myself longer on the job which isn't always a good thing because when you're dealing with, some cases you were dealing with CEOs and things of companies and obviously they were under pressure, they need the vehicle. You've got a limited amount of time to do it so it increased the pressure on me as well'.*
>
> *'…Yes I eventually had to give up self-employment and I then when to work for my local authority. Initially on relief work as a caretaker and then later on I got a full time permanent job as a site supervisor'.*

There is evidence of the financial cost of Parkinson's affecting earnings, and the ability to continue work in section 6.1, but the interviews highlighted the social and psychological

consequences that evolved in later years.

The Sheffield co-researchers felt the pre-diagnostic period to be a time of an increasing sense of vulnerability, as many were not believed when they stated varied non-motor and motor symptoms and had to request reviews. Despite the push for communication and shared-clinical decision-making, few people are prepared to openly question medical authority, or feel comfortable asking for further investigation (Busari 2013).

This happened with both AL and CC, who had to return to the GP for a review after initially being told they did not have Parkinson's.

AL first went to the GP as: '*….my wife made me'* to investigate a tremor she noticed:

> *'…the first time we saw a locum and she said, no, there's nothing wrong at all. My wife wouldn't accept it so she dragged me back again. I was sent over to the hospital and that's when the diagnosis was made.'*

CC story of initial misdiagnosis was different, as his return to the GP was prompted by a different medical problem:

> *'I've always been fairly active throughout my life and I'd started to notice that I was slowing down and my gait wasn't what it used to be. In fact now with the benefit of hindsight I realise I'd developed that Parkinson's gait, you know where you stoop forward and little steps?'*
>
> *'…but at that stage I obviously didn't realise what it was, but the tremor in my hand was the first noticeable thing and I asked my GP, I went to him at one stage saying I was out of sorts, didn't feel in just top form and I said, I've got this tremor in my right hand, and he flexed my muscles, flexed my arms and made me put a finger on my nose and turn around, all those sort of things, and he said, no I don't think you've anything wrong with you, I don't think it's, if you're thinking of Parkinson's, I don't think you have Parkinson's disease, and I went away quite content, although I still had the tremor and I thought, it's just old age. And I had to go back to the surgery about, I don't know, three or four months later, with an ear infection, and I saw a different doctor and she said to me, it was a young girl, she said to me after she'd looked at my ear, I see you've got a tremor in your right hand, obviously you've not said anything about it. Not really, I said, it's just an old age tremor. So she went through this whole process again, finger on the nose, turn your head, stand up, bend over, flex arms and legs and she said, I'm not terribly sure about this, you have an essential tremor, I'd like you to see a consultant.'*
>
> *'…So I saw him one morning and he said to me, after he'd done all the usual tests, he made me walk around the surgery, he said, I'll do two tests, a blood test to make sure it's not, I can't even remember what it was he said, and I'll send you for an MRI scan, but as far as I'm concerned you have Parkinson's, but it's early stages yet and it's quite a mild case.*

Some people, whether given a possible diagnosis, had to await the process of referral to a specialist consultation and investigation as per guidelines (Scottish Intercollegiate Guidelines Network [SIGN], 2010, NICE, 2006), before confirmation of a diagnosis.

AC's wife saw several specialist Consultants plus paid to see a chiropractor in the UK for her chronic back pain, was finally diagnosed by a consultant abroad:

AC described the long process that finally led to his wife's diagnosis:

*'Well actually that was, again, before, prior to 2004* [talking about the purchase of a stick prior to the year his wife was diagnosed with Parkinson's], *we now know she had onset of Parkinson's. For a number of years prior to that probably as early as 1998, 1999, we thought it was something to do with her back.*

*'…We went to, yeah it was, because of her back she used to go to a chiropractor, and the chiropractor mentioned on a couple of occasions that she should really go and see her doctor.*

*'…Yeah she did see a back specialist in* [named town] *and he said yeah you have a bad back but it's not, you know, you just have to live with it, we've nothing we can really do with that. And in his notes he'd wrote that he'd suspected mild dyskinesia, which is mild involuntary movement. Obviously he could see in her eyes and her face there was mild dyskinesia there. And he wrote that in his notes but the doctor didn't pick up on it and just filed the notes and didn't tell us. It was only when we queried the fact that we'd not heard anything back from this back doctor with our own doctor that it came to light that this is what he'd put in his notes. So we weren't very happy at all.*

*'…And it was only when we…I used to work in Oman and I took her back, because NHS here were…they would've taken nearly a year to see a neurologist, I took her back to Oman and she was diagnosed immediately with Parkinson's. So she came back to UK, I was still there, she came back to UK and saw a neurologist here who concurred with the neurologist in Oman that she did have Parkinson's, and that was late 2004.*

**Diagnostic experience**

For the Sheffield group who conceived the social framework for Parkinson's, the period around diagnosis (pre- and immediately post-) was a time they noted as needing the most help to enable development of understanding and acceptance of the implications of the condition (Evans and Norman, 2009).

Two issues are noteworthy from the series of interviews:

The first relates to the fact that individuals are seen to be mobile at the point of diagnosis (the standard by which most Parkinson's assessment is measured) by health and social care professionals, so are often provided minimal or no support. AL, CC and LA comment how in hindsight, it had been difficult to accept the diagnosis, and that this continues to be an issue for some.

The effect on LA has caused her to be signed off work. She since attempted two returns to work, and considered part-time working, but worked irregular hours over a seven-day period, so this was untenable. LA stated:

'*So I tried to work away but a lot of my work is outdoors because it's working in gardens and stuff and that affects and I have digestive problems as a result of the Parkinson's, and some of the medication I'm on, so work was becoming difficult and I was becoming very, very self-conscious to the point where I got quite anxious about it and ended up being signed off by the doctor with anxiety and depression…and at that point in time I realised that I hadn't, well, I thought I had accepted the fact that I had Parkinson's but I don't think I had. I don't think I'd given myself time. I think I just did my usual, put your head down and get on with it*.

*'...I have had to in recent months, not accept but absorb the fact that I've got Parkinson's and the impact that's having on my life as it progressed and the potential impact it has on my life, so I decided to approach my boss…I just asked them to consider ill health retirement'*.

The second issue relates to the physical symptom discussed and investigated at the point of diagnosis i.e. whether it is a tremor or stiffness (Jancovic and Kapadia 2001). Taking an accurate history helps in limiting misdiagnosis, as experienced with three of the interviewees (AL, AC's wife and LA) however AL, MA, and CC were unable to state which symptom presented first, especially as if their presentation was vague.

AL's wife noted his tremor, yet he stated stiffness as his first problem, noticed when typing on the computer. MA reported that a tremor made him seek doctor's advice, but it was stiffness limiting dexterity in his manual labour that he noticed first at least two years prior to the onset of the tremor. CC states:

*'I noticed the tremor first, but I think the doctor based it on stiffness…Yes, the first symptom was not only the tremor, but I was out of sorts, felt under the weather, that sort of thing, I didn't exactly know what'.*

**Elapsing years**

This period encompasses the observation that life with Parkinson's has ups and downs with periods of betterment and sometimes some recovery of lost skills following lapses, especially if due to other medical conditions. The support required during this period was deemed by the Sheffield co-researchers as needing to be relevant to their varied requirements, challenging the current system where people with Parkinson's are expected to fit their needs to available services. Also, whilst the co-researchers knew the condition was progressive, they felt that they needed to pursue things that kept their spirits up even if they took on (paid for) assistance to do so.

CC noted regarding things he and his wife needed help for:

'*We've suddenly realised that the garden is too big for the pair of us to look after it, but we just have to adapt it so that we can manage as best we can before we have to actually hire somebody to do it. Some of the things in the garden that I would have done years ago like hedge trimming and stuff like that, the heavy work, we get somebody to do it for us now'*.

But he still keeps active, and is up for a challenge, now with added incentive:

'*I still like to maintain my independence in my activities. Last year, funnily enough, last year Parkinson's had a sponsored walk in Northern Ireland in June and it was over in the Cave Hill Country Park. Now, it's quite steep and I think it was about four and a half, five miles long. I did that because (a) I wanted to raise some money for the organisation, and (b) because I wanted to prove that I could still do it and I did*'.

CC raised £1,200, an achievement of which he was understandably very proud.

Parkinson's UK networks were noted as a source of information, and for some of the positive support. Whilst all interviewees belonged to the charity, not everyone was ready or able to participate in activities offered.

AL and his wife were fully involved and organised their group events, with unexpected consequences when asked if there was a cost involved. AL, about his and his wife's

involvement*:*

> AL: *'She's got running the group. I don't think there's any cost in that. Collections Funerals, oh yes, yes, yes. We go to a lot of funerals nowadays! ….We've had three Parkinson's ones I think'.*
>
> AL's wife: '*Yeah, three funerals'.*
>
> AL: '*Because we're coordinators we sort of, although we're pleased to go along, we would be expected to go along anyway'.*

LA, on the other hand felt unable to attend meetings:

> LA: '*I pay my membership and I get the newsletter and I printed off all the publications at the time I joined, because I didn't know anything about Parkinson's when I was diagnosed and I didn't know anybody that had it. No, I don't go to support groups. I actively avoid support groups…And the reason for that is I have a fear of meeting people who are at a much more advanced stage of Parkinson's, which I could potentially be as well. I mean they're all different, as you're probably aware, everybody with Parkinson's is different and quite unique, so there's no saying how it will go, but it's just the fear factor of seeing somebody. I experienced it recently, because I've taken part in a Dance for Parkinson's Disease class'.*

MA was unable to participate as fully as he would have liked due to the restrictions placed on him by his pathology:

> *'Well I used to go to meetings because they were quite close by but they've moved further away now so I don't, I do tend to go when they have certain outings although I haven't been this year because I've been in so much pain basically that I haven't really felt like going. But previously I used to take part in the social events quite regularly'.*

The pain affects his general social life:

> Interviewer: '*Right so in terms of your social life have you, you know, do you still see the people who you used to see or once you…'*
>
> MA: '*To a large extent, yes'.*
>
> Interviewer: '*So there is still support there'.*
>
> MA: '*Yes…I'm less inclined to want to do things…because I don't get the, obviously I don't get the enjoyment'.*

There were differences in the provision of services to maintain a person's wellness and fitness whether through the Parkinson's UK body or the NHS. For example, AL and CC are on a regular programme of monitoring by the health professionals; LA had not thought to access any allied health professionals; MA has had to chase the Specialist Nurse for an appointment that should be automatically arranged.

In addition to this, networking through Parkinson's UK gave people access to participate in local research projects, such as the *Dance for Parkinson's* classes LA was attending, giving them an opportunity to try different things.

As the Parkinson's progressed with time, there was occasional disagreement between the insight of the person with Parkinson's and spouse/ carer.

During the interview, AL and his wife noted differences in their opinions of what was due to Parkinson's, and what was AL's character. For example, two years ago AL was talking to a

local when on holiday in Turin, and wandered off from the party he was with. He states:

> *'…I talk to people. I'm very gregarious and I find people very interesting, I always have done and so I love talking to people. Once I get involved in a conversation I'm talking to someone. What else goes on around me like a multiple car crash or something like that, I probably wouldn't notice*.'

His wife felt it had become more of an issue since his diagnosis:

> '*He carries on talking and is not aware, as he says that anything else is happening, and that is fairly new'*.

Last year, AL 'disappeared' for a time when on holiday in Paris. AL's wife reported the issue as AL looking but not seeing, stating:

> '*It meant that he lost the entire party and went up a different flight of steps…We did find him. I'd resigned myself (this would have cost us), because I'd resigned myself to staying put and not going with the rest of the party, when he popped his head out of the train and was noticed. He was sat in a separate carriage to everybody else in the party!'*

AL reflected how his perceptions about his overall progression differ to those of his wife in an email, only noticing the change in his fifth year since diagnosis:

> *'However in year five, there has been a change. The physical side declined at approximately the same rate as previously, but there has been acceleration in the rate of decline in my hearing and ability to deal with more than one thing at the same time. [Named wife] thinks it is not my hearing but is my inability to process information including those relating to sight and hearing. When organising a meeting or event, I now sometimes get stressed and confused. This in turn brings on tremors.*'

His acceptance of the Parkinsonian symptoms was not easy, as reported by his wife:

> AL's wife: *'Yes, I can say year one he didn't accept that he was walking with the Parkinson's gait, the shuffle with the hands. He didn't believe that he was and he didn't believe that he was talking softly, so it took the year I think for that to be accepted.'*
>
> AL*: 'I think I accepted it very quickly'*.
> AL's wife: '*You accepted it once you had been persuaded to go to the doctors and had been diagnosed, although I actually - he didn't have a tremor when he went to the doctors. I had to imitate it to show them what it was like'*.

In CC's case, he felt he got on with life regardless of the diagnosis, but his wife's response and further questioning made him consider his response to the diagnosis was not as he had thought:

> CC: '*I sort of bottled it all up. I didn't join the group until nearly a year after my diagnosis. Sorry, I'm getting feedback in my ear… (wife saying something, so CC asks): Sorry, what did you say?'*
>
> CC's wife: *'Tell her you didn't accept it for a while'*.
>
> CC: *'I didn't accept it for a while apparently…I felt as though I didn't want them to be told about it, if it didn't, in my time …[unclear]. I didn't want it just going round like wildfire, oh, you know, CC's [named self] got Parkinson's disease. So from that*

*point of view, Bhanu, no, I didn't accept it for quite a while after the first diagnosis. I didn't believe that I had it'.*

Interviewer: *'But in terms of the fact that you noticed a tremor, did it ever occur to you that other people might?'*

CC: *'Well, on reflection, yes. Some people that are close to me, whenever I say that to them, I've got Parkinson's disease, eventually they go, well, I sort of guessed you have, because of the tremor and the way I held myself and the way I walked…Most people aren't stupid, they will notice things and it's maybe out of politeness they won't say it to you, but on reflection they probably did know that I had something wrong with me'.*

CC: *'…I probably did isolate myself and stay inside. I certainly didn't mix too often with company at that stage'.*

**Future years**

As noted with the social framework, there is often a reduced inclination for people with Parkinson's to think in terms of future needs. Many deal with issues as they arise, although from the interviews and survey people were aware that there would be deterioration at some point in the future.

For example, after a medical consultation, CC was referred to a physiotherapist:

'*…he said, I think actually you could do with a walking aid, a stick. It's not essential to me. I can walk without it, but it's like a security blanket. If I have it there, I know I'm not going to fall over'* (awareness of a potential characteristic of balance loss).

Interviewer: '*Right, but have you fallen*?'

CC: '*No, it's the worry of it. It boosts your confidence. Luckily enough I haven't fallen yet'* (anticipatory language).

What was notable with the interviewees was how some had taken action that pre-empted a need before it became obvious e.g. CC brought a car with higher seat at retirement without understanding the need for ease when getting into and out of a car:

CC: '*When I retired I changed my car. I changed it from a low slung saloon car to one of these SUVs, you know, people carriers, so it's taller. I find it easier to get in and out of…I think I just did it automatically without realising it would be an advantage. I'm glad I did now'.*

, and MA moved to a bungalow without realising how beneficial it would be, given the pain he was currently experiencing limiting his mobility.

