Inquiry into access to health and social care services for people with Parkinson’s disease and their carers
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Background

Parkinson’s disease is a degenerative, neurological condition for which there is currently no cure. It affects all aspects of daily living and has a major impact on quality of life.

This All Party Parliamentary Group for Parkinson’s Disease inquiry was carried out in response to growing concerns about variations in access to the comprehensive services and expert multi-disciplinary care needed by people with this complex condition.

The evidence submitted painted a stark picture of inequalities in access to services for people with Parkinson’s disease and their carers across England, Wales and Northern Ireland. These inequalities persist despite clear, evidence-based guidelines for the provision of services, including the National Institute for Health and Clinical Excellence (NICE) guideline for Parkinson’s disease, Welsh Neurosciences Expert Review and National Service Framework (NSF) for long-term neurological conditions in England.

The evidence also pointed to a number of major barriers to the delivery of consistent, high quality services.

Summary of findings

The Inquiry found evidence of significant inequalities in service access, including:

- major inequalities across the whole of England, Wales and Northern Ireland in access to all aspects of care, including:
  - significant shortfalls in access to Parkinson’s disease nurse specialists, particularly across Northern Ireland and Wales
  - poor access to therapy services
  - lack of access to deep brain stimulation in many areas, with particular difficulties in Wales
- poor information provision and signposting, especially with regard to social care
- poor understanding of Parkinson’s disease amongst some of the professionals involved
- limited access to respite care and other support for carers
- lack of integrated working between the range of services involved in the different aspects of care for people with Parkinson’s disease and carers
- concerns about access to appropriate services for people living in care homes and for black and minority ethnic groups.

The following key barriers to the delivery of consistent, high quality services were identified:

- little impetus behind implementation of the NICE guideline and other relevant quality frameworks, with limited monitoring for compliance with quality standards
- lack of leadership for neurological services at national and local level
- policy making without due consideration of the impact on long term degenerative conditions such as Parkinson’s disease
- absence of integrated service planning and commissioning to reflect the all-round needs of people with Parkinson’s disease
- lack of awareness of the cost effectiveness of elements of care for people with Parkinson's disease among service planners and commissioners
shortages in the number of appropriately trained professionals in key areas of care for people with Parkinson’s disease
lack of understanding of Parkinson’s disease among the general health and social care workforce.

**Key recommendations**

The Inquiry strongly urges the relevant Governments in England, Wales and Northern Ireland and other bodies to take action to:

- improve leadership for Parkinson’s disease and other neurological services at local and national level
- ensure drivers are in place to support implementation of national guidance for neurological conditions and strengthen service monitoring
- support better commissioning and planning of services for people with Parkinson’s disease through the provision of evidence and guidance
- strengthen workforce planning so that sufficient skilled professionals are available to deliver high quality Parkinson’s disease care.

Conclusions and detailed recommendation are set out in full on page 41 of this report.
Foreword

As someone who has been personally affected by Parkinson’s I understand the importance of good access to services, both for the person with Parkinson’s and their family. Approximately 120,000 people currently have Parkinson’s in the UK and one in eight people are affected by the condition through family and close friends. These people need, and are entitled to, access to high quality health and social care.

It is because of my personal connection to Parkinson’s, through my father being diagnosed with the condition almost 40 years ago, that I wanted to set up the All Party Parliamentary Group for Parkinson’s Disease to highlight Parkinson’s issues within Parliament. When my father was diagnosed there were very limited services and treatment available. The difference in access to services today is immense; however this Inquiry has shown that it is still not good enough. There are still people who struggle to get the vital services they need.

The Inquiry has thoroughly investigated the issues and barriers around access to health and social care services for people with Parkinson’s and their carers. It makes wide-ranging recommendations to the Governments in England, Wales and Northern Ireland, as well as health and social care commissioners and professionals, in an attempt to overcome the problems uncovered.

I am immensely proud to have chaired this important Inquiry and I would like to thank the hundreds of people with Parkinson’s, carers, professionals and organisations who submitted evidence. The incredible response that we have had shows the importance of these issues. The report represents both the written and oral evidence submitted to the Group, as well as the cross-party consensus on the importance of good access to high quality services for people affected.

Baroness Gale
Chair, All Party Parliamentary Group for Parkinson’s Disease
Inquiry into access for health and social care services for people with Parkinson’s disease and carers

About Parkinson’s disease

Parkinson’s disease is a long-term, degenerative neurological condition affecting an estimated 120,000 people in the UK. The condition results from the gradual death of the specific brain cells that produce the neurotransmitter dopamine. The average age of onset is between 55 and 60 years.

Parkinson’s disease has an increasing impact on all activities of daily living as the condition advances. The principal symptoms affect movement, with a general slowness and stiffness making activities such as walking, speaking and writing increasingly difficult, and sometimes there is a tremor of the hands. People will also commonly experience other symptoms such as depression, dementia, sleep disturbances, incontinence and diffuse pain that add to the overall impact on quality of life. The fluctuating and individual nature of the condition requires accurate diagnosis: there is no single diagnostic test so, in its early stages, Parkinson's disease can be difficult to differentiate from other conditions. Care of people with Parkinson's disease requires a complex mix of monitored drug management, social care and support, physiotherapy, speech and language therapy, occupational therapy, nursing care and psychosocial support. Currently there is no known cure.

About the Inquiry

The All Party Parliamentary Group for Parkinson's Disease launched this Inquiry to investigate the availability and quality of health and social care for people with Parkinson’s disease and their carers. The Inquiry looks at services in Wales, England and Northern Ireland where the NICE clinical guideline for Parkinson’s disease applies.

In order to carry out the Inquiry the APPG produced a Call for Evidence at the outset of the Inquiry. They also produced a questionnaire specifically designed for people with Parkinson's disease and their carers. The Inquiry received 364 submissions of written evidence from people with Parkinson's disease, their carers, individual professionals and Government representatives, and a range of organisations. The Inquiry subsequently held five oral evidence sessions during which the Group heard from 28 witnesses, and received supplementary evidence from a further two individuals and one organisation.
Good practice guidance and government policy

The vision for services for people with Parkinson’s disease has been set out in the National Institute for Health and Clinical Excellence (NICE) clinical guideline on Parkinson’s disease, the National Service Framework (NSF) for Long-term (Neurological) Conditions, which covers England, and the recommendations of the Welsh Neurosciences External Expert Review Group.

The NSF, published in 2005 by the Department of Health, is a ten year strategy for improving services for people living with neurological conditions in England. It also addresses the support services required for carers of people with these conditions. The NSF sets out 11 quality requirements for health and social care services, including: integrated assessment and planning of an individual’s health and social care needs; access to neurological expertise for diagnosis and ongoing access to community rehabilitation services; access to a comprehensive range of palliative care services; personal care and support; timely provision of equipment and adaptations to support people to live independently; and flexible and responsive support services for carers.

The NICE clinical guideline on Parkinson’s disease, published in June 2006, which covers England and Wales and was adopted in Northern Ireland in 2007, sets out best practice advice on the diagnosis and management of the condition in primary and secondary care. The guideline echoed many of the NSF quality requirements, and recommended that people with Parkinson’s disease have access to a specialist for diagnosis and ongoing review, regular access to nurse specialist care and access to a multi-disciplinary team comprised of physiotherapy, speech and language therapy and occupational therapy services. It also proposed that palliative care requirements of people with Parkinson’s disease should be considered at all stages of the condition and that deep brain stimulation surgery should be available for individuals assessed as clinically appropriate for this intervention. In addition the guideline placed significant emphasis on the management of non-motor features of Parkinson’s disease including mental health problems, sleep disturbance and pain.

The Department of Health 18 week Commissioning Pathway for Tremor (Parkinson's Disease), which covers England, also highlighted that diagnosis should be conducted by a specialist.

The Welsh Neuroscience External Expert Review Group, an independent review commissioned by Edwina Hart, Minister for Health and Social Services in the Welsh Assembly Government and led by consultant neurosurgeon James Steers, published its All Wales Recommendations in September 2008. The recommendations, in line with the NICE clinical guideline on Parkinson’s disease and vision for health services in England set out in the NSF, called for access to nurse specialists, and for specialist clinics composed of multi-disciplinary teams, to be established as close to patients’ homes as possible.

In Northern Ireland Michael McGimpsey, the Minister for Health, Social Services and Public Safety, has committed to developing a Physical and Sensory Disability Strategy, which is expected by the end of 2009. The strategy will cover the following areas of service provision relevant to Parkinson’s disease services: wheelchairs, community care, respite, neuro-disability and communication impairment.

Other relevant government policies relating to Parkinson’s disease services include the National Dementia Strategy in England, published in 2008. Dementia plans are expected to be published in Wales and Northern Ireland over the coming months, and Social Care Green Papers are also expected imminently in England, and in Wales over the coming months.

Policy covering services and support to carers is set out in the UK carers’ strategy published in 2008. This highlighted the importance of respite, outlining an additional investment of £150 million towards planned short breaks for carers. The strategy also outlined the piloting of carers’ annual health checks for carers and training for GPs to recognise and support carers, as well as further pilots to examine how the NHS can better support carers.