Spouses often consider needs more, anticipating decline, and this was notable in the way AL's wife and AC monitored the progression of their spouses with Parkinson's.

AC noted he had been to the GP with his concerns about how his wife would cope if there was an emergency (he mentioned a fire), or if something happened to him. Although he received advice and a number, the information was poorly communicated, and he continues to be unclear what the advice means:

*'But the doctor… there is a phone number; he did give me a phone number saying that these people can help. God knows who they are but he said these people can help in situations like that. So maybe it's respite where they send a carer in but I mean the carer can't be here 24 hours a day.'*

It was also interesting to note the difference in opinion as to whether people considered themselves a carer or spouse. For example:

AL's wife stated:

> *'I'm still AL's* [names husband] *wife, but I keep an eye and carry large plasters with me!'.*

Whilst AC, when asked if he saw himself as a husband or carer stated:

> '*A carer yes…from day one really…Yeah I don't think there was a transition period. I think it was basically, it's more, it's gradually it became more involved. Because, you know, as it is, disease is, like for example now, she doesn't drive now. So the carer bit has evolved since the initial diagnosis'.*

## 8.2 Discussion

The conceptual social framework for Parkinson's (Appendix 2) proved of use to explore the journey people interviewed had undergone from a point before diagnosis was made, to their current situation (Appendix 6). It is hard to pick up any patterns from only five interviews, however pertinent issues have been selected from the findings and are discussed briefly below.

In the pre-diagnostic stage, not everyone was clear how the symptoms being experienced during that time affected their life (especially for those who were already retired) in terms of a loss of income. For some it was only further questioning that drew out where there had been a psychological cost e.g. increased pressure from slower physical and mental performance at work, or the stress of having to find a new job. Suffering, pain, disability and distress are considered social costs of illness (The Sainsbury Centre for Mental Health 2003). Using a human capital approach, costs cannot be ascribed to those who do not work (e.g. children and retired, older people), but attempts are made by health economists to calculate worth as morbidity costs, worked out by hours lost from underperformance of normally provided services. These become more 'costly' if a person is diagnosed with more than one condition e.g. MA and CA's wife with chronic back pain and Parkinson's (Cooper and Rice 1976). As most of the respondents to the online and paper survey were also older, it might be assumed a proportion also have comorbidities.

At the microeconomic level, although Parkinson's impacts on people's functioning, in the earlier stages, individuals are able to perform their usual day-to-day activities without too great a reduction in efficiency. When this ability deteriorates further, people seem to consider termination of employment and early retirement more often than a reduction in their hours (WHO 2009; Singer 1973; Rice 1967).

In terms of the diagnostic phase, where the diagnosis was not made swiftly, or there was an initial misdiagnosis, there was a time lag impacting on a person's knowledge of the condition they had, adding to the psychological stress. Medical models assume a person to develop symptoms of Parkinson's along a specific prognostic path dependent on whether tremor or stiffness is the first symptom in physical presentation (Jancovic and Kapadia 2001), and are trying to improve the accuracy of diagnostic processes of Parkinson's to influence the basis of how services are allocated or provided. The degree of probing to ascertain whether stiffness-

slowness, or whether a tremor is the first symptom, and the inability for some of the interviewees to decide which it was, may have affected history taking, and hence any subsequent clinical decisions. However, the telephone interviews allowed us to pick up on the fact that despite the SIGN (2010) and NICE (2006) Guidelines recommending diagnosis be made by a specialist, not all GP's are recognising the symptoms from which to make a referral. This was clear in CC's case, as he did not present with a clear physical symptom, but a vague feeling of being 'out of sorts', and also in the case of AC's wife, who he finally took abroad for investigation. Awaiting for a diagnosis of Parkinson's is a stressful time for people (Stewart DA (2007), and hence a recommendation in available guidelines for swift referral and accurate diagnosis.

There was a clear indication of people coping differently, or experiencing difficulty accepting the diagnosis of Parkinson's (Ehmann *et al.* 1990). Social support has a significant effect on predicting how people cope, enabling the development of a more active style of coping, as opposed to commonly demonstrated avoidance strategies where support is minimal (Charlton and Barrow 2002; Ehmann *et al.* 1990). Avoidance tactics however, are how some of the interviewees tackled the diagnosis, whether noted by the spouse or the individual, interpreted as an unwillingness to accept the diagnosis. For some people with progressive conditions, there is an issue of not wanting to see a (possible) future, but if they choose to attend events or meetings with others with the same condition, they see the differences between themselves and other individuals (Mazanderani, Locock and Powell 2012).

For many people, support comes through the voluntary sector networks – often the Parkinson's UK groups. These invaluable sources of knowledge-sharing and social benefit help people accept and incorporate consequences of their diagnosis into everyday life (Charlton and Barrow, 2002). All interviewees were members of a Parkinson's UK Branch or support group, having joined within the first year of diagnosis. Some were more actively involved than others, whether on the organisational side or just in terms of attendance.

The continued activity and support was identified as important as the years diagnosed with Parkinson elapsed – the next phase of the social framework for Parkinson's. Whether accessing service through health provision, the voluntary sector, or local authority, people with LTC are known to try things that might promote better health, even though they would have preferred not to spend time and money on these things had they been healthy; this is considered another economic cost of illness (WHO 2009). Unfortunately, not all people can participate as fully as they would like due to constraints placed on them by personal restrictions (e.g. not wishing to meet others with Parkinson's), or pathology, including conditions in addition to Parkinson's.

A more balanced understanding gained during this stage would encourage acceptance, rather than resignation or denial, increasing the individual's perceived control over their Parkinson's physical and emotional symptoms (Evans and Norman 2009).

The telephone interviews identified examples of where financial costs were saved, but at a psychological and/ or social expense, creating richer insight into areas where resources could be placed to help improve life for people affected by Parkinson's. It is vital to monitor for these in the later (future) years for people with Parkinson's, as without support, continual

encounter of loss can lead to chronic sorrow, a psychological state recognised in people with Parkinson's who experience loss of future plans, restricted social life, and inability to travel and participate in hobbies (Lindgren 1996). There is also a link between personality (towards pessimism as the condition progresses), loss of internal locus of control and greater disability (Gruber-Baldini *et al*. 2009), so interventions and support are needed to minimise this development.

Two examples include the case of AL and his wife who have traded in two cars for one larger one, saving on costs of running both cars, yet increasing the use of taxis, train travel and the stress and time of planning the journey (although AL does like to plan such journeys). The increasing lack of AL's attention to where this sociable man needs to be and at what time is creating increasing stress for AL's wife. On two occasions, this has affected holidays, and last year, nearly resulted in an increased financial cost as they temporarily 'lost each other' on their journey home from a holiday abroad. The behaviour is starting to have an impact on how independent AL will continue to be (social cost). To manage her rising stress and anxiety (psychological cost), it has been suggested AL's wife tries acupuncture (self-funded, so a financial cost).

MA noted he is going on holiday less (financial saving), as the hotels cannot always accommodate his needs (psychological cost), creating fewer opportunities for him to go out with friends and associates (social costs).

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# 9 Summary, Conclusion and Policy Implication

## 9.1 Summary

The main findings that emerged from the literature review, quantitative survey and in-depth case studies examining the economic, social and financial cost of Parkinson's on individuals (i.e. PwP), carers and their families are summarised below.

Literature review

Detailed searches of UK based quantitative and qualitative studies from published and unpublished sources yielded 58 studies for inclusion in the review. These were grouped into six themes: Parkinson's incidence differentials; management and care; impact on QoL and wellbeing of PwP; impact on QoL and wellbeing of carers and family members; the cost of healthcare use; and societal (economic, social and financial) cost of Parkinson's.

The literature is deficient in terms of reporting incidence and prevalence of Parkinson's by countries of UK. However, much UK evidence suggests that Parkinson's management and care responsibility has fallen on spouses and extended family members of PwP, directly affecting their QoL and wellbeing. QoL in PwP deteriorated as the condition progressed, particularly with further development of non-motors symptoms including sleep disorders and depression. The stress and fatigue level among carers also increased as the condition progressed, with resultant further deterioration in their own QoL. Certain incidences, such as falls in PwP were identified as the most significant factor impacting on both caregiver's and PwP social life and wellbeing, and frequent occurrence of falling lessened the chances for carers to go out for their normal activities and decreased their contact with their friends and neighbours. Deterioration of QoL of both PwP and caregivers as the condition progressed puts a tremendous economic and financial burden on society in terms of social care and health care delivery costs.

The UK evidence suggests a marked increase in the total annual costs of Parkinson's per case; specifically, costs have risen from an estimated £13,800 in 2006, to an estimated £29,000 in 2011. These figures show estimated costs have more than doubled in a span of 5 years. However, the latter estimate is based on PwP in late stage. The share of non-medical costs, particularly informal care in the total costs, was the greatest (varied between 80% and 93%). With regard to hospital admissions for PwP, a majority were unplanned and mostly for pneumonia, Parkinson's itself, urinary tract infections, falls and hip fractures. The share of falls and fractures was higher in frequency and length of hospital stay, thus increasing the total costs.

Limited UK evidence is available on the societal costs of Parkinson's in terms of loss of employment, reduced work hours, premature retirement of both PwP and carers. The evidence suggests that as Parkinson's progresses, PwP are forced to withdraw from the workforce, and most have stopped working after having been diagnosed with Parkinson's for more than 5 years. The average time of employment lost related to Parkinson's was 4.9 years. During the course of the condition, PwP were often faced with financial difficulties due to

involuntary early retirement and delays in getting welfare benefits. There was no comprehensive UK-based quantitative study looking at the impact of Parkinson's on the employment and working conditions of carers.

Quantitative survey coverage

About 1000 people had expressed interest in participating in the study (including 220 who requested a postal questionnaire) during July-Sept 2015. Between October 2015 and February 2016 people were invited to fill online and postal questionnaires. Due to a limited response from BME communities a booster sample survey was initiated in Manchester and Sheffield using local community contacts, which recruited 27 PwP families. Information was received from 853 respondents. After careful scrutiny of data, information from 776 PwP and 546 carers was submitted for detailed analysis.

As the response numbers from some of the four Home Countries are low in comparison to the other countries, analyses of costs per country have been difficult to calculate. Where possible, this has been done (see statistical tables in Appendix 6), but on the whole, the report provides aggregated informational costs.

Profile of PwP and Carer respondents

A majority of PwP were men, over aged 65 and studied beyond GCSE (higher education). About four-fifths of PwP were married and over 90% were from a White ethnic background. In contrast, a majority of caregivers were women (mainly spouses of the PwP) with over-representation in younger age groups with a mean age of 62.6 years (compared to 67.1 years for PwP). Over 80% of PwP were living in England followed by Scotland, Wales and Northern Ireland. Three-fourths of PwP were living in their ownership houses and with spouses or with their children and extended family. About one in seven (14%) PwP were living alone. The mean household size was 2.

Economic activity

About three-fourths of PwP and a half of the carers had retired from the workforce; only about 12% of PwP and 31% of carers were currently working. Parkinson's had a direct impact on employment and working conditions of both PwP and their carers as about 36% of PwP were forced to withdraw from work by taking early retirement, or unable to work due to illness/incapacity or looking for a job adaptable to the needs of their Parkinson's. Responsibilities of caregivers increased considerably; not only were they looking after the PwP but had to work to lessen the financial difficulties that arose because of Parkinson’s in the family (see key quotes from PwP and their carers on this issue in Appendix 7).

Duration of Parkinson’s and other LTC

In one-third of PwP, the condition was diagnosed less than 5 years ago, for another one-third it was between 5 and 10 years ago and for the remainder, more than 15 years ago. The mean duration since diagnosis of Parkinson's was 8.37 years, which was significantly higher among men compared to women PwP. Only about 38% of PwP were on one or two prescribed Parkinson's medications and the rest were on a higher number of prescriptions. A further two-fifths of PwP had co-morbidities (and were also being treated for other LTC).

Quality of life and wellbeing

Only one-third of PwP reported their health status to be good/very good. However, a majority of PwP reported a worsening of their health status over the year. Similarly, about a half of carers had reported that their health status has worsened over the year, thus reflecting the dual increased burden of care whilst looking after basic household needs. Between 32% and 60% of PwP needed help in one or more of their usual daily activities within or outside the house. The need was met mainly through their spouses or family members; their dependency increased with age. In contrast, those who were living alone were able to manage better on their own; however it should be inferred that over time as the condition progressed they would in fact require help from private agency carers, or may even end-up living in a nursing/care home. In terms of their HRQoL, a majority of PwP reported between moderate and extreme problems for mobility (63%), usual activities (58%), and pain/discomfort (59%) thus reflecting on their low QoL. The average QALY score for PwP was 0.576 which is much worse than that of a healthy person (QALY=1) or their own carers (0.764). The QALY score fell sharply for both PwP and caregivers with a longer duration since diagnosis of Parkinson's, but stabilised at lower levels in later years. For caregivers, the mean QALY score was significantly lower for women than men carers (0.7465 vs 0.7902) and for carers aged 75 and over (0.7163 vs. 0.7722 for aged under 65). Mean wellbeing scores (on life-satisfaction, life worthwhile, happiness and not-anxiousness) were lower for both PwP and carers when compared to the general population of aged 65 years and over.

Healthcare use and cost

About three-fourths of PwP consulted a GP or a Parkinson's nurse for their Parkinson's, followed by a neurologist (67.5%) and a Physiotherapist (43.3%). The average annual number of consultations was highest for the GP (3.7) followed by Physiotherapist (2.9), Pharmacist (2.8), Parkinson's nurse (2.2), Chiropodist/Podiatrist (1.6) and Neurologist (1.4). On average PwP made 21.8 consultations with various health professionals in a year; this reflected a very high usage of healthcare services (i.e., having consultation every 2-3 weeks). Between 17.4% and 12.8% of PwP reported an accessing problem with three most sought healthcare professionals (i.e. GP, neurologist and Parkinson's nurse). Most of the healthcare services were provided by the NHS free at the point of contact, a significant number of PwP had consulted further utilising private services with OOP payments. In more than 50% Chiropodist, Podiatrist and Chiropractor consultations, PwP incurred OOP expenses; 29% saw an Optometrist privately, and 19.3% consulted a Physiotherapist privately. On average, PwP incurred £180.90 OOP expenditure annually on healthcare consultations. PwP also underwent diagnostic/clinical tests such as a blood test, MRI scan, EEG, CT scan, DAT scan, PET scan and X-ray. On an average 2.65 diagnostic tests were carried out annually, most of which were undertaken via NHS provision.

Emergency and unplanned hospital admissions were quite common among PwP particularly in late stage. Two out of thirteen PwP used A&E services and one-fifth were admitted to the hospital during the last 12 months with an average 12.6 days of hospital stay. The unit cost for unplanned admission is highest, followed by planned and day cases. About 9% of PwP were admitted to a hospital as a day case and 6.2% had a planned inpatient admission.