In addition, the carers’ strategy outlined plans for a more integrated and personalised support service for carers which will be offered through easily accessed information and targeted training for key professionals. However this additional investment, and all of the initiatives outlined above, apply only in England. The Quality and Outcomes Framework (QOF), part of the GP contract in England, also includes incentives to GPs for registering carers.
In Northern Ireland, the carers’ strategy Caring for Carers, published in January 2006 is still in place, although a joint review of provision for carers by the Department for Social Development and the Department for Health, Social Services and Public Safety is expected to be published in the coming months. This review will look at what progress has been made in implementing the 2006 strategy and will examine the provision of support for carers following on from the 2008 UK strategy. In Wales, the Carers Strategy Wales Action Plan was published in 2007. The Welsh Assembly Government is currently seeking the power to make legislation to promote the well-being of carers in Wales. If granted, this would enable them to introduce a statutory requirement for health bodies and providers of social services to identify and inform carers of their rights; and to make provision in relation to referral pathways for carers.
Section 1: A description of a good service and the current experience

A description of good health and social services for people with Parkinson’s disease and carers

1. A clear picture of the key components of high quality services for people with Parkinson’s disease and their carers was provided to the Inquiry through evidence from professionals working in health and social services and those directly affected by the condition.

2. These comprise:
   - integrated multi-disciplinary teams involving medical specialists, nurse specialists, GPs, physiotherapists, speech and language therapists, occupational therapists, dieticians, specialist mental health professionals, palliative care professionals, pharmacists, domiciliary carers, social workers and care home staff
   - services delivered by professionals with a good understanding of the condition including awareness of the full range of symptoms, and its fluctuating and progressive nature
   - services that are joined-up around the needs of individuals living with the condition, with effective communication across primary, secondary, tertiary and social care
   - services that meet the information needs of people with Parkinson’s disease about all aspects of living with the condition, the full range of services and sources of support available, and guidance on how to access these services
   - support for carers through breaks from caring, the provision of emergency planning, and services to address the health and psychological needs of carers.

The current experience of services

3. However, the overriding theme of evidence received by the Inquiry was of significant inequalities in access to those services identified above.

4. Evidence highlighted:
   - major inequalities across all three countries in access to all aspects of care
   - particular concerns regarding access to appropriate services for people living in care homes and for black and minority ethnic groups
   - poor information provision and signposting, with many people with Parkinson’s disease and carers reporting that they did not know how or when to access the services and support available to them, especially with regard to social care
   - poor understanding about Parkinson’s disease amongst some of the professionals involved in the care of people with the condition
   - a lack of integrated working between the range of services involved in the various aspects of Parkinson’s disease care.
Inequalities in service provision

5. People with Parkinson’s disease repeatedly reported great disparities in access to, and quality of, the full range of Parkinson’s disease services.

Access to medical specialists

6. A range of professional bodies including British Geriatrics Society (BGS) Movement Disorder Section, Association of British Neurologists (ABN) and Parkinson’s Disease Nurse Specialist Association (PDNSA), as well as individual professionals, highlighted the importance of access to a medical specialist for diagnosis and ongoing review. This may be a neurologist or a consultant in elderly care medicine with a special interest in movement disorders. In addition ongoing review may also be provided by a general practitioner with a special interest in Parkinson’s disease – although there are only very few of the latter in post in the UK.

7. Diagnosing Parkinson’s disease is challenging. Each person presents with a different range of symptoms and many of the key symptoms are also found in other conditions. There is no definitive test or scan that can diagnose the condition, so accurate diagnosis relies on the clinical experience and expertise of the doctor.

8. The importance of specialist diagnosis was highlighted in written evidence from the BGS Movement Disorders Section:

“Diagnostic error is common with an error rate of up to 50% seen in one community-based study¹. Accurate diagnosis is the cornerstone for predicting prognosis and the planning of management. It is strongly recommended therefore that all patients with a suspected diagnosis of Pd [Parkinson’s disease] be referred for specialist assessment by an experienced clinician².”

9. Dr Peter Fletcher, Chair of the BGS Movement Disorder Section, highlighted the benefit to the patient of those specialists having particular experience and expertise in Parkinson’s disease and similar conditions. He commented:

“In an area of the country where there is only a neurologist or only an elderly care physician the patient will get a relatively good deal. I think they will get a better deal if either of those specialists sub-specialise within movement disorders.”

10. While evidence from the ABN and others highlighted that there had been a significant increase in the number of neurologists in recent years, difficulty accessing specialists and long waits between appointments was a key concern outlined in submissions to the Inquiry from people with Parkinson’s disease. One person with Parkinson’s disease from Carlisle reported not having seen his specialist for five years, and a number of individuals reported having had no access at all. The majority of respondents valued consultations with specialists highly and would like more regular follow-up appointments.

11. Access to specialists was highlighted as a particular issue in Northern Ireland, where the Inquiry heard in evidence from the Parkinson’s Disease Society (PDS) and Dr David Craig, Consultant in Elderly Care at Belfast Health and Social Care Trust, that there were no specialists in post with particular expertise in Parkinson’s disease. Dr Craig commented:

“The lead clinician within Pd [Parkinson’s disease] services in Northern Ireland has now retired on medical grounds and within my trust, the Belfast Trust, the service is now in a position of catch-up whereby people like me who have trained in one area but with some experience of Parkinson’s disease are helping to fill the gaps that have been created through this situation.”

Parkinson’s disease nurse specialists

12. The role played by Parkinson’s disease nurse specialists in the care of people with Parkinson’s disease was strongly endorsed by submissions from people living with the condition, carers and those medical specialists working alongside nurse specialists.

13. Many people with Parkinson’s disease and carers outlined how Parkinson’s disease nurse specialists provided them with a regular point of contact for advice on all aspects of the condition and for

“I have only seen a neurologist once since I came to the Carlisle area five years ago.”
(Person with Parkinson’s, Carlisle)

“[The] biggest help has been Specialist Nurses, bit of a life saver really. Could not imagine coping without them.”
(Person with Parkinson’s, Essex)
adjustment of their complex medication regimes. This service was particularly valued by this group and, when individuals did not have access to a nurse specialist, this tended to be identified as the most significant service inadequacy.

14. Although evidence from a number of sources highlighted the clinical and cost-effectiveness of Parkinson’s disease nurse specialists, it was clear that many areas did not have any, or sufficient, coverage of this service. Clinicians such as Dr Doug MacMahon, Consultant Physician at Cornwall Health NHS Trust, commented on the cost-effectiveness that Parkinson’s disease nurse specialists brought to the health services through providing community and outreach services away from hospital centres, for example in care homes and in individuals’ own homes; providing regular clinical monitoring and adjustment of medication to help avoid unnecessary hospital admissions; and their role in education of both individuals with Parkinson’s disease and of the general health and social care workforce.

15. Particular problems accessing Parkinson’s disease nurse specialists were highlighted in Northern Ireland and Wales. The written evidence from the Royal College for Nurses (RCN) outlined, particularly in relation to the latter, that:

“In Wales there is a sizeable shortfall in the number of specialist nursing posts in the area of Parkinson’s disease. Large sections of the country either have no access or very limited access. For example, there is only one nurse specialist covering the whole of Gwent. The underlying issue is the lack of strategic workforce planning in NHS Wales. The Trusts have short term incentives to cut costs which they can only do by reducing the number of community and specialist nurses at the top of bands 6 and 7. This is in conflict with the stated aims of the Welsh Assembly Government to further develop community provision. This situation is mirrored elsewhere in Northern Ireland and Scotland, and to a lesser extent in England.”

16. The Welsh Neurological Alliance submission also highlighted:

“...inconsistencies of services as some people are able to access a specialist nurse locally... others receive telephone support or have to travel to the Walton Centre [across the border in Liverpool] or other tertiary centres to access the services, whilst some people have no access at all…”

17. Indeed, Edwina Hart, Minister for Health and Social Services at the Welsh Assembly Government told the Inquiry that there was “a paucity of nurse specialists in Parkinson’s in Wales”; an issue that, as the Minister explained, the Welsh Assembly Government was intending to address through the implementation plans to be announced later this year following the Welsh Neuroscience External Expert Review.

18. Jack Glenn, a person with Parkinson’s disease from Londonderry who provided evidence to the Inquiry, spoke of the poor access to Parkinson’s disease nurse specialists in Northern Ireland. Irene Falloon, a carer from Hillsborough, Northern Ireland, also compared the number of Parkinson’s disease nurse specialists with other specialist nursing posts in Northern Ireland. She highlighted how there were significantly more multiple sclerosis specialist nurses than Parkinson’s disease nurse specialists in Northern Ireland.

Therapy services

19. A range of individuals and organisations outlined the value of therapy services such as physiotherapy, speech and language therapy, occupational therapy and dietetics. Evidence from a number of clinicians emphasised the importance of a preventative approach with access to these interventions from an early stage in the condition.

20. Research into speech and language therapy provision for people with Parkinson’s disease conducted by Dr Nick Miller and a group of clinicians and academics at Newcastle University revealed that in many parts of the UK access to this service is minimal or even not possible for people with the condition. Even in main hospital centres where speech and language therapy is provided, the research
The PDS evidence pointed to the findings of its survey members from 2007. More than 13,000 responses were received including more than 10,000 from people with Parkinson’s. It revealed significant gaps in all aspects of health and social service provision for people with the condition. Of those respondents with Parkinson’s disease:

- more than one in four people have never spoken to a Parkinson’s disease nurse specialist
- approximately two-thirds have never been assessed by a speech and language therapist or occupational therapist in connection with their Parkinson’s
- almost half have never been assessed or had treatment by a physiotherapist in connection with their Parkinson’s
- more than one in four of people who reported needing home help have never received this
- one in five felt that the condition and its treatment were not explained clearly to them at diagnosis, including almost one tenth of this group who reported being given no explanation at all
- almost one in twelve reported that they needed, but had not received, advocacy support
- almost one in five of those who reported having personal care needs were not receiving support in this area
- of those individuals who purchased the equipment they needed to live at home, almost half of those who purchased their own bathroom aids, and more than four in five of those installing ramps or rails outside their house from their own funds, did so without advice.