However, unplanned admissions (13.2%) were higher than planned ones (4.8% and 8.4% of PwP reported unplanned admission for up to 3 days and more than 3 days respectively). After applying a unit cost by type of hospital admission, on average £1241.49 per PwP per annum was the cost to the NHS. Similarly £95.37 per PwP was towards using emergency services. As most of the hospital admissions were handled by the NHS, the OOP expenses were small. However, PwP had incurred OOP expenses on travel to use these healthcare services as well as on prescription and non-prescription medicines. There were also indirect costs to the person who accompanied the PwP to attend various medical appointments. The percentage of PwPs who travelled alone varied between as low as 21.2% when consulting a specialist such as Neurologist/Geriatrician/Elderly Care Consultant or 28.8% for a Parkinson's nurse to as high as 48.1% in the case of a Pharmacist. A relatively small number of PwP walked to attend these appointments, the proportion of which was relatively higher when using community-based services such as GP services (18%) and Pharmacy (28%). Those who incurred OOP expenses on travel, on an average a visit to their GP cost them £8.82 whereas for the Mental Health Professional £35.24 and the Optometrist £39.81. On an average PwP were taking 4 prescribed medications and only 15% of PwP were paying prescription charges (majority of PwP were over aged 65 and thus entitled for free medication). About one-third of PwP were having side effects of Parkinson's medication as a result most of them were purchasing medicines over the counter to subside side effects (on average spending £45.81 a year).

Further, two-thirds of PwP purchased equipment mainly to improve mobility within the house (bedroom, bath/shower room, kitchen and stairs), house entrance and garden, and outside the home so as to improve balance and reduce falls due to tremor as well as for better management of Parkinson's. The most common items purchased were walking sticks, walkers, medicine dispenser/timer, reclining chairs, raised toilet seats, wheelchairs, special cutlery, furniture, stair-lift chair, grip handles in the shower, bedrooms, entrance and walkways, special hospital type beds and mobility scooters or Wheelchair Accessible Vehicle (WAVs). About 82% of equipment purchases were fully self-financed, with the NHS the equipment provided mainly through the Continuing Care Programme by either supplying equipment for free or at a subsidised rate. The support from the local council and a charity was minimal. The average annual OOP expenditure for equipment was £1923.

Direct and indirect healthcare cost

Putting all together the use of healthcare services by 610 PwP over the last 12 months, the total direct medical cost of consultations, diagnostics, call and ambulance, A&E and inpatient services was £1,186,451 to the NHS and £128,050 as OOP expenses; on average this added up to £2155 per PwP. Including costs towards medication, the total annual medical cost was £2388 per PwP. Taking into account OOP expenses towards travel (£36) and equipment purchased (£1923), the total annual healthcare cost per PwP raised to £4347. Importantly, the share of the non-medical cost, usually an oversight by health policy makers, was 45% in the total healthcare cost.

Economic and financial cost

The economic and financial conditions of families changed due to Parkinson's and thus detailed information was collected on changes in income and expenditure both directly and

indirectly affecting their household budget. The most critical among these was the loss or reduction in earnings due to changes in employment and working conditions of PwP and carers. More than 50% of PwP and one-third of carers reported having a direct impact on their employment and working conditions. On average working PwP lost 62.1 workdays in a year and reduced weekly hours by 12.4. Similar although the smaller impact was noted for the caregivers; on average caregivers lost 18.9 annual workdays and reduced their weekly working hours by 10.7. Using £496 as average weekly earnings for the working people reported by the ONS, this loss equated to £1,444,299 per annum to working PwP and carers and overall average loss worked out to be £1981 per household. We have also estimated indirect earnings loss for those PwP and carers who are currently aged under 65 but took early retirement or were unable to work or became unemployed due to Parkinson's during the current year. The annual earnings losses to both PwP and carers (unable to work and took early retirement) worked out to be £4,612,179, with an overall average of £6013 per household. Further, many carers aged under 65 are not enrolled with DWP for carer allowance and thus providing unpaid care to their family members. The annual unpaid caring earnings loss was £947,232 which worked out to be £1235 per household. Thus direct and indirect annual employment earnings loss added up to £9229 per household.

We also computed working lifetime earnings loss of all PwP and caregivers who took early retirement at different ages in their working life. Assuming the stipulated retirement age of 65 for men and 60 for women for this group of elderly people, the average working years lost was 6 years for PwP and 3.6 years for carers which worked out to be a loss of 1078 man-years for PwP and 206 man-years for carers. At current monetary values the total lifetime earnings loss as a result of premature retirement for PwP households added to £33,111,254 or £43,170 per household.

Non-healthcare expenditures

PwP households made direct expenses towards alterations in accommodation, payments for daily living assistance for PwP, additional expenses on utility (energy cost) and takeaway foods. About half of PwP households made changes to their accommodation since the diagnosis of Parkinson's, particularly in order to adapt to emerging motor and non-motor symptoms. The type and extent of the alterations depended on the condition (severity) of Parkinson's and this included changing toilets, bathrooms/shower, bedroom, broadening main-doors, building a ramp, etc. Some of the PwP moved to a bungalow thus involving a heavy capital expenditure even after retirement from work (however, such lumpy costs were not included in calculation). Most alterations done were self-financed with few PwP received some meagre subsidies from NHS and local government; the cumulative OOP expenses were £1857 since the diagnosis of Parkinson's.

Two-thirds of PwP household reported additional expenses on utilities; on average their additional energy expenses were £74.23 per month. One-third of PwP were spending more on takeaways and convenience food every month on a regular basis which on an average amounted to £25.44 per month. The major weekly or monthly expenses were towards DLA help. More than one-third of PwP needed help with personal care and bathing and about a

half for cooking a meal. For cleaning their house, 62% of PwP needed help on a daily or weekly basis. As and when required, between 41% and 49% of PwP needed help for ironing, decorating and gardening. Similarly, for outside the house tasks, 52% of PwP needed help for daily or weekly shopping. About a half of them needed help for transport and attend to medical appointments as and when these were scheduled. Several PwP had reported needed help to attend weekly or bi-weekly physiotherapy/exercise classes. The DLA dependence to formal or private arrangement increased with advances in symptoms and condition, when the spouse was unable to provide adequate support. Most of the formal carers were hired through agencies on the weekly or monthly basis. The total OOP expenses incurred aggregated to £1,104,380 with annual mean expenses estimated at £2088 per PwP household.

Changes in income and social benefits

Nearly a half of PwP received income as state pension and a similar proportion of them as an occupational pension; this was followed by 13% who received income from employment and 9% from other sources. In terms of benefits received 83% received incomes from various state allowances and credits; however, about 8% received Local Council for housing and other benefits. Carers reported a similar pattern in sources of income and benefits; however, the magnitude was relatively smaller compared to those for PwP. Further, just under a half of carers received incomes from various state allowances and credits. Over the last year some PwP had reported discontinuance of income from employment (3%), state pension and occupational pensions (5%), and state allowances and credits (12%). The respective discontinuance rates for carers were 4%, 3%, and 6%. An estimated discontinuance of pensions and state benefits for PwP and carers amounts to an annual loss of £875,394 with and overall mean at £1502 per household.

Societal cost

The combined magnitude of both annual health and social care cost of Parkinson's to society is summarised as follows. The direct annual healthcare cost, which was mainly borne by the NHS, was £2388 per PwP; the indirect annual healthcare cost, mainly borne by the PwP, was £1959; and thus, the total annual healthcare cost per PwP was £4347 of which £2229 (51%) was OOP expenses borne by PwP. Further, there were other non-healthcare expenses related to changes in living arrangements and environment that were directly borne by PwP households. The average annual non-healthcare cost was £3622 per PwP household. The total annual healthcare and non-healthcare cost per household added up to £7969. To arrive at the total societal cost, current direct and indirect employment earnings loss to both PwP and carers as well as an unpaid caring earnings loss to carers were included; this was calculated as £9229 per PwP household. Many PwP and carers had reported a loss of certain benefits and cut in pension since registering with DWP as an elderly disabled person or carer. This amounted to an annual loss of £1502 per household. Thus, total current annual income loss per household amounted to £10,731.

Aggregating all direct and indirect costs, the annual financial burden of Parkinson's on society was £20,123 per PwP household. This included the annual financial cost to the NHS of £2118 (just 10.5% of the total) per PwP for their treatment and loss of exchequer of £1423

(7.1%) per household. Thus, the direct annual financial burden on Parkinson's household was £16,582 or £1382 per month.

Financial impact on households

The majority of PwP (56%) or carers (60%) reported their annual income to be under £20,000 with combined household income of under £30,000 by 60% of households. This income distribution suggests that the financial impact of Parkinson's was huge for a majority of households receiving gross annual income under £30,000. About one in four households reported a reduction in their monthly income as a consequence of Parkinson's and the underlying reasons were a reduction in working hours, given-up work completely and moved to less demanding jobs.

Overall the financial impact of Parkinson's on a family was wide-ranging. On an average PwP household felt three types of impact on their financial situation. The share of direct monetary impact in terms of reduced savings and increased borrowings including mortgage equity release was the highest (26%); followed by the changed priorities for spending (20%), reduced social activities (19%), reduced holidays (18%) and reduced spending on festive gifts (11%). Thus PwP household budget had been compressed significantly due to a reduction in income and increase in expenditure; ***the candle is burning at both ends***.


Case study interviews

In contrast to the cross-sectional approach to data collection of survey responses gathered, the case studies permitted insight into the impact of costs at a financial, social and psychological level of those interviewed. The longitudinal view of their experiences with Parkinson's pre-dated the actual point of diagnosis. The issues identified in the case studies utilised a social model developed by PwP and captured costs to health and wellbeing over a longer period of time i.e. from a time pre-diagnosis to the current day. The interview contribution enabled a perspective of combined financial, social and psychological cost impact during the progression of the condition, and as needs altered over time.

## 9.2 Conclusion

Published studies presenting the cost of illness information for Parkinson's, as expected, unveil many differences in terms of methodological decisions and type of costs measurements to be included and ways in which those costs are monetised. Direct medical

costs are easily assessed and quantified, especially hospitalisations and consultations with health professionals as outpatient and visits to A&E, thus accounting for a substantial part of the total direct healthcare costs. The difficulty lies in the assessment of indirect costs due to Parkinson's, particularly in studies with higher numbers of subjects enrolled. Indirect costs however are significant, and quantification of these is of great worth as the prevalence of Parkinson's, the experiences and symptoms over the course of progression pose a significant challenge to those affected by the condition. This includes individuals with Parkinson's, their family, friends and carers, formal health and social services and on society as a whole.

The survey conducted in this study asked people about their experiences of using the health system, and the sorts of items they had to pay for, or the adaptations they had made to homes or work environments to better manage their Parkinson's. Not all the questions were answered in full, and the tendency was toward the collection of financially pertinent information to costs related to having a diagnosis of, or being affected by Parkinson's. This fulfilled an aim of the study to assess the economic cost of Parkinson's in the UK.

The five telephone interviews utilising a social framework constructed by, and for people affected by Parkinson's broadened the informational content gained through the online survey research to provide results that are more holistic than other studies, with the implication of financial, social and psychological costs.

When considering the results from the survey and interviews, the demographics of most included reflect what one would expect of membership of a large charity such as Parkinson's UK, i.e. older and/ or retired, white, middle-class people, many of who still live in their own home (with or without assistance), and have higher levels of education (Deane *et al.* 2014). This was despite the effort made to recruit people from a black or ethnic minority background.

Most participants were in the middle stages of the condition (over 5 years since diagnosis, but are likely to have experienced the onset of symptoms many months or years prior to diagnosis).

In addition to the changing needs of respondents in employment, many taking retirement earlier or altering their working conditions to accommodate their Parkinson's, the costs associated with informal care represent a significant share of the total costs for society. It should be noted that those costs fall on elderly spouses or working-age children. The burden assumed by informal caregivers highlights the importance of using a societal perspective when estimating the economic burden of Parkinson's.

This study highlighted aspects of the impact of an increasing burden of care over time resulting in a more steady deterioration in the health of carers compared with the health of people with Parkinson's, although the majority of carers still reported their health status as 'Good'. The areas of decline were more notable in the less tangible and measurable domains of 'Pain/ discomfort', and 'Anxiety/ depression'.

In terms of utilisation of healthcare and identification of services that might benefit people with Parkinson's outside of the NHS, the study highlights the continuation of inconsistent

service provision, onward referrals to specific health professionals or access to non-NHS provision. These were stressed as requiring improvement following the 2008 Parkinson's Members survey (Parkinson's Disease Society 2008), and subsequent review by the All Party parliamentary Group for Parkinson's Disease (1999). It is worrying to see that little seems to have altered since these two documents were published.

## 9.3 Policy Implication

This study collected online and paper survey information about the costs of Parkinson's to people directly affected by the condition and to society, enriching the data with experiences through in-depth interviews with people affected by Parkinson's.

The improved understanding of the economic and social consequences of Parkinson's have implications for policy makers, professionals and people with Parkinson's across the health and care sectors supporting those affected by the condition.

Below we suggest some of the issues for stakeholders to consider in light of the findings of this research.

**For policy makers**

There continue to be inconsistencies in the provision of services, and funding accessible to people with Parkinson's across the UK. This is despite ongoing work to improve the quality and variability of services following identification of problems encountered in a survey of Parkinson's UK members (2008), an All Party Parliamentary Group on Parkinson's report on the state of health and care services, and bi-annual UK-wide audits of Parkinson's services across the NHS.

The information gathered also identified a high incidence of work-related problems including a reduction in hours worked, the need to change jobs, or roles within existing employment, or taking early retirement. These issues all impact on households affected by Parkinson's.

To enable people living with, or affected by Parkinson's to stay independent and well for as long as possible we encourage policymakers to:

- Ensure there is consistent provision of health and care services from diagnosis across the health, social care and independent sectors
- Facilitate communication between statutory and voluntary sectors across the four countries to ensure people get access to the right support from diagnosis to end of life
- Organisations such as the Department of Work and Pensions, and Local Authorities to revisit income support and benefits for people required to reduce working hours as a consequence of Parkinson's (whether a person with the diagnosis, or a carer)
- Undertake research to understand the socio-psychological and societal impact of people living with the condition retiring early.

**For providers of support (health, social and voluntary sector)**

Utilising cost of illness models has enabled the researchers to gather a basic understanding of societal costs in the longer term. However it is important that providers across the sectors consider:

- The provision and promotion of services and support to help people with a new diagnosis to come to terms with the diagnosis, and develop relevant coping strategies and mechanisms
- Encourage people living with the condition to stay positive and plan interventions that allow them to manage their own condition
- To advocate for the needs of caregivers and close families who support people with Parkinson's without seeking financial recompense, but whose psychological and social needs are adversely affected as they take on these roles
- Supporting their staff to develop a positive attitude and empower people living with the condition to manage themselves, and also acknowledge the support available from non-health resources such as voluntary organisations.

**For people affected by Parkinson's**

People affected by Parkinson's need support from the point of diagnosis to better understand the condition, and help plan how they cope in the long term. This is very rarely available through the NHS, given the current financial and political position of the Government. It is therefore important that:

- People with Parkinson's are supported to stay positive and make contact with organisations that provide advice, guidance and support like Parkinson's UK. This support could be anything from signposting and advice on benefits from central Government, advice on how to claim from Grants that can be utilised to purchase, or support the purchase of equipment, or support from organisations such as Parkinson's UK, and the local groups and branches that offer activities and a chance for people to meet and to exchange experiences and strategies for coping with Parkinson's as it changes over time.