The survey, which was completed by over 3,000 carers of people with Parkinson’s, also revealed that:

- just over one in ten carers were receiving support from their local authority in spite of the fact that nearly two-thirds of carers were caring for 50 hours a week or more, with just a fifth caring for less than 20 hours per week
- nearly two thirds of carers were not aware of their right to a carer’s assessment
- three-quarters of carer respondents reported wanting help with day-to-day caring; of these fewer than a fifth were getting the support they required
- carers are unlikely to receive the support they need from their GP, with just one in four of respondents registered as a carer with their GP
- over half of carers who need a break are not able to get one; while almost 9 out of 10 carers stated that they needed a break from caring for a few hours, less than half had actually managed to have a break
- many carers indicated that they needed more than a short break; seven out of ten carers indicated that a break from caring for a few days was important or very important. Of these, fewer than one in five were getting the type of break they needed
- under half of carers who responded to the survey were getting information and advice about Parkinson’s, even though almost all rated this as important or very important.
identified that the nature of services is such that not all people will be able to access the service or receive the desired amount of input. Particular problems were also identified accessing speech and language therapy for people living further away from major hospital centres and those who have greater mobility or transportation restrictions.

21. For those who were able to access these services, a number highlighted in their evidence to the Inquiry how, despite their long term need for support due to the chronic and progressive nature of their condition, they only received short spells of therapy services, and were then “signed off” by services. For example, a person with Parkinson's disease from Belfast highlighted how, after every contact he has with the occupational therapy services, his case is closed and he then has to endure a lengthy waiting period for a new assessment and for support to be provided. This is of particular concern in the light of evidence from the PDS that, according to their Members’ Survey, a significant minority of people who had accessed therapy services were having requests for further courses of treatment denied.

22. Some key regional variations in access to therapy services were also highlighted in the PDS submission. For example, in the North West of England, the proportion of people who had never had an assessment or course of therapy was consistently higher for all therapies. This evidence also highlighted difficulty in accessing ongoing assessment and treatment from therapists in the South West, where people were more than twice as likely to be refused ongoing access for speech and language therapy, physiotherapy and occupational therapy services, compared to the UK average.

23. A number of submissions from people with Parkinson's disease have revealed that in some areas PDS voluntary branches are filling the gaps in statutory services by funding therapy input.

Mental health services

24. Many people with Parkinson's disease experience mental health symptoms. These include: dementia, which affects a third of people with Parkinson's disease; depression, affecting up to half of all people with the condition; and compulsive behaviours, a side-effect of medication affecting an estimated 14% of people taking dopamine agonists, a class of Parkinson's drugs.

25. Although a number of clinicians identified that there had been a step change in understanding the mental health aspects of Parkinson’s disease amongst specialists, evidence to the Inquiry has revealed that many people with the condition are not receiving specialist mental health services. This is of particular concern given the high levels of people with Parkinson's disease experiencing mental health symptoms. The British Psychological Society commented on the lack of access to psychologists, comparing provision to that available for other conditions:

“Relatively few [people with Parkinson's disease] are thought to have psychologists as core members of the multidisciplinary team, in stark contrast with many services developed for people with Alzheimer’s disease, in which clinical psychologists/neuropsychologists often play a central or lead role in the management of teams and in the development and delivery of clinical services.”

(Person with Parkinson's, Worcs)

“I have worked hard to get counselling with a qualified, experienced psychologist... my GP has been very helpful but the waiting time has been many months.”

(Person with Parkinson's, Worcs)

26. Very few people with Parkinson's disease or carers commented that they were accessing mental health services. The PDS also provided evidence from its Members’ survey that less than one in eight people with Parkinson's disease have ever received an assessment or course of treatment in connection with their Parkinson's disease from a mental health professional. Further evidence from a training needs analysis and members’ consultation project conducted by the PDS also revealed that one third of people with Parkinson's disease are not referred to mental health services despite experiencing mental health symptoms.
Surgery
27. For some people with Parkinson's disease, a form of surgery called deep brain stimulation (DBS) is a clinically effective and cost-effective intervention. However, this can only be performed at highly specialist units.

28. Medtronic Ltd highlighted that “ready and appropriate access to a multi disciplinary Deep Brain Stimulation service” was “far from universal” with particular issues in Bristol and Gloucester PCTs which “require patients to clear additional hurdles by proving ‘exceptionality’…”, while Hillingdon PCT was judged to have a blanket no funding policy for the operation.

29. Dr Sandip Raha, Associate Specialist, of Movement Disorder Clinic at the Princess of Wales Hospital, Bridgend, described particular problems in accessing DBS in Wales. In Wales DBS is commissioned by Health Commission Wales, which currently identifies a limited budget for DBS on a yearly basis.

30. The experience of clinicians providing evidence to the Inquiry was that the budget for DBS in Wales was inadequate to cover all appropriate cases. Dr Raha indicated that clinicians were unsure about how much funding was left in the budget at any point, a fact which was resulting in appropriate patients not being referred to this service. Dr Raha commented that according to a colleague:

   “...at the moment there are probably between seven and eight patients on whom they have no information. He said he has three or four patients he cannot refer because he is completely uncertain about the funding.”

31. Evidence from Edwina Hart, Minister for Health and Social Services at the Welsh Assembly Government, highlighted that new funds for the procedure had recently been fully committed for 2009/10, clearing a backlog of 14 or 15 cases. However the Minister noted that the short term nature of funding was “far from ideal”.

Palliative and end of life care
32. A range of evidence from carers, health care professionals and the PDNSA highlighted the importance of access to specialist palliative care services for people with Parkinson's disease. A number of clinicians including Dr Doug MacMahon and Professor David Burn emphasised the need for strong links between these services and the Parkinson's disease multidisciplinary team.

33. Professor George Kernohan of the University of Ulster provided evidence of poor access to palliative care from the preliminary findings of his study into palliative care provision for people with Parkinson's disease8. In his research no patients recalled having access to palliative care. This was in part attributed to a perception of palliative care as terminal and end-of-life care.

34. Dr Nick Miller also pointed to a lack of provision of speech and language therapy in the later stages of the condition, where speech and language therapists “might be expected to play a key role in dysphagia [swallowing problems] management and the provision of alternative or supplementary means of communication.”

Social care
35. Evidence from people with Parkinson's disease and carers highlighted how aids and adaptations provided by social services had enabled individuals to maintain independence and also how care services provided at home enabled people to continue living in their own homes. Evidence from the PDS pointed to the cost-effectiveness of low-level early interventions in social services support.

36. However people with Parkinson's disease and carers from across England, Wales and Northern Ireland reported great difficulty in accessing the social care support they needed.

37. The PDS submission also highlighted evidence of significant unmet need for social care services from its 2007 Members’ Survey. A particularly high level of unmet need was identified in Northern Ireland: of the 31% of respondents who needed home help services, more than two-thirds (38%) had not received these. This was more than 10% higher than the UK average, where just over a quarter (28%) of those who needed home help did not receive it9.

“...at the moment there are probably between seven and eight patients on whom they have no information. He said he has three or four patients he cannot refer because he is completely uncertain about the funding.”

(Former carer, Lisburn, NI)

“My only involvement with Social Services was [with] regards to a seat for the bath and I had to wait 16 weeks for this.”

(Person with Parkinson's, Cumbria)
38. Of all social services, evidence to the Inquiry highlighted that access to aids and adaptations was particularly variable. The PDS pointed to a series of focus groups they had held across the UK, in which many individuals had identified long waits for equipment as one of their main concerns. Many people with Parkinson's disease highlighted to the Inquiry how they had experienced long waiting times for this service, although fortunately some reported a better experience.

39. In their written evidence, the PDNSA commented that many people with Parkinson's disease have difficulties accessing aids and adaptations, with people often waiting many months for these. They also identified wheelchair provision as a serious concern, an issue that was also highlighted by a number of people with Parkinson's disease.

**Carers' support**

40. Figures from the PDS evidence provide a picture of the role played by carers of people with Parkinson's disease from their survey of over 3,000 carers: over half (55%) had been caring for five years or more. Nearly two-thirds (63%) of carers were caring for 50 hours a week or more, with just over a fifth (21%) caring for fewer than 20 hours per week.

41. Arranging support services for carers proved particularly difficult, with carers describing “a feeling of abandonment and loneliness”, with some reporting that they had “never at any time been offered or given help”.

42. Many carers said they were not getting the respite care services they needed due to funding restrictions in many areas. Denise Maule, a carer providing round the clock care for her husband who has Parkinson’s disease and dementia, described in oral evidence to the Inquiry how she had eventually managed to access a short period of respite care support after reaching “breaking point”. However, soon after this period of respite, she was informed by social services that she was no longer eligible, despite her need being ongoing.

43. Access to breaks from caring, and the suitability of the respite care that was available, were highlighted as a concern in the oral evidence session about services in Northern Ireland. Irene Falloon, a carer from Hillsborough, commented:

“It is difficult to put into words the feeling of abandonment and loneliness I feel... Carers have enough to cope with without the constant battle to get some attention for their loved ones.”