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# *Appendix 1*

## Profile and Role of the Members of Research Team

Dr Anil Gumber is Reader in Health Economics and Statistics at the CHSCR with specialisation in health economics and health inequalities. He has extensive experience of undertaking economic evaluation of health interventions/programmes as focused his research on utilisation and financing of health care of people with long-term conditions. Some of his policy level research works on health inequalities are: ethnicity and bowel cancer screening uptake (funded by the Department of Health); occupational health and work place injuries among ethnic minorities (funded by the Health and Safety Executive); ethnic communication in health services (funded by the Department of Health); racial inequality in health (funded by the Home Office); and community cohesion (funded by the Home Office). He also has considerable experience of undertaking economic analyses of internationally relevant clinical trials with focus on South Asian in the areas of diabetes, whiplash injury and cancer funded by the NHS, NIH and other UK bodies. His most acclaimed work economic evaluation of the UK Asian Diabetes Trial published in Lancet. Dr Gumber was also involved in evaluating information leaflets on osteomalacia for South Asians developed by Arthritis Research Campaign charity and contributed in the development of health promotional DVDs on Healthy Life for South Asians for Warwickshire PCT trust and Heart risk factors for British Heart Foundation which is also available at NHS Choices. Anil's detailed CV is available at https://www.shu.ac.uk/about-us/our-people/staff-profiles/anil-gumber. He has recently developed culturally appropriate cancer information leaflets for Muslim community in their own language which is available at http://www.shu.ac.uk/research/hsc/cancer-awareness-information-sheets-muslim-communities .

Ms Bhanu Ramaswamy is a qualified physiotherapist and an Honorary Visiting Fellow at the CHSCR. She is currently working part-time as a private practitioner and educator. Her main areas of clinical interest include rehabilitation and the treatment of neurological conditions (Stroke and Multiple Sclerosis), but is better known for her national and international work with people with Parkinson's. Clinically, she works at two clinics in Sheffield, plus uses her qualifications as a Fitness (gym) Instructor and in Exercise Referral to run classes for people with Parkinson's in Sheffield (posture and balance, circuit classes and hydrotherapy / aquarobics classes). Last year, she was one of the research assistants involved in a project for Parkinson's UK investigating the issue of '*Putting people with Parkinson's in control: Exploring the impact of quality social care*'. Bhanu retains her input to Parkinson's UK and is currently a Chair of the Service User Involvement working group of the Parkinson's Excellence Network. She writes a column about activity for their quarterly magazine, lectures at several of the voluntary organisation's branches around the country, to professionals and people affected by Parkinson's, and has also co-authored chapters in various text books over the years. She recently received an OBE for her services to physiotherapy practice specifically for PwP.

Mrs Rachel Ibbotson (nee Linacre) is a Research Fellow at the CHSCR. She has primary responsibility at CHSCR as the Fieldwork, Analysis and Support Team (FAST). Rachel has over fifteen years of experience of research in the community. Her key projects are: 'Social capital, health and economy in South Yorkshire coalfields communities' and 'Social Exclusion Amongst Older People in Former Industrial Areas'. She recently completed a project for Age Concern Barnsley which involved recruiting older people from Barnsley and equipping them with interviewing/research skills to conduct interviews within their peer group.

Mr Mubarak Ismail is a researcher at the CHSCR since 2007. Mubarak's research interests include health inequalities, ethnicity, social exclusion and exploration into barriers to health specifically those which are experienced by most excluded and 'hard-to-reach' groups, and strategies to recruit and engage socially excluded groups in health research. Mubarak has experience of qualitative research methods and participatory research approaches. Besides research in health and social care, Mubarak has a background in IT & Management and has worked 19 years with the voluntary sector in the UK, particularly working with and for people from ethnic minority communities. He has extensive experience of community engagement with hard to reach groups and has undertaken the community health promotion initiatives/dialogue with ethnic minority communities in Sheffield.

Ms Oranuch Thongchundee is a full-time PhD student at the CHSCR working on 'Cost-Effectiveness of Atypical Antipsychotics for the treatment of Dementia in Thailand' under Dr Anil Gumber supervision. She has developed a questionnaire for piloting to measure direct and indirect medical costs and informal care costs of dementia and thus burden of treatment on patients and their carers.

Ms Deborah Harrop is an Information Scientist and part-time lecturer at the CHSCR. Deborah has over eight years of experience in the higher education library and information sector in the health, social care and bioscience subject areas. She is an expert at designing, undertaking and writing up literature searches as well as bibliometrics.

Dr Peter Allmark is Principal Research Fellow at the CHSCR. He has published extensively in peer reviewed international journals as well as in books and peer reviewed conference papers. His expertise includes research methodology and, in particular, the use of realist approaches to literature synthesis and the creation of logic models. With a team at Sheffield University he helped create a logic model of the public health effects of welfare benefits and advice which is highly accessed.

Mr Abdur Rauf is the manager of a Manchester based health charity (Ethnic Health Forum) and a freelance researcher in health and social care with particular interest in public health issues among BME communities in the UK. His areas of expertise are developing, delivering and evaluating community-based health promotion projects around minority ethnic communities and mental health, cancer support and information gaps in health education programmes among non-English speaking communities. He has worked alongside leading academicians in the field of ethnicity and health based at Warwick Medical School, Mary Seacole Research Centre - De Montfort University and Sheffield Hallam University and was also an Information Scientist for the NHS specialist Library for ethnicity and health. His current research interest includes studying health disparities among Muslims in the UK.

| ***Team*** | ***Role in the Project*** |
|---|---|
| Anil Gumber<br>*Principal Investigator* | Develop health economics framework and cost of illness questionnaire, survey and statistical design, data cleaning and analysis, report writing |
| Bhanu Ramaswamy | Piloting questionnaire, in-depth interviews with PwP & carers, report writing |
| Rachel Ibbotson | Design online questionnaire, monitor questionnaire returns, data download |
| Mubarak Ismail | Co-ordinate online survey, recruitment of PwP from nursing homes and BME |
| Oranuch Thongchundee | Contribute in questionnaire on cost of treatment, undertake literature review |
| Deborah Harrop | Literature search from database, quality check to include papers for review |
| Peter Allmark | Chair for Project Advisory Group meetings, comments and editing of report |
| Abdur Rauf | Recruitment of PwP from nursing homes and BME from Manchester |

## Conceptual framework for costing Parkinson's experience: Medical and social models

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| **Medical Model – disease staging Hoehn & Yahr (1967)** | 0: No signs of disease | 1: Unilateral disease | 2: Bilateral disease without impairment of balance | 3: Mild to moderate bilateral disease; some postural instability; capacity for living independent lives | 4: Severe disability; still able to walk or stand unassisted | 5: Wheelchair bound or bedridden unless aided |
| Linear, progressive older model understood by healthcare professionals as still useful for research (hence the numbers) and clinical/ hospital records | | | | | | |

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| **Medical model – Clinical staging model – permits more flexibility in experience of health Thomas & MacMahon (1998)** | **Diagnosis / early**<br>▪ From first recognition of symptoms/ sign/ problem<br>▪ Diagnosis not established or accepted | **Maintenance**<br>▪ Established diagnosis of Parkinson's<br>▪ Reconciled to diagnosis<br>▪ No drugs or single drugs, four or less doses/ day<br>▪ 1 - 2 drugs but stable medication for >3/12<br>▪ Absence of postural instability | **Complex**<br>▪ Drugs. > 5 doses or > 2 drugs<br>▪ Inability to accept diagnosis despite adequate information and education<br>▪ Any parenteral medication (e.g. apomorphine)<br>▪ Dyskinesia<br>▪ Neurosurgery considered<br>▪ Psychiatric manifestations – mild symptoms of depression/ anxiety/ hallucinations/ psychosis<br>▪ Autonomic problems<br>▪ Unstable co-morbidities<br>▪ Frequent changes to medication (< 3/12)<br>▪ Significant dysphagia or aspiration | **Palliative**<br>▪ Inability to tolerate adequate dopaminergic therapy<br>▪ Unsuitable for surgery<br>▪ Advanced co-morbidity (life threatening or disabling) |
| More allowance to fluctuate between phases. Expect acceptance of Parkinson's in 'Maintenance' phase. Used more by allied healthcare professionals | | | | |

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| **Social framework – conceptual model of lived experience of people affected by Parkinson's (MontyZoomers*, 2014)**<br>Non-linear (meandering) new model understood by people affected by Parkinson's. | **Pre-diagnostic phase**<br>Disconnect between medical model and service provision when comparing services available to need for support into next phase.<br>Many people not believed, or given possible diagnosis with long wait for confirmation. May look on Internet for information.<br>Some would appreciate support immediately post-diagnosis to counsel through difficult experience pre-diagnosis, and up to 2 years post-diagnosis. | **Diagnostic and immediate post-diagnostic experience**<br>Very different for each person. Often better experience with geriatricians compared with neurologists.<br>The more recent experiences are better because of support from nurses and Parkinson's UK groups.<br>Little support for mental health; most caters for physical needs.<br>Paradox in messaging: social support gives hope; clinical message stresses decline | **Elapsing years**<br>Noting that life with Parkinson's has ups and down with periods of betterment and sometimes some recovery of lost skills following lapses, especially if due to other medical conditions.<br>Not always the straight path to decline stated by the medical models.<br>Need relevant support as time elapses, NOT the current system of people with Parkinson's fitting their needs to available services. | **The future: Holding onto hope**<br>Research promises a cure, plus taking part in activity (attitude, behaviour) slows decline, and coping is better.<br>Reduced inclination for most people with Parkinson's to think in terms of future needs. Carers often consider needs more, pre-empting decline. Person with P might consider needs more if they had annual support and built rapport with staff and services. |
| ***MontyZoomers** are a Sheffield-based group of people affected by Parkinson's looking at support needs for members of the Sheffield Branch of Parkinson's UK. | | | | |

# Diagnostic code and residence site with examples of how to interpret the framework

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| **Sheffield group preferred the use of the Social model to probe for indirect and direct costs.** Coded for symptoms (onset age and subtype), where they reside and (personal) costs incurred | **Coding 1**: Age at onset<br>1a) Juvenile onset [JOPD] – onset pre age 21<br>1b) Young onset [YOPD] – age 21 to 40<br>1c) Late onset cases [LOPD] – onset > 40 years<br>1d) Older onset > 75 | **Coding 2:** Subtype<br>2a) Tremor dominant<br>2b) Stiff and slow | **Coding 3**: Resides (service access)<br>3a) City<br>3b) Town<br>3c) Rural |

| **Social model – From person with lived experience of Parkinson's and carers/ spouses** | | | | | | | |
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| **Person 1: AL** | **Pre-diagnostic phase** | **Diagnostic experience** | **Elapsing years** | | | | **The future** |
| AL is in his 5th year since diagnosis. Lives with wife; has a daughter who is an Occupational Therapist so informative<br><br>Codes:<br>1c<br>2a from wife; AL thinks 2b<br>3c | Stated he did not retire as a consequence of Parkinson's, yet noted 'sticky fingers' when on computer affecting work, memory (something he prided himself in) was slightly slower affecting work in own business of small finance company.<br>Greater recollection of falls that occurred in the five years prior to diagnosis due to his 'clumsy' nature – this is contradictory to medical pathway of falls occurring | Always a faller – from childhood rickets, so may have affected how diagnosis was made. Cannot gauge Hoehn & Yahr stage. | Year 1:<br>Joined Parkinson's UK – so initial membership cost.<br>Still driving. And people he collected for support group helped pay for petrol when 'taxied' to events and meetings.<br>Wife believes still has poor acceptance of sign e.g. shuffles and talks softly.<br>AL became aware (humour) notes spend less when out as AL drinks less alcohol as | Year 2:<br>Has more fixed vision – finds it difficult to follow a ball in table tennis; spent money on two sets of glasses (£400 – £500.00).<br>Links need for glasses a change due to medication (hallucinations).<br>Employed a gardener to stay on top of garden and stay in the house – decision based on both their needs. | Year 3:<br>Increased use of bus (1 bus an hour); also train journeys as got Senior Railcard.<br>Changed from having two cars to one larger car.<br>Car parking skill affected as judging distances deteriorated. AL's wife started helping direct into parking spaces.<br>Noted change in dexterity e.g. Upgraded to android phone, but could not cope, so uses a big-buttoned phone; battles with the parking machines at hospital appointments. | Year 4 into year 5:<br>Licence not renewed, so takes taxis more; as ALW drives, still has costs of the car.<br>Bought new bed for ease of movement – to help with the getting out of bed, and new sofa; higher and more upright.<br>Bumps into things more and is a DIY disaster, so spending more on first aid!<br>Increasingly less aware of people and surroundings; lost again on holiday in Paris, and if he had not been found would have incurred a cost.<br>AL becoming aware of stresses and strains of carers in support group. | In the process of changing bathroom to a shower room in anticipation of decline.<br>AL and wife do not consider her role is yet a carer, but notes she is increasingly anxious when he heads off on trips by himself, so increasingly rings to check he has arrived and is not asleep on a train.<br>His wife may consider acupuncture for stress, and is more acutely aware of the strains placed on some of the |

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| | after several years | | affected more quickly. | | Computing slow – affected by tremor. Lack of attention noted by his wife, as AL wandered off when on holiday in Turin and again in Paris | Watches others in Parkinson's group, and also aware of the changes secondary to Parkinson's, and other medical condition. AL and his wife went to House of Commons to demonstrate about cuts in care costs due to their involvement – own cost of train and meals. | carer's in later years with Parkinson's |
| Things with no set time | AL finds it hard to judge his rate of deterioration; informed of changes by wife and Specialist Nurse. ALW states AL '*looks but does not see*'.<br>Joined and involvement in a local Parkinson's support network. The costs include providing occasional refreshments, contribute to attend meetings attendance at other members' funerals. AL and ALW have taken responsibility and organise members' events, take and return telephone calls, do all the related administration. Raise money to support the group, and extra towards research into Parkinson's. AL notes that the meetings create pressure in terms of time and stress BUT state the benefits of belonging far outweigh any of these incidental costs. AL now not embarrassed to shake a tin at people who come calling at the door!<br>Continues to exercise. Plays table tennis through Parkinson's network (a couple of pounds cost); aware he is slower and loses more. Started exercise classes for the support group.<br>Bought a Doset box with timer to keep medications, and ALW occasionally oversees medications are taken on time.<br>There is more direct cost as hospital visits create costs – travel and parking. Holiday insurance costs more.<br>Indirect costs as increased clothes washing as AL spills more food. When out, AL will ask for things in restaurants like a cup with a large handle.<br>From survey, note accesses NHS multi-disciplinary services | | | | | | |

| **Person 2: MA** | **Pre-diagnostic phase** | **Diagnostic experience** | **Elapsing years** | | | | **The future** |
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| MA is in 9th year since diagnosis. Lives alone in bungalow<br><br>Codes:<br>1c<br>2a and b | Initially self-employed (installed hand's free radio and car stereo systems) but noted decreased dexterity and taking longer on a job with regards to manipulating wiring and cables (costs in terms of time and stress as jobs might have been for large firms who had timescales for | Year 1:<br>Tremor in left hand noticed (took six months to diagnose), but there was stiffness affecting nimbleness on feet and dexterity as an issue too. Becoming stiffer and slower in this first year, affecting ability to walk | Year 2:<br>MA took early retirement (loss of earnings)<br>He hired a cleaner | Year 3 - 4:<br>Was provided with a stick (cost to health services) as toes started to claw affecting mobility.<br>In old property, was provided a | Year 5 – 6:<br>Had operation to straighten left big toe (cost to health services March 2014).<br>MA moved to sheltered housing | Year 7 onwards:<br>Still goes on some outings with the support group (direct cost), but restricted in the outings he joins in | In the process of buying an adjustable bed (£1,000.00) to make it easier to get into and out of bed in the morning.<br>Does not foresee a need for |

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| 3b | the work).<br>Found employment in local authority (2002 – 2009). Initially relief work, then full time as Site Supervisor. Full support from managers as diagnosed in 2007, but as started to struggle with the manual tasks (lifting) due to Parkinson's more so than the administrative tasks, taking longer on jobs, took early retirement after Occupational Health interview and doctor's advice.<br>Also has co-morbidity, plus operations secondary to tonal problems, so difficult to pin-point issues just to Parkinson's, as stress affected all medical problems. MA stiff feels that Parkinson's was the over-riding reason for earlier retirement | (part of work).<br>Had all necessary equipment provided by work.<br>Joined the local Parkinson's group (membership cost and cost of activities), but the worsening pain in his toe limited ability to participate in exercise classes, so he stopped attending | | seat to help get into and out of the bath | bungalow; new furniture cost over £3,000, and although he would have bought new anyway, he paid heed to needs secondary to Parkinson's.<br>Purchased a shower seat<br>Pain worsened affecting ability to walk. | with. In part, restricted also because they have moved where they hold meetings.<br>Noted in last year becoming more forgetful e.g. can forget to take medication, or forgets if he has taken them. Has forgotten some appointments, and becoming more distractible, and unable to sustain attention. | alterations to the bungalow, as already built for people with disabilities |
| Things with no set time | From survey, increased use of convenience food and increasing heating costs.<br>Keeps self busy with hobby of amateur radio, and radio-controlled model building, but no longer attends events as less enjoyable as pain affects how long he stays. It is a cost saving but psychologically distressing to be restricted.<br>Some problems accessing services – e.g. had to ring and request for Nurse Specialist appointment, and is to go to clinic next month – an appointment he felt should be generated automatically; also was becoming inconvenient to visit hospital podiatry every 6 – 8 weeks, so arranged to pay for monthly podiatry appointment due to clawing creating painful calluses, and a knock-on effect on walking.<br>Change in how he holidays as finds many hotels not accommodating; no lift, no shower. So whilst a cost saving as not going on holiday much, has less social contact as used to go with friends. One booked in April in the Norfolk Broads with a friend, but apprehensive about how stiff and immobile he will be following a long coach journey.<br>Sleep is becoming a worsening problem over the years; now gets average 4 hours sleep. Dystonic cramping is an issue. | | | | | | |

| **Person 3: CC** | **Pre-diagnostic phase** | **Diagnostic experience** | **Elapsing years** | | | **The future** |
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| CC is in 3rd year since | Slowness and feeling 'out of sorts'; went to GP and told not Parkinson's, | Diagnosis came as a shock, based on a vague | Year 1:<br>Only joined a | Year 2:<br>Received a | Year 3:<br>Slight change in | Garden is getting too large to manage, so |

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| diagnosis.<br>Lives with wife.<br>Codes:<br>1c<br>2 a & b – slowness at least a year, but tremor most evident symptom<br>3b | but went again and saw a different GP who referred him through the NHS to a private consultation (waiting list initiative).<br>Initially stated this had no impact on retirement decision as diagnosis was made 4 years after retirement. On probing, CC realised his work at an outdoor museum (walking 8 – 10 miles a day) was suffering. He was becoming increasingly slow, clumsy and experiencing loss of concentration. He did not take the option to retire at 60 as was available from Local Authority, but expected to keep going to 65 years; in the end, retired at 61 (has enough income, but less than if had gone to 65) | recollection of a vision of someone he knew with Parkinson's 15 – 20 years prior to this.<br>He realises now that he bottled the diagnosis and didn't want people to know. His wife states he didn't accept it as he didn't tell people and didn't mix with people.<br>Did not choose to join a support group. | Parkinson's support group (cost for membership) when passed information by a friend who knew someone else with Parkinson's.<br>They run varied activities, which CC now chooses to join in with, occurring a small cost and other contributions. | bed rail from the therapists to help with the getting into and out of bed | holidays, choosing ones where he would be less active than prior holidays.<br>Received a stick from Social Services at recommendation of a physiotherapist, after referral from Consultant. For posture and confidence. No falls.<br>Took part in sponsored walk for Parkinson's (4 – 5 miles), so still walking a good distance. Raised £1,200.00.<br>Physiotherapist also organised access to a paid (Health for life) exercise referral scheme 2 x week.<br>When the period stopped, CC has continued to pay to attend 2 x week sessions. | thinking of employing a gardener.<br>Continue with access to therapists and nurse specialist for monitoring purposes. |
| Things with no set time | Continues to do some of the guided tours at the outdoor museum for the Local Authority, but notices he forgets words.<br>Had changed car at retirement, and subconsciously chosen one with a higher seat that was easier to get into and out of.<br>Keeps up with physical activity walking daily between 2 – 2.5 km, plus a weekly longer walk with a friend. Tend to keep to flatter routes now. | | | | | |

| **Person 4: AC** | **Pre-diagnostic phase** | **Diagnostic experience** | **Elapsing years** | **The future** |
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| AC is a 66 year carer whose wife (ACW) is in | Although diagnosis made in 2004, AC can trace back symptoms to at | AC considered himself a carer since | Things with no set time lines that have occurred over the years with ACW.<br>Costs such a prescriptions and bus pass are free in Scotland, so no expense.<br>The costs related to joining Parkinson's UK includes annual membership renewal, outings, contributions at monthly meetings and events. | Sees future costs as transport – about to stop the only bus service, so will be dependent on the car. |

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| her 11th year since diagnosis. Lives in a house<br><br>Codes:<br>1c<br>2b<br>3c | least 1998. Diagnosis made in Oman, although had seen specialists in the UK. Back in UK, specialist concurred with diagnosis. The issue of stiffness and slowness has been compounded with ACW's chronic back problem, with trips to NHS specialists. Unclear of reason for back pain (accident in youth or Parkinson's tone) | the day of diagnosis, but is more 'involved' now. They joined Parkinson's UK within a year of diagnosis | ACW attends Branch hosted exercise classes including singing when physically able (currently clashes with another social event) (£2.00 per session plus money for refreshments), and hydrotherapy.<br>ACW continues to see a chiropractor paid for privately, as the physiotherapy services they can access via the NHS do not have specialists in Parkinson's'. Hence ACW has not seen a physiotherapist or Occupational therapist.<br>Re the household, ACW still does the cooking, and they both shop. They did engage a cleaner 5 years ago to come 2 x week.<br>Re equipment/ adaptations, ACW bought own stick for mobility in the late 1990's due to back pain; in 2011 took delivery of a special chair from the Local Authority, and in 2012 self-funded a bed that raised up and down, to make getting into and out of bed more easy.<br>ACW now experiencing greater fluctuations with on and off periods. has affected holidays. Cancellation of holiday to South Africa 2013 last minute as ACW was 'off', plus had an exacerbation of back pain; in 2015 they went to Peterborough on holiday, taking the train. Incurred more cost as for comfort, have to take First Class travel, plus taxis to and from station<br>ACW was asked to give up her driving licence in 2015, which fitted well with AC's retirement | AC considers costs are not insurmountable, but is aware the condition may progress. Some concerns he is in conversation with GP (and awaiting Social Service input for), regarding how ACW will get out of the house in an emergency when she has a bad back.<br>AC may consider starting a Carer's group, or looking into joining a generic carer's group |
| Issues pertinent to AC | AC only retired at 65 years as expected last year from a job as a helicopter engineer, with no time off work to see to ACW's needs.<br>He has some health issues.<br>He finds the role of carer can be difficult, but realises ACW has problems related as much to fluctuating and long standing back problems as well as Parkinson's. He sees his role as driver and carer. | | | |

| **Person 5: LA** | **Pre-diagnostic phase** | **Diagnostic experience** | **Elapsing years** | | | | **The future** |
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| LA is in her 5th year since diagnosis. Lives alone in house<br><br>Codes:<br>1c<br>2b<br>3b | | At diagnosis, supportive employer in a prior role where LA expected to write meeting notes, engaged clerical support worker for admin tasks as developing micrographia, and couldn't understand own writing. | Year 1:<br>Issues with bowels, so purchased (self cost) a toilet pedestal from health catalogue posted | Year 2:<br>Nil | Year 3:<br>Moved to bungalow 'back home', as relationship broke up, and to be nearer mother who was unwell.<br>Employed as a Local Authority Greenspace Officer (supports | Year 4 – 5:<br>Increasing stiffness, pins/ needles, loss of dexterity and constipation. Made work hard, as also had fatigue. Was off work with anxiety and depression since October 2015. Tried to return twice, but signed off again. Work times are | About to take early retirement (April 2016) on the grounds of Parkinson's-related ill health.<br>Still coming to terms with the diagnosis of Parkinson's, and looking forward to the fact that in a |

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| | | Joined Parkinson's UK but does not attend meetings – receives Newsletter/ information | through door. | | people's vision of space use and help them to develop skills to achieve the vision).<br>Employed a gardener for tiered garden | irregular, but can be 7 days a week, so hard to build a routine, including rest and meal times.<br>Participates in local research (tied in with hospital consultant visits).<br>Attended a dance event in Glasgow (petrol and parking costs as research paying for the class to happen). | month she will have time to look after herself.<br>Converting bath to shower (awaiting quotes, and will be self-funding).<br>Signed up now to attend weekly dance for a year |
| Things with no set time | LA has not accessed any health services apart from medical and nursing care. She is unaware how easy referral would be as never accessed.<br>Medications have altered bowel habits, and whilst there is no extra cost in terms of her diet, she has altered what she eats to higher fibre content.<br>As she lives alone, does not notice some of the symptoms others pick up on | | | | | | |

# *Appendix 4*

## Information Sheet for Participants and Leaflet

### Research into the Economic and Social Cost of Parkinson's

You are being invited to take part in a research project. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully, and discuss it with others if you wish so you can decide whether or not you wish to take part. Thank you for reading this.

**Research project title**
Assessing the economic and social cost of Parkinson's on people with the condition, their carers and families.

**What is the purpose of this research?**

Parkinson's is a progressive, degenerative condition that primarily affects the nervous system. Individuals experience it in different ways throughout its course. The provision of both health and social care services to address the management of Parkinson's comes at great economic and financial cost to the government and to society. The purpose of this project is to assess what that cost might be.

**Why is this research needed?**

There is a lack of research in estimating total economic cost and burden of Parkinson's in the UK, and a study such as this can assess in detail the expenses of the condition for the individuals and carers, health and social care providers, and to the wider society.

**Am I eligible to take part/ why have I been chosen?**

Any person with Parkinson's, their carer and family members are eligible to take part. We hope for approximately 1200 people to participate in this study from across the four home countries.

**How will this research be carried out?**
If you agree to take part, you will be either sent a questionnaire to fill-in or invited to be interviewed by a member of the research team. The interview will last about 1 hour and take place at a time and venue that is convenient to you. Information will be asked on income, living conditions, use of the health and social care system, wellbeing of the households, and indirect costs to the individual and their families over the year as well as likely to occur over the individual's lifespan as a result of the progression of Parkinson's.

**Do I have to take part?**

It is up to you to decide whether or not to take part. A decision not to take part will not affect you in any way. If you agree to take part you will be offered a signed consent form to keep.

**Will my taking part in this project be kept confidential?**

All information which is collected from and about you during the course of the research will be kept strictly confidential. The information you give will not be used in any way that could identify you.

**What will happen to the results of the research project?**

The results of this study will be a report with case studies to Parkinson's UK and published in academic journals. Nobody will be able to identify you in any reports or publications. If you would like a copy of these results please contact the research team.

**Who is organising and funding the research?**

The Centre for Health and Social Care Research at Sheffield Hallam University are undertaking the research, and it is funded by Parkinson's UK.

**Who has ethically reviewed the project?**

This research project has been reviewed by the Sheffield Hallam University Research Ethics Committee for ethical aspects.

**If you have any questions about the about the research, please contact:**

Centre for Health and Social Care Research, Sheffield Hallam University

For more information about the research

Email: Parkinsons@shu.ac.uk

Please Contact

Rachel Ibbotson Tel: 0114225 5793
Anil Gumber Tel: 0114225 5915
Mubarak Ismail Tel: 0114225 2239

***Thank you very much for reading this sheet.***

**Parkinson's Leaflet**

# HELP US TO CALCULATE THE COST OF PARKINSON'S

Parkinson's UK commissioned Sheffield Hallam University to calculate the economic and social cost of Parkinson's to people living with the condition and their families across the UK.

This research will help us understand where Governments should target resources to improve life for people affected by Parkinson's.

Sheffield Hallam University | Centre for Health and Social Care Research

PARKINSON'S UK
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

# WHY THIS RESEARCH IS NEEDED?

## This research is needed to assess the impact of the cost of living with Parkinson's. It covers everything from paying for prescription charges, to adapting your home, lost income through having to give up work or even any money that's been spent on care.

We're looking for people with Parkinson's, their families and carers to participate in this. We need people at all stages of the condition, from newly diagnosed to those who have lived with Parkinson's for decades.

We'd like people across England, Wales, Scotland and Northern Ireland to take part.

If you are living with Parkinson's, help care for someone with the condition, or are a family member, you can make a difference by being involved in this research.

To register your interest, please complete and return the form overleaf and Sheffield Hallam researchers will contact you. Or you can complete the survey online at **surveymonkey.com/r/cost_of_parkinsons.**

Please share this with anyone else affected by Parkinson's who may wish to participate.

For more information about this research please contact:

- Rachel Ibbotson, Research Fellow at Sheffield Hallam on **0114 2255793** or **parkinsons@shu.ac.uk**
- Laura Cockram, Policy and Campaigns Manager at Parkinson's UK on **020 7963 3915** or **lcockram@parkinsons.org.uk**


## Please complete your contact details below

Fold here Fold here

Full name of person with Parkinson's/family/carer:

.....

Address:

.....

.....

.....

Post code: .....

Telephone: .....

Email: .....

My preferred method of contact:

Telephone ☐ Email ☐ Post ☐

Moisten here

Moisten here

Moisten here

Cost of Parkinson's
Sheffield Hallam University
Montgomery House
City Campus
Howard Street
SHEFFIELD
S1 1AY

Business Reply
Licence Number
RLSE-KLKU-ETSE

PARKINSON'S UK CHANGE ATTITUDES. FIND A CURE. JOIN US.

# *Appendix 5*

## Search strategy

Pilot searches have been undertaken in MEDLINE (EBSCO).