(Carer, Hemel Hempstead)

44. The need for appropriate respite was also identified as an issue in a number of responses which highlighted the importance of respite services being able to meet the needs of people with this complex and fluctuating condition. The Welsh Neurological Alliance highlighted this issue in their submission:

“Carers of people with neurological conditions receive less respite than carers of people with other conditions because of difficulties in recruitment of care staff with expertise in specific neurological condition needs.”

45. The need for emergency planning was highlighted by many carers, which would set out how the person with Parkinson’s disease for whom they cared would be looked after, should they experience an emergency such as a hospital admission. This would bring important cost benefits – for example the potential to prevent unnecessary admissions to hospital for people with Parkinson’s disease as a result of their carer experiencing an emergency.

“It is difficult to put into words the feeling of abandonment and loneliness I feel... Carers have enough to cope with without the constant battle to get some attention for their loved ones.”

(Carer, Leicester)
46. However, a number of carers and people with Parkinson’s disease described the way support was lacking when they most needed it. One carer in London commented:

“I have to go to hospital for an operation [but] no one can explain to me what respite to expect. So how can I plan for this event? I need to arrange care for my wife. I need to arrange care for me… The response is – ‘[you] need to fill out new re-assessment..., [have a] social worker visit..., [get an] appointment in ten days’ – then forms are reviewed by a panel some time later. How can I plan?”

47. A person with Parkinson’s disease from Poulton-le-Fylde who was cared for at home by her husband described how, when her husband had an accident and broke his hip, no support was provided to the couple:

“I asked how I was supposed to cope not only with my own illness but also to look after my husband. I was told ‘contact us if you get into too much of a mess’. I feel very strongly that I should have been provided support over that period.”

48. The PDS commented that recent focus groups they had carried out highlighted that most carers would like to have an emergency plan in place, yet only one of the carers spoken to actually had one. Carers reported having to cancel their own medical appointments because alternative care was not provided.

**Conclusion**

49. It is clear there are major inequalities in access to the full range of services for people with Parkinson’s disease and carers. We conclude that there are systemic problems throughout England, Wales and Northern Ireland with many areas falling below those standards set out in the NICE guideline, and in some areas significantly below. We also conclude that the NSF for Long-term (Neurological) Conditions is not being implemented in many areas in England.

50. Although assessments of carers’ needs is being undertaken to comply with regulations, too often no action is being taken and no funding follows. We question the cost efficacy of this approach.

**Recommendations**

51. Commissioners, planners and health service managers responsible for services for people with Parkinson’s disease across England, Wales and Northern Ireland should audit their services against the NICE guideline.

52. Local Authorities and Primary Care Trusts in England should also audit their services against the NSF for Long-term (Neurological) Conditions.

53. Where services are found to be below the standard set out in the NICE guideline and, in England, the quality requirements of NSF for Long-term (Neurological) Conditions, plans should be made to improve services in line with these standards.

**Preventative services and early intervention**

54. Evidence to the Inquiry highlighted the benefits of early and ongoing access to a range of services including physiotherapy, speech and language therapy and social care services such as aids and adaptations in maintaining independence and quality of life. This showed how a preventative approach to a progressive condition like Parkinson’s disease is cost-effective by avoiding unplanned admissions to hospital and supporting people in the community for longer. However evidence revealed that in many areas these interventions are not available until too late, or not at the level required to be of benefit.

**Therapy services**

55. Dr Nick Miller provided evidence about the importance of seeing patients from the point of diagnosis to prevent, or delay, many serious complications that may be experienced by people in the later stages of Parkinson’s disease, such as swallowing problems and malnutrition, as well as speech problems. However his research findings highlighted major shortfalls in preventative interventions:
“In general, responses indicated referrals occurred too late and important opportunities for delaying or rehabilitating communication decline were being missed... Greater awareness is required amongst referrers of communication and swallowing changes in PD and how they can be managed.”

56. Bhanu Ramaswamy, consultant physiotherapist in intermediate care in Derbyshire and post graduate lecturer at Sheffield Hallam University, outlined how early referral to physiotherapy services for people with Parkinson's disease can help avert crises, such as falls. She also echoed the importance of early intervention:

“... just getting into general activity early and keeping active is going to be one of the biggest pushes rather than waiting until crisis point when they are at stage three... [to refer] to the therapist. It has to come from the beginning, from diagnosis.”

Aids and adaptations
57. Evidence to the Inquiry from many people with Parkinson's disease, the PDS and PDNSA highlighted a significant level of concern about long waiting periods for aids and adaptations to help individuals remain independent in their own homes. The PDS evidence outlined that these long waits can result in earlier deterioration of both the person with Parkinson’s disease and their carer’s health; they regularly hear from carers who have developed back problems from lifting the person they care for without hoists, whilst waiting for these to be fitted.

58. The PDNSA highlighted that the long waits were leading to many individuals purchasing their own equipment. The PDS commented:

“...The current system includes a perverse financial incentive on local authorities not to address long waiting lists, as people are frequently forced to pay for their own adaptations to avoid the wait, thus saving the authority money.”

59. Evidence from the PDS pointed to people purchasing aids and adaptations without obtaining professional advice. This may result in the purchase of inappropriate equipment, with consequences for the safety of the individual.

Conclusion
60. The value of therapy and social care services in the management of Parkinson's disease is not being recognised by many health and social care professionals making referrals to, and delivering, these services. This can result in early decline in an individual's condition, and impact on the carer's health. This has implications on quality of life and cost effectiveness of health and social services. There is strong evidence that the current provision of services at a later stage or after long waits is a false economy.

Recommendations
61. Professional and patient organisations should raise awareness amongst professionals who make referrals of the benefits of a preventative approach to services for people with Parkinson's disease.

62. Commissioners and planners of health and social services should consider the long-term cost implications of providing services that only respond to those with high end needs, and the benefits of a more preventative approach for Parkinson's disease services.

Information, self care and knowing how to access services
63. A large number of submissions to the Inquiry from people with Parkinson's disease and from carers highlighted how information and signposting to services were critical to managing their condition effectively. A number of submissions also highlighted the value of self-care courses in helping people to manage their own condition.

Information about living with Parkinson's disease
64. Evidence from people with Parkinson's disease and carers revealed significant unmet need in terms of information about their condition.
65. The Neurological Alliance, an umbrella organisation for charities representing people with neurological conditions, also highlighted the fact that people wanted a point of contact within their care team. Referring to a survey conducted by the Alliance\(^{11}\) Lucy Brazg, their Chief Executive, stated:

"...a large number of respondents said that what they would really have liked to have was a contact number with the specialist team [so]... that they would have a chance to go back and ask those kind of questions and remain in on-going contact with that team in its broadest sense."

**Signposting to services and support**

66. One of the key themes that emerged from submissions to the Inquiry from people with Parkinson's disease and carers was that they did not know how to access services, particularly social services support. Many people did not know about their right to an assessment of need for care services, and many also wrongly expected that social services would approach them proactively. There is a sense that many people feel they have to “fight” for information about, and how to access, services, and are not being directed to other services by health and social care professionals.

67. Irene Falloon, a carer from Hillsborough, Northern Ireland, told the Inquiry how other carers locally came to her for advice about accessing services:

"I had been a district nurse in the area and I knew who to go to, but my experience with other carers in the branch is that they phone me, probably because of my nursing background and say ‘What do I do here?’ Their GPs do not seem to have the time I would say...”

68. Lucy Brazg outlined research they conducted last year on access to information for people with neurological conditions\(^{12}\), which revealed that people were not being directed to relevant patient support organisations when they were diagnosed.

"Over a third of people said that they left the appointment at which they received their diagnosis with really very little understanding of what their condition entailed, but also without contact details for a patient support organisation."

69. Professor George Kernohan, who is conducting research into palliative care provision for people with Parkinson's disease, outlined that people were not clear about what palliative care services were available to them. This was in part attributed to a perception of palliative care as terminal and end of life care.

70. People with Parkinson's disease and carers also spoke of not knowing when to seek the support of social services. Brian Lymbery, a person with Parkinson's disease who provided oral evidence to the Inquiry, commented that information about what to expect and what services and support is available is particularly crucial because of the progressive nature of the condition:

"One of the challenges of Parkinson's is that things creep up on you, and you suddenly find something else does not work or something else seems to be going wrong. If you have got the information, you can be prepared for that and that makes it a lot less scary to deal with, and it means that you are less likely to take yourself off to A&E... to reassure you that the problem you are going through now is one that can be handled...”

71. A carer from Devon commented:

"I am not sure about when to obtain support and what the implication of having support will be. How bad do things have to..."

\(^{11}\) "Information is not automatically available... I feel it is very important to have guidance as to where and how to access information."

(Person with Parkinson's)

\(^{12}\) "It has been necessary to make personal investigations as to what is available to match, and supply help for, the ongoing changes in Parkinson's disease. Also it is helpful to join a Parkinson's group and make use of all the available literature and ask questions."

(Carer, Norwich)

\(^{13}\) "I have found that I have to pursue help and support rather than it be automatically available. This has often taken a great deal of time and is not easy for someone who is disabled. Stress can be a major factor for those people with Parkinson's. Information that is needed about services should be available easily and quickly, rather than having to be searched for."

(Person with Parkinson's, Bromsgrove, Worcs)
get? I have seen leaflets but generally I feel I have to get on with the task of caring on my own and make the best of the situation."

72. Evidence also shows that many carers are not receiving necessary information about support for their role. Denise Maule, a carer who provided evidence to the Inquiry, spoke about how in her own experience information about carer support services, and specifically respite care, was only made available to her once she had already reached breaking point. Denise identified that the most important thing that could be done for others in her situation was to have information provided about what services are available, and how to access them.

73. The PDS submission also provided further evidence that carers were not getting access to appropriate information about services and support (see table on p9).

### Conclusion

74. Information provision is a key component of quality health and social care services. However it is clear that many people with Parkinson's disease and carers are not receiving the information and signposting that they need. This demonstrates that many services are not meeting standard of care set out in the NICE guideline, and, in England, the quality requirements of the NSF for Long-term (Neurological) Conditions, covering information provision.

75. There is strong evidence that people are not being signposted to social services in particular. Parkinson's disease is a progressive condition, requiring more and more complex interactions with health and social care over time. Therefore it is important that people with Parkinson's disease and carers receive information about what to expect, how to manage their condition and how to access the full range of services they may need as their condition develops.

### Recommendations

76. All health and social care professionals working with people with Parkinson's disease and their carers should take responsibility for ensuring individuals' information needs are met as a key aspect of their role, including signposting people to other relevant services. In particular health professionals working with people with Parkinson's disease and carers should ensure they provide information about how to access social care services wherever relevant.

77. Commissioners and service planners should specify, as a key requirement, the need for services to provide information and signposting, and ensure services fulfil this role through monitoring.

### Integrated services

78. Much of the evidence to the Inquiry highlighted that services are not fully joined-up around the needs of people with Parkinson's disease and carers. As Professor Carl Clarke, Professor of Clinical Neurology at Birmingham City Hospital, commented:

> “There is a lack of integration of local rehabilitation services, social services, GP, and hospital-based services. This has not improved since the publication of the NSF for Long-term Conditions.”

79. The PDS submission identifies that the lack of joined-up working between health and social care, including limited use of joint working such as joint assessments, results in users becoming confused about where to go for help and missing out on support.

80. The British Psychological Society called for greater integration between mental health services and neurology services:

> “Where clinical psychologist/neuropsychologists are not embedded within multidisciplinary teams, greater links are required between neurology services and local mental health services... New
developments in service provision could include psychiatric/psychological liaison services for people with non-
dementia neurological disorders.”

81. The PDS submission pointed to a National Council for Palliative Care survey which identified a lack of clear links between long-term conditions services and palliative care services and a reliance on informal links.

82. Barbara Howe, Director of Specialised Commissioning, London Specialised Commissioning Group, commented that person-centred commissioning processes, such as those set out in the Motor Neurone Disease Association Year of Care package, provide better outcomes for the individual. She outlined that commissioning a package of care for an individual would help ensure people with long-term conditions receive all of the key elements of care, with individuals told at the point of diagnosis the services they should expect to receive. She added:

“I think… a much more sensible way to commission [would be] to actually commission for that person rather than…[as at present] a range of services and just hope that people manage to dip in and out…”

**Conclusion**

83. Evidence to the Inquiry indicates that services are commissioned and planned in segments rather than across the full patient pathway, pointing to a lack of integration between services.

**Recommendations**

84. Commissioners and service planners should work to develop service specifications for integrated models of service delivery which reflect the holistic needs of people with Parkinson’s disease.

85. Governments in England, Wales and Northern Ireland should work with patient and professional groups to develop a blueprint for Parkinson’s disease services for commissioners and service planners.

**Training and awareness of Parkinson’s disease amongst professionals**

86. A strong theme to emerge from the evidence was that, due to the complexity of the condition, health and social care professionals involved in the management of Parkinson’s disease require an appropriate level of training and experience. As a consequence, people with Parkinson’s disease, their carers and general health and social care professionals should have access to professionals with specific expertise in the condition.

87. One of the key themes to emerge from evidence to the Inquiry was a lack of knowledge and understanding about Parkinson’s disease amongst many health and social care professionals.

88. The PDS submission highlighted concerns amongst people with Parkinson’s disease and carers about professional awareness of the condition. They commented:

“The PDS Members’ Survey highlighted concerns about knowledge of Parkinson’s among health and social care professionals, with only 19% of those responding feeling that doctors, nurses and other hospital staff understand the condition very well. The PDS believes that poor awareness of Parkinson’s amongst health and social care professionals can be a detrimental factor in terms of people with Parkinson’s accessing appropriate services.”

89. Evidence has highlighted that training is required across the whole workforce involved in the care of Parkinson’s disease, with a particular emphasis on key professional groups.

**Palliative care**

90. Professor Kernohan’s written evidence outlined his research findings into palliative care provision for people with Parkinson’s disease15, which identified a lack of recognition amongst health and social care professionals of the palliative care needs of people with the condition.

“Many were ok but a lot of Carers who visited my husband did not deserve the name Carer. My husband would say “they treat me like a lump of meat on the slab…” Often the care plan was ignored, using the wrong straps on the hoist to lift him into his wheelchair [which] left him in an impossible position.”

(Former carer, Bexleyheath)
Mental health

91. The PDS provided evidence on professionals’ awareness and understanding of the mental health aspects of Parkinson’s disease, from a Department of Health funded project they conducted looking into the mental health training needs of a range of different health care professional groups. This revealed:

- mental health symptoms are given less of a priority than physical symptoms of Parkinson’s disease by health and social care professionals
- understanding and awareness of the mental health aspects of Parkinson’s disease is inadequate, leading to low levels of diagnosis and subsequent referral
- a high level of uncertainty about identifying mental health symptoms of Parkinson’s disease and interactions between the condition itself and other drugs. Around a third of professionals identified they were not confident in these areas
- 70% of the professionals surveyed identified a training need around dementia
- approximately one third of professionals are not confident in identifying the mental health symptoms associated with Parkinson’s disease. The level of confidence varies by professional discipline
- amongst general nurses and mental health nurses approximately one third are unsure about the side effects of both mental health and anti-Parkinson’s disease drugs.

General practitioners

92. Many professionals who provided evidence to the Inquiry noted the important role played by GPs in the coordination of care for people with Parkinson’s disease. Dr Graham Venables, President of the ABN, emphasised the importance of specialists “working jointly with primary care”, and endorsed the Royal College of Physicians’ work on ‘teams without walls’:

“...[joint working] is bringing down the barriers between primary and secondary care and moving specialist services into the community in partnership with primary care.”

93. Clinicians, such as Dr Paul Worth and Dr Paul Morrish, outlined the important role that should be played by GPs in the care of people with Parkinson’s disease, in their capacity as professionals who often know the individuals and see them relatively often. The PDS also highlighted their role in the management of non-motor symptoms such as depression, anxiety, sleep disorders and urinary and digestive problems, and in signposting individuals to other key services.

94. However, evidence from a number of sources identified a knowledge gap amongst GPs. The PDS pointed to findings from a recent skills audit they had conducted which identified a particular area of concern as being GPs’ ability to identify and manage the non motor symptoms associated with Parkinson’s disease. Half of the GPs participating in the audit stated that they were not confident in their abilities to identify these symptoms.

95. The Welsh Neurological Alliance written evidence also drew attention to this issue:

“Concern has been expressed about the general lack of understanding of neurological conditions by GPs. There is often a delay in GP referral to a neurologist because the presenting problems are not recognised as arising from a neurological condition, and patients consider GPs’ lack of condition specific knowledge impairs the delivery of good after care.”

96. Dr David Craig, Consultant in Elderly Care at Belfast Health and Social Care Trust, commented:

“GPs’ comfort levels with Parkinson’s disease are historically low... Implements such as shared care guidelines or clear referral pathways, better liaison and education with GPs... will increase the comfort levels.”

97. Many submissions from people with Parkinson’s disease and carers also pointed to a lack of understanding about the condition amongst GPs.

Therapy services

98. Dr Nick Miller revealed a major shortage in the number of speech and language therapists with experience and expertise in treating people with Parkinson’s disease. His research identified that very few speech and language therapists have any involvement with people with the condition, and, even in major centres, the number of people with Parkinson’s disease on speech and language therapists’ caseloads is tiny compared to the number that would be expected.
99. The research also highlighted that assessment of people with Parkinson's disease falls short of Royal College of Speech and Language Therapy guidelines, and concluded that speech and language therapists “require a greater awareness and training regarding appropriate assessment tools and techniques”. However Dr Miller identified that “the workforce is, and perceive themselves to be, undertrained in the treatment of people with PD” and that a high proportion of both specialist (76%) and general (75%) speech and language therapists wanted further training.

100. The PDS evidence also highlighted a project they had carried out on therapy provision. This revealed a lack of knowledge amongst therapists on best practice, with the absence of agreed protocols for managing Parkinson's disease within the different therapy disciplines resulting in a lack of focus for postgraduate training. The project also identified a lack of short programmes that are profession-specific to act as an introduction to Parkinson's disease for clinical staff, and variable access to funding and opportunities for education and training for therapists across the UK.

Social care workforce

101. Many people with Parkinson's disease and carers commented that domiciliary care staff often do not demonstrate skills and knowledge in care for the particular needs of people with the condition. Lucianne Sawyer, President of the UK Home Care Association and former carer of her father who had Parkinson's disease, highlighted to the Inquiry that independent agency care workers are not informed about a person's condition due to 'confidentiality issues'. These paid carers are therefore unable to meet the specific needs of people with Parkinson's disease.

102. Similar issues exist in relation to the education and training of care home staff. Sue Thomas, from the RCN, commented:

“There is a huge shortfall in education in nursing homes and care homes. A lot of care assistants would benefit greatly from being taught about how to manage people with Parkinson's disease.”

103. A skills audit carried out by the PDS revealed that social work participants highlighted significant training needs around the physical, mental and social care aspects of the condition.