The searches have been written up for MEDLINE using the EBSCO interface and are detailed below.

Explanation of search terms used: ti = title field; ab = abstract field; af = author affiliation field; / = controlled vocabulary term; exp. = controlled vocabulary term exploded; asterisk (*) = denotes any character; "" = phrase search; n = proximity operator.

1. parkinson*.ti,ab
2. parkinsonian disorders/
3. parkinson disease/
4. or/1-3
5. cost*.ti,ab
6. financial.ti,ab
7. finance*.ti,ab
8. fiscal.ti,ab
9. economic*.ti,ab
10. socio-economic*.ti,ab
11. wage*.ti,ab
12. expenditure*.ti,ab
13. debt*.ti,ab
14. income*.ti,ab
15. saving*.ti,ab
16. employment*.ti,ab
17. unemployment.ti,ab
18. pension*.ti,ab
19. housing.ti,ab
20. salary.ti,ab
21. salaries.ti,ab
22. paid.ti,ab
23. outlay.ti,ab
24. outgoings.ti,ab
25. expense*.ti,ab
26. price*.ti,ab.
27. spending.ti,ab
28. earn*.ti,ab
29. budget*.ti,ab
30. payment.ti,ab
31. burden.ti,ab

32. sacrifice.ti,ab
33. deprive*.ti,ab
34. "quality of life".ti,ab
35. carer* N3 health.ti,ab
36. carer* N3 impact.ti,ab
37. carer* N3 "well being".ti,ab
38. carer* N3 wellbeing.ti,ab
39. carer* N3 "quality of life".ti,ab
40. family N3 health.ti,ab
41. family N3 impact.ti,ab
42. family* N3 wellbeing.ti,ab
43. family* N3 "well being".ti,ab
44. family* N3 "quality of life".ti,ab
45. families N3 health.ti,ab
46. families N3 impact.ti,ab
47. families N3 "well being".ti,ab
48. families N3 wellbeing.ti,ab
49. families N3 "quality of life".ti,ab
50. caregiver* N3 health.ti,ab
51. caregiver* N3 impact.ti,ab
52. caregiver* N3 wellbeing.ti,ab
53. caregiver* N3 "well being".ti,ab
54. caregiver* N3 "quality of life".ti,ab
55. cost of illness/
56. costs and cost analysis/
57. health care costs/
58. health expenditures/
59. direct service costs/
60. hospital costs/
61. drug costs/
62. cost savings/
63. financial support/
64. financial management, hospital/
65. financial management/
66. economics/
67. models, economic/
68. economics, hospital/
69. socioeconomic factors/
70. salaries and fringe benefits/
71. employment/
72. health expenditures/
73. income/
74. pensions/
75. housing/

76. quality of life/
77. or/5-76
78. "united kingdom".af
79. uk.af
80. britain.af
81. scotland.af
82. england.af
83. wales.af
84. "northern ireland".af
85. exp. great britain/
86. england/
87. northern ireland/
88. exp. scotland/
89. wales/
90. channel islands/
91. guernsey/
92. or/78-91
93. 4 and 77 and 92
94.

## Grey literature searches

**NICE Evidence Search = 1015 results**

((parkinson*) AND (cost* OR financ* OR economic* OR expenditure* OR debt* OR income* OR pension* OR salar* OR spending OR earn* OR budget* OR burden OR sacrifice OR "quality of life" OR carer OR famil* OR caregiver))

*This search was shortened as the number of characters allowed was limited. The results were also limited to anything published in the last three years.*

**Google.co.uk = 36,700,000 results**

((parkinson*) AND (cost* OR financ* OR economic* OR expenditure* OR debt* OR income* OR pension* OR salar* OR spending OR earn* OR budget* OR burden OR sacrifice OR "quality of life" OR carer OR famil* OR caregiver))

*This search was shortened as the number of characters allowed was limited.*

# *Appendix 6*

## Breakdown of Annual Healthcare and Societal Costs by Home Countries

**Figure A1: Annual NHS healthcare costs to the NHS and PwP by home country and UK**

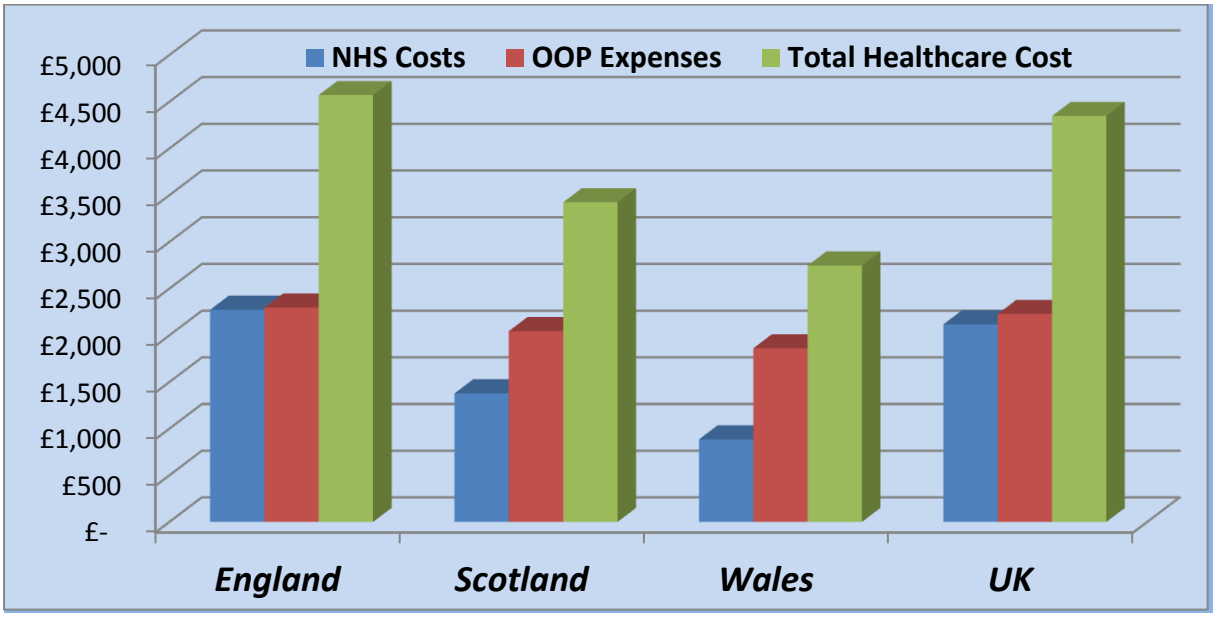



**Table A1: Annual healthcare costs by type across home country**

| Type of costs | Country | Number of Responses | Cost to NHS (£) | | Cost to PwP (£) | | Mean Cost (NHS+OOP) |
|---|---|---|---|---|---|---|---|
| | | | Total | Mean | Total | Mean | |
| Consultations | Not Reported | 1 | 0 | 0.00 | 0 | 0.00 | 0.00 |
| | England | 500 | 228422 | 456.84 | 93275 | 186.55 | 643.39 |
| | N Ireland | 5 | 3262 | 652.40 | 1100 | 220.00 | 872.40 |
| | Scotland | 75 | 30519 | 406.92 | 11975 | 159.67 | 566.59 |
| | Wales | 29 | 8049 | 277.55 | 4000 | 137.93 | 415.48 |
| | **UK** | **610** | **270252** | **443.04** | **110350** | **180.90** | **623.94** |
| Diagnosis | Not Reported | 1 | 0 | 0.00 | 0 | 0.00 | 0.00 |
| | England | 500 | 90014 | 180.03 | 9350 | 18.70 | 198.73 |
| | N Ireland | 5 | 1256 | 251.20 | 650 | 130.00 | 381.20 |
| | Scotland | 75 | 7460 | 99.47 | 1125 | 15.00 | 114.47 |
| | Wales | 29 | 1986 | 68.48 | 75 | 2.59 | 71.07 |
| | **UK** | **610** | **100716** | **165.11** | **11200** | **18.36** | **183.47** |
| Call/Ambulance | Not Reported | 1 | 0 | 0.00 | **0** | 0.00 | 0.00 |
| | England | 500 | 19194 | 38.39 | **150** | 0.30 | 38.69 |
| | N Ireland | 5 | 333 | 66.60 | **0** | 0.00 | 66.60 |
| | Scotland | 75 | 1431 | 19.08 | **0** | 0.00 | 19.08 |
| | Wales | 29 | 111 | 3.83 | **0** | 0.00 | 3.83 |
| | **UK** | **610** | **21069** | **34.54** | **150** | **0.25** | **34.79** |
| A&E | Not Reported | 1 | 0 | 0.00 | 0 | 0.00 | 0.00 |
| | England | 500 | 31570 | 63.14 | 475 | 0.95 | 64.09 |
| | N Ireland | 5 | 1640 | 328.00 | 0 | 0.00 | 328.00 |
| | Scotland | 75 | 3075 | 41.00 | 100 | 1.33 | 42.33 |
| | Wales | 29 | 820 | 28.28 | 0 | 0.00 | 28.28 |
| | **UK** | **610** | **37105** | **60.83** | **575** | **0.94** | **61.77** |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| Inpatient | Not Reported | 1 | 0 | 0.00 | 0 | 0.00 | 0.00 |
| | England | 500 | 684443 | 1368.89 | 4400 | 8.80 | 1377.69 |
| | N Ireland | 5 | 18804 | 3760.80 | 0 | 0.00 | 3760.80 |
| | Scotland | 75 | 44227 | 589.69 | 1375 | 18.33 | 608.03 |
| | Wales | 29 | 9835 | 339.14 | 0 | 0.00 | 339.14 |
| | **UK** | **610** | **757309** | **1241.49** | **5775** | **9.47** | **1250.96** |
| **Sub-total** | Not Reported | 1 | 0 | 0.00 | 0 | 0.00 | 0.00 |
| | England | 500 | 1034449 | 2107.29 | 107500 | 215.30 | 2322.59 |
| | N Ireland | 5 | 24962 | 5059.00 | 1750 | 350.00 | 5409.00 |
| | Scotland | 75 | 85281 | 1156.16 | 14575 | 194.33 | 1350.49 |
| | Wales | 29 | 20690 | 717.28 | 4075 | 140.52 | 857.79 |
| | **UK** | **610** | **1165382** | **1945.00** | **127900** | **209.92** | **2154.92** |
| Medication | Not Reported | 1 | 213 | 213.20 | 0 | 0.00 | 213.20 |
| | England | 472 | 78630 | 166.59 | 8210 | 17.39 | 183.98 |
| | N Ireland | 5 | 640 | 127.92 | 0 | 0.00 | 127.92 |
| | Scotland | 67 | 14911 | 222.56 | 100 | 1.49 | 224.05 |
| | Wales | 27 | 4531 | 167.80 | 0 | 0.00 | 167.80 |
| | **UK** | **572** | **98903** | **172.91** | **8310** | **14.53** | **187.44** |
| Non-Prescription Medication | Not Reported | 1 | | | 60 | 60.00 | 60.00 |
| | England | 456 | | | 21300 | 46.71 | 46.71 |
| | N Ireland | 5 | | | 60 | 12.00 | 12.00 |
| | Scotland | 68 | | | 3120 | 45.88 | 45.88 |
| | Wales | 28 | | | 1020 | 36.43 | 36.43 |
| | **UK** | **558** | | | **25560** | **45.81** | **45.81** |
| **Total Direct Medical** | Not Reported | | 213 | 213.20 | 60 | 60.00 | 273.20 |
| | England | | 1113079 | 2273.87 | 137010 | 279.40 | 2553.28 |
| | N Ireland | | 25602 | 5186.92 | 1810 | 362.00 | 5548.92 |
| | Scotland | | 100192 | 1378.72 | 17795 | 241.71 | 1620.42 |
| | Wales | | 25221 | 885.07 | 5095 | 176.95 | 1062.02 |
| | **UK** | | **1264285** | **2117.91** | **161770** | **270.25** | **2388.16** |
| Travel | Not Reported | 1 | | | 0 | 0.00 | 0.00 |
| | England | 500 | | | 18705 | 37.41 | 37.41 |
| | N Ireland | 5 | | | 10 | 2.00 | 2.00 |
| | Scotland | 75 | | | 2790 | 37.20 | 37.20 |
| | Wales | 29 | | | 370 | 12.76 | 12.76 |
| | **UK** | **610** | | | **21875** | **35.86** | **35.86** |
| Equipment | Not Reported | 1 | | | 1200 | 1200.00 | 1200.00 |
| | England | 484 | | | 958625 | 1980.63 | 1980.63 |
| | N Ireland | 5 | | | 1575 | 315.00 | 315.00 |
| | Scotland | 74 | | | 130725 | 1766.55 | 1766.55 |
| | Wales | 30 | | | 50150 | 1671.67 | 1671.67 |
| | **UK** | **594** | | | **1142275** | **1923.02** | **1923.02** |
| **Total Healthcare Costs** | Not Reported | | | | 1260 | 1260.00 | 1473.20 |
| | England | | | | 1114340 | 2297.44 | 4571.32 |
| | N Ireland | | | | 3395 | 679.00 | 5865.92 |
| | Scotland | | | | 151310 | 2045.46 | 3424.18 |
| | Wales | | | | 55615 | 1861.37 | 2746.44 |
| | **UK** | | | | **1325920** | **2229.13** | **4347.04** |

**Table A2: Distribution of PwPs and Carers by economic activity across home country**

| Main Economic Activity | NR | England | N Ireland | Scotland | Wales | UK |
|---|---|---|---|---|---|---|
| **PwPs** | | | | | | |
| Paid employment - full time | 0 | 30 | 0 | 2 | 2 | 34 |
| Paid employment - part time | 0 | 25 | 0 | 2 | 2 | 29 |
| Self-employed with employees | 0 | 4 | 0 | 1 | 0 | 5 |
| Self-employed (working alone without employees) | 0 | 23 | 0 | 2 | 2 | 27 |
| **Sub-total Workers** | **0** | **82** | **0** | **7** | **6** | **95** |
| Unemployed (looking for work) | 0 | 8 | 0 | 1 | 1 | 10 |
| Not working due to illness or incapacity | 3 | 63 | 2 | 12 | 7 | 87 |
| Caring for relatives | 0 | 3 | 0 | 0 | 0 | 3 |
| Early retired due to ill health | 2 | 149 | 1 | 18 | 12 | 182 |
| Retired/pensioner | 9 | 308 | 5 | 48 | 16 | 386 |
| **Sub-total Retired/pensioner+ Early retired** | **11** | **457** | **6** | **66** | **28** | **568** |
| Homemaker | 0 | 0 | 0 | 1 | 0 | 1 |
| Others | 0 | 2 | 0 | 0 | 1 | 3 |
| **Total** | **14** | **615** | **8** | **87** | **43** | **767** |
| **Carers** | | | | | | |
| Paid employment - full time | 0 | 48 | 3 | 8 | 3 | 62 |
| Paid employment - part time | 0 | 46 | 1 | 5 | 2 | 54 |
| Self-employed with employees | 0 | 11 | 0 | 2 | 1 | 14 |
| Self-employed (working alone without employees) | 0 | 31 | 1 | 4 | 3 | 39 |
| **Sub-total Workers** | **0** | **136** | **5** | **19** | **9** | **169** |
| Unemployed (looking for work) | 0 | 9 | 0 | 0 | 0 | 9 |
| Not working due to illness or incapacity | 0 | 6 | 0 | 2 | 0 | 8 |
| Caring for relatives | 0 | 14 | 0 | 1 | 1 | 16 |
| Early retired due to ill health | 0 | 45 | 1 | 7 | 3 | 56 |
| Retired/pensioner | 1 | 204 | 1 | 26 | 17 | 249 |
| **Sub-total Retired/pensioner+ Early retired** | **1** | **249** | **2** | **33** | **20** | **305** |
| Homemaker | 0 | 14 | 0 | 1 | 2 | 17 |
| Volunteer | 0 | 0 | 0 | 2 | 0 | 2 |
| In education or training | 0 | 1 | 0 | 0 | 0 | 1 |
| Others | 0 | 12 | 0 | 2 | 0 | 14 |
| **Total** | **1** | **441** | **7** | **60** | **32** | **541** |