Conclusion

104. There is a large body of evidence demonstrating major shortfalls in the general health and social care workforce regarding the knowledge and skills needed to care for people with Parkinson's disease.

Recommendations

105. Service managers should ensure that all professionals involved in the care of people with Parkinson's disease are able to take up education and training opportunities in the condition, including those provided by the PDS.

106. All GPs and care home professionals should take up education and training opportunities available to them through the PDS.

Other areas of inequalities

People with Parkinson's disease in care homes

107. A range of professionals raised concerns about access to appropriate health care services for people with Parkinson's disease resident in care homes.

108. Professor Burn talked about there being “lost tribes” of people with Parkinson's disease in care homes:

“One would have to say the nursing home population is always a recurring area which is neglected, sadly... It need not necessarily be that we expect them [care home staff] to be doing huge amounts for these people but to have an awareness and to be referring on to Parkinson's nurse specialists.”

109. Dr Duncan Forsyth, Department of Medicine for the Elderly, Addenbrooke's Hospital, echoed this point:
“The general poor medical supervision of care home residents may also mean that such individuals are not recognised as having PD or become lost to specialist follow-up.”

110. Dr Nick Miller provided evidence that many people with Parkinson’s disease in care homes were not receiving therapy for swallowing problems, although they are likely to have a need for this service:

“Services by Speech Language Therapists into nursing homes are very patchy; but there are some good services where they actually do deliver services into nursing homes, not just one to one with the person with Parkinson’s disease, but in training up care assistants and the people working with the person with Parkinson’s disease in the nursing home, around swallowing, around nutrition, around mealtimes and the type of meal and consistencies of food and timing in relation to drug doses and whatever.”

People with Parkinson’s disease from black and minority ethnic communities

111. Other evidence provided by Race on the Agenda (ROTA), the Delivering Race Equality Programme at the National Mental Health Development Unit and the PDS indicates that people with Parkinson’s disease from black and minority ethnic communities may not be receiving appropriate services for their condition.

112. The written evidence from ROTA highlighted that people from black and ethnic communities may be less likely to access services for the mental health aspects of their condition, due to negative perceptions about how they will be treated. They commented:

“It is well documented that people from BAME [black and minority ethnic] communities, and African Caribbean people in particular, fare worse under the mental health system… The implications that this may have for people who experience depression, for example, as a sufferer of Parkinson’s disease, or as one of their carers, is very important. The support for improved mental health of BAME communities is crucial if they are able to take on the challenges of conditions such as Parkinson’s disease and manage the impact that it can have on their lives. If mental health services are not improved it reduces the likelihood of BAME people seeking their support, alongside other health services when coping with an illness such as Parkinson’s.”

113. ROTA and the Delivering Race Equality Programme evidence highlighted that people from black and minority ethnic groups were often subject to multiple forms of discrimination. ROTA observed that many people from these communities:

“… have multiple needs and can suffer from discrimination based on more than one aspect of their identity; gender, ethnicity, age, disability, sexuality, income, family and social networks, beliefs, material circumstances, nature of migration, area of living, type and level of care needed. Many BAME people have unmet needs which affect their participation in wider society. ROTA has not witnessed yet a culture where healthcare services respond to BAME people’s needs in a way that promotes independence and acknowledges their individuality.”

114. Both ROTA and the Delivering Race Equality Programme evidence strongly recommended that people from black and ethnic community groups are involved in the development of services. And the Delivering Race Equality Programme noted that in their view a key aspect to improving access was:

“good data collection and monitoring at a local and regional, as well as national levels to improve awareness of diverse population’s needs.”

115. A PDS project on reaching black and minority ethnic groups found that:

- many community organisations for people from these communities did not understand or know about neurological disorders and did not therefore direct people who use their services to specialist organisations or to their GPs

- many people from those communities held GPs in very high esteem and would not ask their GP if they could see a specialist so, if GPs did not refer them, the patients themselves wouldn’t challenge or ask for this
people's experience was that where a GP does diagnose a neurological disorder (or is persuaded that there is one present) there is no reference to the support services that could be offered by neurological charities

sessions with volunteers and staff at black and minority ethnic community organisations showed that people seemed largely to get support from the family and faith groups. The only reference to clinical services was with regard to GPs and this was usually in terms of misdiagnosis.

**Conclusion**

116. Evidence has highlighted particular concerns about how far people with Parkinson's disease from black and minority ethnic groups and people living in care homes have access to appropriate health and social care services.

**Recommendations**

117. Commissioners and service planners must ensure that people from black and minority ethnic communities are involved in the development and review of services to ensure these meet their needs, working through community groups as appropriate.

118. Commissioners and service planners should ensure that services are signposted effectively to black and minority ethnic communities and that uptake of services by these groups is monitored.

119. Commissioners and service planners must ensure provision is made for full access to appropriate services for people with Parkinson's disease in care homes.
Section 2: What are the barriers to a universally good service?

Lack of leverage of Parkinson’s disease and neurological policy

NICE clinical guideline on the diagnosis and management of Parkinson’s disease

120. Section 1 of this report has indicated key areas in which the services set out in the NICE guideline are not being delivered. For instance:

- major shortfalls in access to Parkinson’s disease nurse specialists in many areas, and in particular across Northern Ireland and Wales
- poor access to therapy services
- surgical interventions not being available in some areas, with major concerns about access across the whole of Wales.

121. Commissioners, professional groups and clinicians highlighted that that the degree to which the NICE guideline has been implemented across England, Wales and Northern Ireland has been very inconsistent. For instance, the ABN submission commented:

“Despite the ABN having been involved in the NICE guideline’s development, we are still left feeling that they has [sic] made little impact, perhaps because they are perceived as being of little relevance to real life practice, possibly because of lack of widespread awareness.”

122. Dr David Craig commented on take-up of the guidance in Northern Ireland:

“Implementation and adherence to the guideline has been patchy. There are some aspects, for example in terms of access to drugs, funding for therapies such as neurosurgical interventions, which have been without problem, but in terms of maintaining audit standards whereby people get an assessment for physiotherapy by a physiotherapist at diagnosis, or an occupational therapist at diagnosis, or yearly follow-up assessments by those sorts of allied health professionals, that does not happen in a very common way at all.”

123. Dr Craig also commented that, apart from the announcement that the NICE guideline had been adopted in Northern Ireland, there are no measures to drive or monitor implementation.

National Service Framework for Long-term (Neurological) Conditions

124. The Inquiry heard evidence from Dr Chris Clough, neurology adviser to the Department of Health and consultant neurologist, that – unlike policy for other condition areas – responsibility for overseeing implementation of the NSF for Long-term (Neurological) Conditions has been completely devolved from the Department of Health to a local level. Dr Clough commented that the NSF:

“...has now been rolled out, if you like, to be implemented by the PCTs/strategic health authorities. It is still there, embedded in the system, but there is no longer a central team making sure that it is being implemented in the usual way of things.”

125. A number of other witnesses to the Inquiry commented on the ways in which neurology policy differed significantly from Government policy for other condition areas, such as the stroke strategy and coronary NSF, in that it did not have the same level of resources or measures to drive implementation.

126. While other strategies and frameworks have had clear targets attached to them, the NSF for Long-term (Neurological) Conditions had looser descriptions of what services should consist of, called quality requirements. Dr Clough himself commented:

“Our NSF did not have any fixed standards in the same way as perhaps diabetes did or other NSFs. They are “quality” requirements, so the way you interpret it might be crucial...”
127. Dr Venables, President of the ABN, compared the low impact that the NSF for Long-term (Neurological) Conditions has had, to the coronary NSF and Stroke Strategy. He outlined that both of them had very clear targets and short time frames, which were achieved “very quickly and very effectively,” and that:

“Oh, once you move from targets to quality standards and down the line to softer and softer end points, people do not achieve [these]...”

128. Commissioners also provided evidence that frameworks such as the NSF that don’t have targets attached to them are given a lower priority. Janet Lewis, Assistant Director Commissioning and Quality, East and North Hertfordshire PCT and West Hertfordshire PCT, explained:

“I think there is competition for funding, out in PCT land. Obviously things that have national targets to them do attract some degree of importance within the PCT, and particularly things around the Healthcare Commission and fair policy standards... would be prioritised. The fact that there is no specific target relating to the NSF and NICE guidance makes it not as high on a PCT’s agenda as it might otherwise be.”

129. Liz Wolstenholme, a person with Parkinson’s disease who was also a retired senior civil servant in the Department of Health, commented that, in her opinion, conditions such as Parkinson’s disease were not considered a priority when performance measures were set:

“Performance measures in the NHS focus on the fast changing high profile conditions amenable to quantification. In my experience it was never the standards of care for vulnerable groups of long-term patients that made or broke careers within the NHS.”

Inspection and monitoring of NICE and the NSF for Long-term (Neurological) Conditions

130. Evidence to the Inquiry clearly highlighted the lack of monitoring of implementation of NICE and NSF for Long-term (Neurological) Conditions as one of the key factors behind the stark variations in services we have described in Section 2.

131. A range of clinicians such as Professor Carl Clarke and Dr David Craig provided evidence that the existing framework for ensuring implementation is inadequate.

132. A number of clinicians commented that enforcement of the NICE guideline should be strengthened. Dr Graham Venables, from the ABN, highlighted the lack of impact of NICE Guidelines for Parkinson’s disease:

“...This is the problem with the NICE guidelines. They are guidelines, it is not NICE guidance, it is non-mandatory.”

133. Professor Carl Clarke commented in his written evidence:

“If Government is serious about NICE treatment guidelines then it must make implementation mandatory and PCTs must be forced to comply. The existing framework for ensuring implementation is clearly inadequate.”

134. Dr Chris Clough, Neurology Adviser at the Department of Health, also alluded to this point but did not consider it a practical solution:

“...clearly it would help if it were mandatory, but practically speaking... a huge shift... would be required to do that, to make them mandatory, in terms of resource and how to allocate resource.”

135. Respondents indicated strong support for greater inspection and monitoring in this area. For example Dr Venables, of the ABN, identified the need to drive PCTs that are under-achieving and under-commissioning, and called for better monitoring:

“These very long ten-year time-frames, for example, for the long-term conditions NSF need very regular monitoring.”

136. Lucy Brazg, Chief Executive of the Neurological Alliance, called for national reports on the performance of services as a measure that could alleviate some of the more stark disparities between services for people with neurological conditions. She suggested that making the performance of local services available at a national level would “make a great difference” to the quality of services.
Dr Craig endorsed the idea of national level monitoring of the NICE guideline:

“There is no national audit and I think that is one of the things that the Northern Ireland Executive could do as well as engage in the review process. The development of a national strategy within Northern Ireland… to audit what is happening with the NICE guidelines. I think there will be fairly striking gaps.”

On monitoring implementation of the NSF, Dr Clough commented that there were no plans at present to review this, but outlined his expectation that the Care Quality Commission (CQC) will take responsibility for this. The CQC’s predecessor, the Healthcare Commission, outlined in their evidence to the Inquiry plans to conduct a survey of neurology services; however the PDS submission raised concerns about the loss of focus on monitoring national guidelines in the work programme of the recently merged organisation.

**Conclusion**

2010 will mark the half way point of the NSF for Long-term (Neurological) Conditions’ ten year implementation period. Evidence to this Inquiry has highlighted major concerns that this strategy is not considered a priority at a local and Government level and implementation has been extremely inconsistent.

The NICE guideline sets out evidence-based good practice for Parkinson’s disease services, against which health service managers, commissioners and clinicians can measure their performance and accordingly develop services. However, this Inquiry has seen evidence that services in many areas do not yet meet these standards, and there is a lack of impetus behind implementation. The fact that the NICE guideline is not mandatory and that there are no financial incentives for implementation has been particularly highlighted.

**Recommendations**

1. The Government should conduct a review of the NSF for Long-term (Neurological) Conditions to measure progress made towards implementation at this half-way point, against its 11 quality requirements for health and social care.

2. The Welsh Assembly Government should outline a clear timetable for implementation of the recommendations of the Welsh Neuroscience External Expert Review Group and how it intends to monitor outcomes.

3. The regulators across England, Wales and Northern Ireland should introduce measures to ensure services and commissioning and planning processes are monitored in relation to their adherence to the NICE guideline and that there are stronger drivers for implementation.

4. Consideration should be given to seeking mechanisms to ensure stronger incentives are in place to encourage implementation of the NICE guideline.

**Leadership for improving Parkinson’s disease services**

**National leadership**

A number of organisations called for greater leadership to be taken at a national level to oversee improvements in services for people with neurological conditions, including implementation of NICE guideline for Parkinson’s disease across England, Wales and Northern Ireland, and the NSF for Long-term (Neurological) Conditions in England.

Dr Clough provided evidence to the Inquiry about where the leadership has rested for the NSF within the Department of Health since its publication:

“We did have a small central team for a while, but the last NSF did not get central funding, and so it was expected that those NSFs would be a part of and inform other policy initiatives”.

On the question of where leadership lies for overseeing this policy area within Government, Dr Clough commented:
“Initially we were under the social care directorate and the leadership fell within the [responsibilities of the] elderly care tsar at that time. In retrospect we did not make a lot of progress at that time. The leadership now for long-term neurological conditions falls into ‘long-term conditions’. I have to say that one of the problems that we had in the early days was confusion between the two.”

148. Lucy Brazg, of the Neurological Alliance, commented on the role of the existing Department of Health adviser on neurology, an appointment now occupied by Dr Chris Clough: that this role was not a full time responsibility, only accounting for a small fraction of his time, and that the position was not fully integrated into the key decision-making processes within the Department.

149. Barbara Howe commented on the impact of the central teams on implementation of other policies.

“I think it [the NSF for Long-term [Neurological] Conditions] has influenced [services] but perhaps not quite in the same way as some of the other NSFs for, say, cancer or cardio, where they set up large teams and funded directors and administrators; that did not happen with neurosciences.”

150. Steve Ford, Chief Executive of the PDS, summarised his vision for a national level neurology champion as:

“Someone to really champion neurology services, champion the NSF, to be able to speak at conferences and write articles and produce annual reviews and identify good practice and build networks of clinical champions across the UK who all want to move this forward.”

Local leadership

151. The value of champions at a local level and the role of clinician leadership in local service development was highlighted by a number of witnesses to the Inquiry. Steve Ford set out the difference, in his view, that a local champion can have on services:

“I think it has been illustrative that when we identify good Parkinson’s services locally... normally what we find is not sophisticated commissioning arrangements or... a rigorous performance management framework, but we find a neurologist, a geriatrician, a nurse, someone who is able to knock heads together, to develop pathways, to sort out flows of patients around the system. I do not think it is about having budgets necessarily, because I think a lot of the evidence we have seen is that making improvements in Parkinson’s services, [and in all] neurology services, do [sic] not require lots of money; it is about focus and energy and planning and listening to patients and bringing people together.”

152. Dr Chris Clough commented on the importance of local clinical champions:

“I think there is something about how we behave as clinicians, which is to act as champions and advocates for our patients. Part of the reason we have inequitable services, in a sense, is because there are champions in some parts of the UK and there are not in other parts.”

Conclusion

153. There is evidence of a lack of leadership for development and implementation of policy on neurology services at a national level. Evidence points to the positive impact that local clinical champions can have on service improvement in line with the NICE guideline and NSF for Long-term (Neurological) Conditions.

Recommendations

154. There should be clearer lines of responsibility for neurological policy and implementation of guidelines with national leadership at government level in England, Wales and Northern Ireland.

155. Professionals and commissioners involved in the care of people with Parkinson’s disease should identify local leads to drive forward service improvement across both health and social care.
Impact of other policies

156. There is evidence that other policies are having an impact on Parkinson's disease services including waiting time targets and Payment by Results (the funding system for secondary care in England).

Waiting time targets

157. In both England and Northern Ireland, evidence to the Inquiry highlighted some unintended consequences of these targets on Parkinson's disease services.

158. However, support for the principle of waiting time targets, to improve patient's access to care was provided by Dr Venables, President of the ABN:

“The referrals target in terms of the 18-week pathway is a good thing. It has reduced waiting times remarkably for people, both for new patient appointments and follow-up appointments. In most parts of England where these apply you will be seen with Parkinson's disease or any other neurological disease within four to six weeks. That is a huge improvement on five years ago and 108 weeks, or whatever it was.”

159. In addition, Dr David Craig, Consultant in Elderly Care, Belfast Health and Social Care Trust, commented that:

“It does focus the mind, obviously, and targets if they are worked in the right way can have a valuable role in reducing delay.”

160. Despite this, evidence from a number of sources outlined how, in order to meet the 18 week target from referral to treatment for outpatient appointments in England, hospitals have adopted ‘new to review’ ratios, setting out the number of new patients they must see for every patient they are seeing for a review appointment. A range of witnesses provided evidence that this was affecting access to ongoing review for people with Parkinson's disease.

161. The PDNSA submission highlighted the fact that Parkinson's disease nurse specialists working in secondary care had revealed that consultants were being pushed to discharge people with Parkinson's disease from their list of patients who should receive regular follow up appointments, in order to improve their performance against the ‘new to review’ ratio. They commented:

“This is on the pretext that patients don't need regular follow up, despite the recommendation by the NSF that patients require regular review by a specialist. Patients who have been discharged by a consultant will often be referred back within a very short time frame due to the complex symptoms of Parkinson's disease. The patient will be classed as a new referral at this stage, which generates a bigger fee for the hospital than a regular follow up.”

162. Dr Venables provided evidence of the knock-on impact this was having on the appointments of review patients:

“Every week, as a clinical director, I get reports on displaced appointments where people have been told to come back in three months' time or one month's time, and they have [actually] come back in four or six months' time because the slots have been taken by new patients.”

163. Annette Hand, Nurse Consultant at North Tyneside General Hospital, commented:

“Our service policy is never to discharge patients as this is a LTC [long-term condition]. One concern I have is the ‘new to review’ ratio policy in clinics and the pressure to keep to this due to funding issues. There are times when we need to review patients frequently due to problems; we have a steady stream of new referrals into the service but we will always end up with a greater ratio of review people being seen than DH [Department of Health] figures suggest. To overcome this we could discharge our patients back to the GPs to re-refer them when problems arise so we can count them as a ‘new’ again but are reluctant to do this.”

164. Dr David Craig outlined that the nine-week outpatient target for new referrals in Northern Ireland had resulted in similar dis-incentives to provide ongoing review for people with Parkinson's disease. He commented:

“There seems to be a bias towards new patient need and unfortunately review patients who have just as much if not more need get a secondary look in.”

Payment by Results (England)

165. Payment by Results (PbR) is an acute sector funding mechanism in England, where set tariff prices are attached to specific procedures, and the Trusts get paid for each intervention they provide. A number of witnesses
highlighted the impact of this funding system on the ability of services to provide ongoing review to people with Parkinson's disease.