**Figure A2: Annual financial costs to families by type across home country and UK**

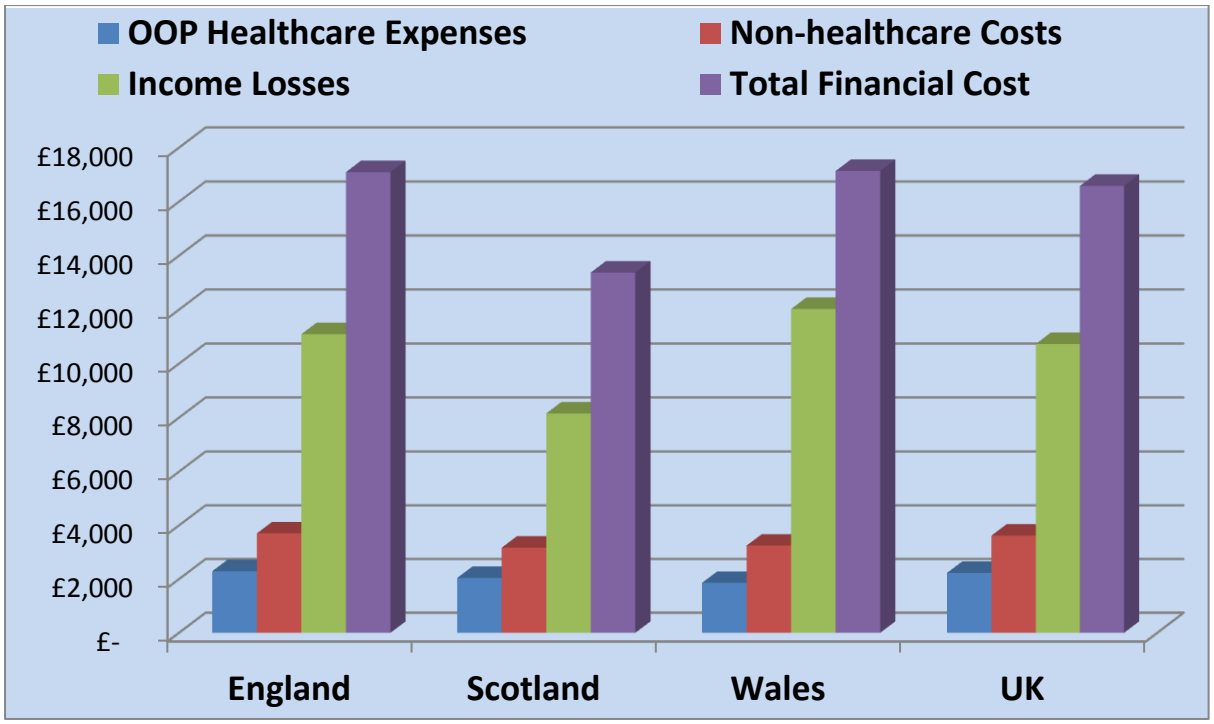
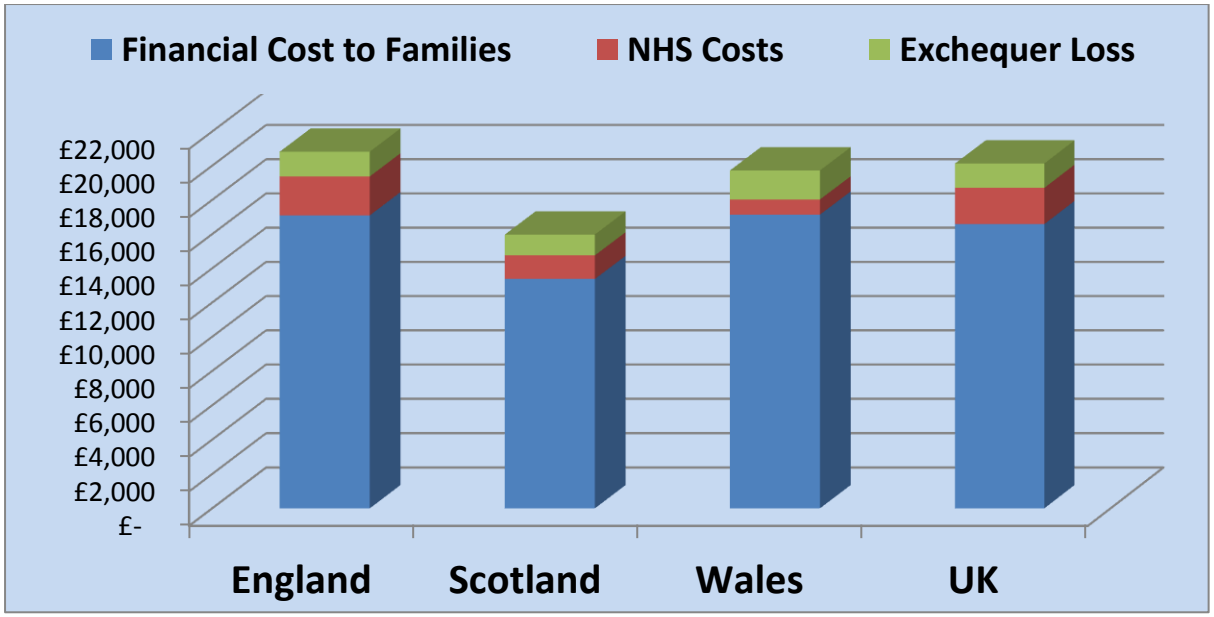



**Figure A3: Societal costs of Parkinson's by home country and UK**

***(Mean Costs per PwP household)***



## Table A3: Aggregated annual health and social care costs by home country

| Annual Direct and Indirect Cost | Cost/Income Loss Description | Number of Responses | Country | Total Cost (£) | Mean Cost per family (£) |
|---|---|---|---|---|---|
| | | | Not Reported | 213 | 213.20 |
| | | | England | 1,132,273 | 2273.87 |
| | | | N Ireland | 25,935 | 5186.92 |
| | | | Scotland | 101,623 | 1378.72 |
| | | | Wales | 25,332 | 885.07 |
| | Health services (NHS) | | UK | 1,285,354 | 2117.91 |
| | | | Not Reported | 60 | 60.00 |
| | | | England | 137,160 | 279.40 |
| | | | N Ireland | 1,810 | 362.00 |
| | | | Scotland | 17,795 | 241.71 |
| | | | Wales | 5,095 | 176.95 |
| | Health services (PWP) | | UK | 161,920 | 270.25 |
| | | | Not Reported | 273 | 273.20 |
| | | | England | 1,269,433 | 2553.28 |
| | | | N Ireland | 27,745 | 5548.92 |
| | | | Scotland | 119,418 | 1620.42 |
| | | | Wales | 30,427 | 1062.02 |
| | sub-total of Direct Medical | | UK | 1,447,274 | 2388.16 |
| | | | Not Reported | 1,200 | 1200.00 |
| | | | England | 977,330 | 2018.04 |
| | | | N Ireland | 1,585 | 317.00 |
| | | | Scotland | 133,515 | 1803.75 |
| | | | Wales | 50,520 | 1684.43 |
| | Travel and Equipment (PwP) | | UK | 1,164,150 | 1958.88 |
| | | | Not Reported | 1,473 | 1473.20 |
| | | | England | 2,246,763 | 4571.32 |
| | | | N Ireland | 29,330 | 5865.92 |
| | | | Scotland | 252,933 | 3424.18 |
| | | | Wales | 80,947 | 2746.44 |
| Total Healthcare Cost | | | UK | 2,611,424 | 4347.04 |
| | | 1 | Not Reported | 1,000 | 1000.00 |
| | | 480 | England | 251,763 | 524.51 |
| | | 5 | N Ireland | 5,000 | 1000.00 |
| | | 69 | Scotland | 28,713 | 416.12 |
| | Alterations in accommodation | 30 | Wales | 20,688 | 689.58 |
| | (PwP) | 585 | UK | 307,163 | 525.06 |
| | | 0 | Not Reported | 0 | 0.00 |
| | | 378 | England | 212,760 | 562.86 |
| | | 4 | N Ireland | 3,480 | 870.00 |
| | | 58 | Scotland | 35,220 | 607.24 |
| | Living environment - energy | 26 | Wales | 14,880 | 572.31 |
| | cost (PwP) | 466 | UK | 266,340 | 571.55 |
| | | 0 | Not Reported | 0 | 0.00 |
| | | 476 | England | 141,204 | 296.65 |
| | | 5 | N Ireland | 3,480 | 696.00 |
| | | 72 | Scotland | 21,216 | 294.67 |
| | | 29 | Wales | 11,760 | 405.52 |
| | Takeaways (n=582) | 582 | UK | 177,660 | 305.26 |
| | | 1 | Not Reported | 0 | 0.00 |
| | | 413 | England | 51,063 | 123.64 |
| | | 5 | N Ireland | 0 | 0.00 |
| | | 58 | Scotland | 15,000 | 258.62 |
| | | 24 | Wales | 250 | 10.42 |
| | Mobility vehicle/car (n=501) | 501 | UK | 66,313 | 132.36 |
| | | 0 | Not Reported | 0 | 0.00 |
| | | 432 | England | 948,900 | 2196.53 |
| | | 5 | N Ireland | 9,360 | 1872.00 |
| | | 66 | Scotland | 105,280 | 1595.15 |
| | Daily living assistance | 26 | Wales | 40,840 | 1570.77 |
| Non-Healthcare Costs | (n=529) | 529 | UK | 1,104,380 | 2087.67 |

| | | | | | |
|---|---|---|---|---|---|
| Total Non-Healthcare costs | | | Not Reported | 1,000 | 1000.00 |
| | | | England | 1,605,689 | 3704.18 |
| | | | N Ireland | 21,320 | 4438.00 |
| | | | Scotland | 205,429 | 3171.80 |
| | | | Wales | 88,418 | 3248.59 |
| | | | UK | 1,921,855 | 3621.90 |
| Income Loss (Direct and Indirect) | Current Workdays lost and reduction in weekly hours (n=729) | 13 | Not Reported | 0 | 0.00 |
| | | 585 | England | 1,213,676 | 2074.66 |
| | | 8 | N Ireland | 0 | 0.00 |
| | | 82 | Scotland | 98,643 | 1202.96 |
| | | 41 | Wales | 131,980 | 3219.03 |
| | | 729 | UK | 1,444,299 | 1981.21 |
| | Current Indirect employment earnings forgone due to early retirement or inability to work (n=767) | 14 | Not Reported | 86,733 | 6195.24 |
| | | 615 | England | 3,722,932 | 6053.55 |
| | | 8 | N Ireland | 40,628 | 5078.45 |
| | | 87 | Scotland | 490,729 | 5640.57 |
| | | 43 | Wales | 271,157 | 6305.97 |
| | | 767 | UK | 4,612,179 | 6013.27 |
| | Unpaid caring (earnings loss) | 14 | Not Reported | 0 | 0.00 |
| | | 615 | England | 823,680 | 1339.32 |
| | | 8 | N Ireland | 0 | 0.00 |
| | | 87 | Scotland | 54,912 | 631.17 |
| | | 43 | Wales | 68,640 | 1596.28 |
| | | 767 | UK | 947,232 | 1234.98 |
| | State pension and benefit loss (n=583) | 1 | Not Reported | 0 | 0.00 |
| | | 478 | England | 776,989 | 1625.50 |
| | | 5 | N Ireland | 24,118 | 4823.52 |
| | | 69 | Scotland | 47,146 | 683.27 |
| | | 30 | Wales | 27,141 | 904.71 |
| | | 583 | UK | 875,394 | 1501.53 |
| Total Income Loss | | | Not Reported | 86,733 | 6195.24 |
| | | | England | 6,537,278 | 11093.03 |
| | | | N Ireland | 64,745 | 9901.97 |
| | | | Scotland | 691,430 | 8157.97 |
| | | | Wales | 498,918 | 12025.99 |
| | | | UK | 7,879,104 | 10730.99 |
| Annual Financial Burden of Parkinson's | On Families | | Not Reported | | 8455.24 |
| | | | England | | 17094.65 |
| | | | N Ireland | | 15018.97 |
| | | | Scotland | | 13375.24 |
| | | | Wales | | 17135.96 |
| | | | UK | | 16582.03 |
| | Adding NHS costs | | Not Reported | | 8668.44 |
| | | | England | | 19368.52 |
| | | | N Ireland | | 20205.89 |
| | | | Scotland | | 14753.95 |
| | | | Wales | | 18021.03 |
| | | | UK | | 18699.94 |
| | Adding Exchequer (Revenue) Loss | | Not Reported | | 9771.20 |
| | | | England | | 20815.34 |
| | | | N Ireland | | 21109.85 |
| | | | Scotland | | 15972.10 |
| | | | Wales | | 19716.48 |
| | | | UK | | 20122.96 |

# *Appendix 7*

## Select Quotes on Parkinson's Impact on Employment, Quality of Life and Income

Parkinson's had a varying impact on people's working life. PwP whose job responsibilities involved commuting, physical/manual work, vehicle/taxi/train driving, office work (including typing), catering, painting/decorating or even talking to customers felt an immediate impact on their working conditions. As a result, resignation was considered unavoidable. Few were able to retire in a phased manner, with no option of reducing working hours, job responsibilities or of demotion. This was in contrast to those in lighter occupations (e.g. teaching or employed in their family business). In most cases, employers were unsympathetic and not accommodating to PwP (in terms of reducing their responsibilities or working hours, remuneration and redundancy payments), but instead offered redundancy or early retirement on medical grounds. Some PwP who were able to carry on with work remained dependent on medication, reporting increasing guilt at not doing a proper job, or increasing stress, which for some led to depression. Several PwP felt the impact on their earnings and household income immediately, whilst for others, this was delayed. The worsening in their economic wellbeing compounded deterioration in their Parkinson's symptoms and QoL as noted in quotes from PwP and their carers below. At the end of each quote, we have mentioned in parentheses whether the respondent is a PwP/Carer, male/female, his/her current age, last job/occupation held, and Parkinson's duration (PD) since the diagnosis, as well as the country they are from.

There were many more responses, and representative of people from each country. Not all have been included however, as they either confirm or are similar to the quotes first submitted and used.

- Earnings loss/reduced pension, some with the additional psychological cost of losing a self-built business, and some the psychological cost of accepting work of lower status

*'I was offered redundancy due to the effect Parkinson's was having on my ability to carry out my work role. I was made redundant at the age of 62.My husband also retired the same year (he was 63) to provide full time care for me. That year we lost two sources of income although my husband has a private pension'* ***(PwP, F 70, Clerical, PD 14.3 years, England).***

*'I have gone from being a voluntary sector senior manager through being self-employed part-time to being semi-retired on my occ. pension from £51K down to circa £17K in 5 years'* ***(PwP, M 51, Senior Manager, PD 5.3 years, England).***

*'I had to retire on medical grounds from a well-paid job and because of my condition have had to accept a much lower paid job'* ***(PwP, M 58, Clerical, PD 12.3 years, England).***

*'I lost ten years pension as I had to retire early from my Primary School Headship. I was then unable to do any teaching without losing the whole of my pensionable rights. This was an all-or-nothing approach which was disappointing and didn't make use of my good days'* ***(PwP, F 63, School Head, PD 13.3 years, England).***

*'In 2009, 3 years after diagnosis, I had to close down a highly regarded nursery school which I founded in 1981. This had provided a good income which I lost'* ***(PwP, F 72, Anglican Priest, PD 9.3 years, England).***

*'Own business lost due to not being able to do physical work. 15 years unemployed before being offered a role one day a week over two afternoons with Parkinson's UK'* ***(PwP, F 74, Self-employed Manager, PD 12.8 years, England).***

*'When diagnosed I was a chemical engineer with a job earning £60K+. I had to stop this job within a year due to safety. I then took an administration job in a College for 8 years earning £23K. I am now medically retired'* ***(PwP, F 42, Engineer, PD10.3 years, England).***

*'When first diagnosed I reduced my hours to 4 days a week, however the work load did not decrease. I was also working between two sites. By this time I was 63 with an open contract (no end date). I had intended to work for 4 to 6 years more to enable us to save towards our retirement as we used much of our existing savings towards a short fall on our mortgage. My decision making at meetings and in urgent situations was becoming hesitant and my typing and use of my right hand was becoming problematic. I requested early retirement on ill health grounds, I was offered part time lower graded post. The difference between this offer and my pension was less than £1000, I took the retirement option'* ***(PwP, F 66, Junior Manager, PD 3.3 years, England).***

- Work involved commuting and physical labour and the costs to the work place

*'I worked for London underground as a Signal Operations Manager on a 24/7 shift rota managing staff involved in the maintenance and fault finding of the signalling equipment. This at times involved me going onto the track to manage the staff while trains were still running. When I was diagnosed with Parkinson's I informed work and was immediately put on light duties. I went into depression and long term sickness and was eventually medically sacked'* ***(PwP, M 66, Middle-level Manager, PD 8.3 years, England).***

*'I was commuting a 1.5 hour journey into London (on a good rail/underground day, bad day up to three hours) which was very debilitating. I also have osteoarthritis in both knees, so used crutches then and still do. My Parkinson's affected my handwriting to the extent it was almost illegible and my thought processes were slowing down. Not good as part of my job was proofreading. Eventually I asked for voluntary redundancy which the management accepted and gave me a most generous redundancy payment, way above the state requirement'* ***(PwP, M 60, Clerical, PD 11.8 years, England).***

*'I was employed by Tesco as a HGV driver with almost 40 years in service. I was having difficulty staying awake and needing to park up for a 15 min break several times in a shift. I put this down to not getting enough sleep. On one occasion I feel off the trailer, I simply lost my balance'* ***(PwP, M 71, HGV driver, PD NR, country not recorded).***

*'Cannot work at height on ladders, etc. - May lose my driving licence as ability is getting worse. - Loss of business due to customers' wanting continuity of service knowing that realistically I cannot give them long term contracts. - Difficulty using mobile phone. - Cannot write important forms (the more important the form the worse my shake becomes)'* ***(PwP, M 55, Technical Craftsman, PD 5.8 years, Scotland).***

*'I worked for many years as a football pools collector but had to give up my round shortly before I was diagnosed with Parkinson's because it involved 2 to 3 hours walking and I could no longer stand doing this with a heavy bag over my shoulder. I still collect from three very local clients'* ***(PwP, F 62, Self-employed Manual, PD 8.2 years, England).***

- Alteration in ability to manage job responsibilities, with an impact on QoL (some issues pre-dating the diagnosis of Parkinson's)

*'Mobility slow- I run a diversified farm estate so have to rely on others for feedback about many areas which I now struggle to reach. Less strength…Ordinary routine tasks round the estate are now beyond my ability. Sleep patterns disturbed. This affects my cognitive ability - not easy to focus, much slower at organisational tasks & paperwork in general. Shakiness- much slower to type up reports and information of all kinds. Confidence reduced due to all of above, plus incontinence problems. It means that I am less good as a manager and decision maker'* ***(PwP, F 64, Senior Manager, PD 3.8 years, England).***

*'I became ill over a period of time, at the time I didn't have an answer too what the illness was, It deeply affected my life, I went from very able too unable, physically & mentally, I was a danger to myself and those I worked with, working in a kitchen, I had to finish work, then a yearlong investigation resulting in the end a Diagnosis of Parkinson's. I applied for ESA and was placed within the support group of ESA'* ***(PwP, M 46, Semi-routine Manual, PD 2.1 years, England)***.

*'My last employment was at the University of Oxford where I worked with…the business orientated functions of the University and businesses worldwide to help initiate new research projects…and encourage other interactions of mutual benefit. The work required good interdisciplinary skills and the ability to engage effectively with the interests and aspirations of academic staff and business leaders alike. I found it progressively more difficult to "keep up" with academic staff and, on reflection; I think that some of the physical symptoms of Parkinson's were starting to intrude into my work by 2008. In 2010 I was diagnosed with Parkinson's and at the end of that year I retired on medical grounds with a reduced pension from the Universities Superannuation Scheme. I now spend my time either at home or helping Parkinson's charities as much as my condition allows'* ***(PwP, M 62, Senior Manager, PD 5.3 years, England).***

*'My husband was diagnosed with Parkinson's at 50 and had to retire at 57 due to ill health and the restrictions and restraints of the disease. I had to be the sole bread winner and was also looking after teenage family and elderly parents. The on-going effect of looking after him and being a full-time carer is very tiring and as I am getting older feeling weary with many broken nights sleep, doing everything in the house, garden, working and caring. You need to include this in your questionnaire. I am not depressed but finding it physically and emotionally challenging and very tiring'* ***(Carer, F 69, Modern Professional, PD 29.8 years, England).***

*'Having sold 65% of my general accountancy practice just before being formally diagnosed in February 2011 as having Parkinson's ( which was approx. one year earlier than planned due to the symptoms), I have slowed down consistently since in managing the client based retained whereby it is approaching full time work again. I am accordingly disposing of my remaining client base so as to fully retire a year or so earlier than anticipated'* ***(PwP, M 69, Accountant, PD 4.7 years, England).***

*'He was being treated for anxiety and depression before his diagnosis of Parkinson's was made. He was asked to resign as he could not do the job he had been employed for and they offered him an alternative but changed the job which was even more unsuitable when he tried to go back to work'* ***(Carer, F 66, Senior Manager, PD 7.8 years, England).***

- Reduction in working hours/responsibilities/demotion/job change, some which have been psychologically beneficial, impacting positively on health, and others detrimental to psychological wellbeing

*'Was full time but struggled with health issues but changed to 3 days per week now down to two days due to head teacher wanting to change my working days to every other day. I work with autistic and multi disability 5 year olds on my feet and working on my knees most of the day which I need a block of days off together to recover, rest & therapies. She [Head Teacher] had no understanding how part day working would not work for me'* ***(PwP, F 57, Teacher, PD NR, Wales).***

*'I resigned from my fulltime teaching as stress was aggravating my condition. Began, and still do, supply teaching which I find less stressful'* ***(PwP, M 52, Teacher, PD 1.4 years, England).***

*'I am self-employed in family business so have taken on another member of clerical staff to cover on a daily basis, meaning I can stay at home as and when I feel necessary'* ***(PwP, F 60, Self-employed Manager, PD 1.3 years, England).***

*'When I informed my employer they 'froze' my remuneration package at my original senior level and demoted me 5 jobs levels to 'remove any stress'. I worked for a further 5 years before being forced to give up work. I was not forced by my employer who made strenuous efforts to retain me'* ***(PwP, M 67, Modern Professional, PD 15.2 years, England).***

*'The Special school that I worked in for 15 Years decided that I was unable, in their opinion, to carry out the majority of my job description as a Senior Teaching Assistant and they could not find me any other position in the school I had to take early retirement due to ill health or have my employment terminated. I was at one time classed as a health and safety risk as I might freeze and fall on one of the children. I was stopped from going on school trips and banned from the weekly trip to the swimming pool as I could fall over. They kept focusing on this and the fact that Parkinson's is a progressive illness. This only applied when they decided as I had to go with the school when they did a performance out of school. I was watched and coerced into not doing bits of my job description by members of staff and senior management. I also had to be assessed by Atos and other outside agencies. I was of ill, recovering from a lumpectomy and facing radiotherapy, when I was told that I was to be terminated by the county councils human resources'* ***(PwP, F 61, Senior Teaching Assistant, PD 8.8 years, England).***

*'Well supported for first 2 years of diagnosis. I planned to take early retirement when offered by NHS scheme, and was also offered part time employment by my service manager. Unfortunately my service manager wrote a referral to Occupational Health which I had not seen or signed which included symptom's which was very offensive and distressing for me and my family which I did not have and in the words of the occupational health lead nurse had been copied from a book or internet. This resulted in Grievance against my manager. Due to changes in service and informed I do longer had a 'safety net'! I felt vulnerable and retired'* ***(PwP, F 57, Nurse, PD 3.3 years, England).***

- Forced early retirement/unable to do work/redundancy/ psychological cost from lack of understanding

*'I was diagnosed with PD in summer 2005 and forced to take ill health retirement aged 57 years. My job entailed counselling and training with much travel involved. The job was very satisfying, well paid but also quite stressful. I had successfully undertaken the job for 10 years when I was diagnosed and foolishly confided in my boss. I was subjected to considerable pressure to retire, which as the chief earner in our home, added to the stress I was already suffering whilst coming to terms with the diagnosis. Once defeated and retired (unwillingly) I was then pressured by the Jobcentre to look for alternative poorly paid unskilled work. However it was soon apparent, even to them, that this was more than I could cope with at the time as I was extremely tearful and emotional about the job I had loved and lost and the PD diagnosis. In retrospect I can see that I really needed to retire from my job as I was under too much stress to function well and the stress worsened my symptoms'* ***(PwP, F 68, Modern Professional, PD 11.3 years, Wales).***

*'Currently my Parkinson's prevents me from working. Previously it had astronomical effects upon my working life, resulting in losing jobs and having to have endless medical tests and reports, 'disciplinarians' for not successfully meeting my targets, and hours spent with senior union representatives to defend me'* ***(PwP, M 63, Cleaner, PD 11.2 years, England).***

*'For some years my ability to complete my duties efficiently suffered even prior to my diagnosis. Eventually, I had some time off due to this when my manager offered me the chance to retire early. I initially, I declined the offer in the hope that medication changes may enable me to return to work but I eventually had to retire early'* ***(PwP, F 69, Clerical, PD 11.3 years, England).***

*'Was made redundant, then couldn't find a job when I informed prospective employers of my condition. Most were sympathetic but wouldn't take the risk of me needing special facilities. The*

*Parkinson's nurse advised me to sit on my hand (The one that shakes most of all) at interviews so they didn't know I had Parkinson's and NO SHE WASNT JOKING!'* ***(PwP, M 61, Junior Manager, PD 15.3 years, England).***

*'My employers did not understand my condition and put pressure on me which resulted in me having a bit of a nervous breakdown and, as I was off work for a long time, they dismissed me'* ***(PwP, F 67, Modern Professional, PD 7.3 years, England).***

*'I was given ill health retirement from my job as I was a kitchen assistant in a busy school, it was very hard, hot, and none stop for 4 hours a day. I was very stiff when I got home and exhausted, I would sit in my arm chair, sleep and when come to get up could not straighten my back, it was almost locked and I had to walk round slowly till I loosened up. It was getting hard also with my left hand shaking as my Parkinson's is in my left side, also I am left handed, to serve the children hot gravy, custard, any hot liquid, I could have easily hurt them and or even myself'* ***(PwP, F 58, School Dinner Lady, PD 14.3 years, England).***

*'All of my work is done by hand so it has had a massive effect on my work. Having being diagnosed I stopped painting for almost ten years and pretty much gave up on self-employment, taking part time work where I could. Only starting painting (though differently now) and doing design work professionally again about two years ago'* ***(PwP, M 48, Self-employed Architect, PD 11.8 years, England).***

*'Was a senior Secretary to Managing Director, but eventually could not take shorthand or minutes at Board meetings. Typing was also effected, speed reduced to 100 wpm to 15 wpm. I stepped down to a less pressured role. The company provided a voice activated programme to assist but this did not prove to be practical. Eventually I was unable to do my job due to pain in neck, shoulders and hands, inability to do shorthand anymore and difficulty writing. Sitting for long periods was problematic and eventually my memory and organisational skills were affected. After being in the job for 16+ years I took early retirement. Losing a good salary and now have a reduced pension…'* ***(PwP, F 58, Senior Manager, PD 2.3 years, England).***

- Negative consequences of Parkinson's creating social/family problems impacting on QoL

*'I managed to work part-time for 10 years before it all got too much for me. I no longer felt motivated to get the work done and didn't feel on top of the job at all. I was struggling with sleepiness, soft voice, problems with continence, depression, loss of self-esteem, and lack of mental sharpness while at home I was dealing with the breakdown of my marriage and debt. I was dismissed on the grounds of incompetence due to ill health (with my agreement) and received an enhanced occupational pension'* ***(PwP, F 63, Modern Professional, PD 16.9 years, England).***

*'PD mainly affects my voice: I moved back to UK from Moscow (my home of almost 20 years), leaving behind a wife & daughter who couldn't support me. I chose to leave: It broke my heart'* ***(PwP, M 53, Self-employed Tutor, PD 2.8 years, England).***

*'I personally feel that my PD was a contributing factor in our company's liquidation; because I made so many mistakes as Finance Director, whilst trying to get my medications working for me English tutor'* ***(PwP, M 69, Junior Manager, PD 11.1 years, England).***

*'I was medically retired from my job as medical secretary to a local GP practice. I was conscious that I was beginning to lose concentration and was worried about making mistakes which could affect other people's lives. I was becoming forgetful and not meeting deadlines, routine computer work was taking longer. The crunch came when I crashed the practice computer system. I knew then that I could not carry on and sought medical retirement'* ***(PwP, F 60, Clerical, PD 7.4 years, England).***

*'Had to give up work soon after we married to preserve his health and quality of life in order to live as normally as possible and stay off PD drugs for as long as possible as diagnosed so young'* ***(Carer, F 56, Teaching Assistant, PD 29.3 years, England).***