166. The ABN commented:

“This is entirely inappropriate and counterproductive for patients with long-term neurological conditions. Pd [Parkinson's disease], like many neurological disorders, is a life-time condition and we believe that PbR [Payment by Results] in England has been a perverse incentive in the management of patients with chronic conditions with a reduction in the standard of specialist care for people with long-term conditions, including Pd [Parkinson's disease]. Lack of outpatient care is inevitably reflected in increasing hospital admissions.”

167. Dr Peter Fletcher, Chair of the Movement Disorders Section of the BGS commented that this policy resulted in a loss of flexibility for an area of care that demands a flexible approach due to the individual nature of the condition:

“The risk associated with initiatives like Payment by Results is loss of flexibility because every patient is different and the follow-up recipe for each patient is also different, depending on their exact needs.”

168. A number of witnesses, including Barbara Howe, Director of Specialised Commissioning, London Specialised Commissioning, and Annette Hand, Nurse Consultant, North Tyneside, provided evidence that current tariffs also acted as a disincentive for community-based multi-disciplinary services because the tariff for these interventions was not high enough. In addition the RCN outlined that in their view the Payment by Results tariff for the contribution of specialist nurses was inadequate.

Social services eligibility criteria

169. Concerns were raised about the systems used by local authorities to determine need for social services, which in England falls under the Fair Access to Care Services (FACS) framework. Due to a shortage of resources, local authorities in many areas only provide assistance for those who meet the highest thresholds of need.

170. Evidence by the PDS and Lucianne Sawyer, President of the Home Care Association, highlighted concerns that this system produced disincentives for providing preventative social care services.

171. The PDS observed:

“Prevention has a low priority under the current system – by their nature preventative measures are most likely to be appropriate for low and moderate levels of need and the current system means that low-level early interventions are frequently not provided, even though these are often more cost effective...”

172. They also commented that the criteria do not currently include a sufficient requirement to take account of the long-term impact of a condition, and pointed to people's files being marked as closed after the provision of an initial service, such as a one-off respite break or installation of a piece of equipment, despite their ongoing and growing need. They recommended:

“Once identified, a person with a long-term condition should be brought under the umbrella of social services support for the length [sic] of the condition.”

173. Lucianne Sawyer commented that FACS also leads to care being highly standardised, with little room for flexibility to respond to an individual's changing or fluctuating needs.

Carers' policies

174. Patient and carer representative groups provided evidence to the Inquiry that Government resources designated for carers services were not getting through to their intended target. Evidence from the PDS questioned whether the £150 million for breaks for carers identified in the 2008 carers’ strategy, and provided to PCTs in April 2009, was going to reach carers and commented on the lack of monitoring of how these funds were spent.

175. Gordon Conochie, Joint Policy and Parliamentary Officer for Princess Royal Trust for Carers and Crossroads, highlighted a survey they were conducting which indicated that this money was not being allocated on the services for which it was intended. He commented:

“The money is not being ring-fenced and, worse than that, the individual primary care trusts are not being told how much of the £150 million they are receiving. It has just been slipped into their total baseline allocation without any information or guidance being given to the individual primary care trusts.”
176. Gordon Conochie provided evidence of research they had carried out last year which suggested only a small fraction of the Carers Grant was being spent on carers’ services.

**Conclusion**

177. Evidence to the Inquiry highlighted that Government policies on waiting time targets, Payment by Results in England and frameworks for eligibility criteria for social care services were having unintended consequences on the delivery of services for people with Parkinson’s disease and their carers. It is also clear that policy making around carers’ services was not always having the desired effect.

**Recommendations**

178. Governments in England, Wales and Northern Ireland must have regard to the impact of new policies on services for people with long-term neurological conditions such as Parkinson’s. This includes the setting of new Payment by Results tariffs (England) and eligibility criteria for social care.

179. In addition, the setting of targets and policy milestones, for example, waiting time targets, must accommodate the needs of people with progressive conditions for ongoing management and support.

**Commissioning and planning services**

180. A number of obstacles to commissioning Parkinson’s disease services were highlighted to the Inquiry.

**Commissioning across boundaries**

**Commissioning across localities**

181. A number of witnesses highlighted difficulties in engaging primary care commissioning processes, such as practice-based commissioning in England, for the commissioning of service for people with Parkinson’s disease.

182. A recurrent theme amongst commissioners and clinicians (such as Dr Worth) was that because Parkinson’s disease is not a hugely prevalent condition it was a challenge to get this on the agenda of commissioners. Evidence pointed to particular challenges with Practice Based Commissioning in England in which GP practices can commission services.

183. Janet Lewis explained:

   “We have got 11 practice-based commissioning groups and that can be a challenge. Bringing all the different locality-focused groups together with something like Parkinson’s disease… You have got to work with a number of groups and bring them together into a cohesive decision-making group; and that is quite challenging…”

184. A further obstacle that was identified in the evidence was that, because each GP practice only has a few people with Parkinson’s disease on their books, commissioning services for people with this condition was not high on their priorities.

185. Dr Chris Clough commented on the importance of getting PCTs to work together to commission services:

   “That is a real problem because some of the PCTs are quite small and so their capability and capacity is not as good as some [other PCTs].”

186. Janet Lewis recommended introducing measures to ensure Practice Based Commissioning groups work in partnership with other groups to commission services across a wider area.

187. Collaborative commissioning is also key to the success of commissioning highly specialised services that are high cost and low volume such as Deep Brain Stimulation. Dr Graham Venables, President of the ABN, commented that the success of specialised commissioning arrangements for neurosciences still reflects the success of commissioning collaborations formed ten years ago when the national specialist services definition was devised:
“Some of those collaboratives got off the ground, some did not. Those that did, by and large, for example the Kent model based on King's and certainly the South Yorkshire model and the Liverpool model and others, have been very effective in developing services. Where collaborative commissioning failed to get off the ground, services, by and large, are a long way behind. That was a failure of central direction to ensure that collaborative commissioning worked, because it does work.”

188. This suggests a lack of effectiveness of commissioning across boundaries for these services in the past decade.

**Between different services**

189. Many submissions to the Inquiry point to a lack of integration between different aspects of services for people with Parkinson's disease and carers.

190. Janet Lewis highlighted how commissioners were still: “in our infancy in joined-up commissioning if I am being truthful.”

191. Although she identified that the recent commissioning framework in England, World Class Commissioning, was helping commissioners, she admitted that:

> “We are still probably commissioning a little bit in silos even though we are commissioning together as an organisation. [For example] you will get a commissioner that commissions for mental health..., long-term conditions commissioners..., acute services commissioners..., and then the specialist commissioners that commission... tertiary [care services]. We need to do much more work about joining up [commissioning] across pathways.”

192. A range of witnesses to the Inquiry, including commissioners, the PDNSA and John Nawrockyi of the Association of Directors of Adult Social Care (ADASS), attributed the piecemeal approach to commissioning the range of services for people with Parkinson's disease to the separation of health and social care budgets. Barbara Howe explained that there was a lack of incentive to commission across the boundaries of health and social care because the benefit (in terms of cost savings) of an intervention funded by health budgets may be felt in social care, which is funded by a completely separate system. She said:

> “If you did a benefit analysis on some of these, the benefit is further down the line in Social Services, it is not in health, so the PCT will say: ‘Why should we invest now?’.”

193. She added:

> “It is such a bad use of resources. I have had cases where patients are in very high cost beds waiting for some housing adaptation. I would rather just pay for the housing adaptation; it would cost me less and the patient could move on through the pathway. It is quite frustrating as a commissioner not to be empowered to be able to deal with that.”

194. Sally Reed, Head of Strategic Commissioning (Physical Disability & Sensory Impairment), Adult Social Care, East Sussex County Council, agreed that stronger measures, “around investments and planning”, were needed to facilitate better joint working between health and social care.

195. Janet Lewis identified that the way to get around this issue of commissioners operating in silos is by commissioning in regions. She commented:

> “What has been useful is the regional SHA [Strategic Health Authority] groups that have been working with primary care trusts to commission pathways across boundaries and across organisations... That has had a lot of multi-agency groups working together to develop pathways that are across organisations with the support and back-up of the SHAs: some quite innovative work coming out of there in terms of the integrated care projects and pilots.”

196. Also Janet Lewis commented that, while there may not be any regional groups at present specifically aimed at Parkinson's disease, lessons from these programmes should be shared with those commissioning services for people with neurological conditions.

197. Also Janet Lewis commented that, while there may not be any regional groups at present specifically aimed at Parkinson's disease, lessons from these programmes should be shared with those commissioning services for people with neurological conditions.

198. A number of stakeholders (ADASS, Janet Lewis, Sally Reed and Lucianne Sawyer) identified that the personalisation agenda held the promise of providing more seamless services for people with Parkinson's disease.

199. John Nawrockyi, co-chair of the Disabilities Network at ADASS, also identified that the personalisation agenda could help commission more preventative services:
"...we are trying to stress a move towards lower level services on what is called the prevention or the intervention agenda. If we can build those kinds of services into a resource allocation system we can start to move away from those FACS criteria which have been so limiting over the last five to ten years."

Support and guidance for commissioners and planners

199. A number of witnesses spoke of the lack of data on people with Parkinson's disease at a local level, and how these can hinder commissioning services in this area.

200. Janet Lewis commented that registers of people with Parkinson's disease in the local area would be helpful for commissioners:

“We have found recently with the QOF [Quality and Outcomes Framework] registers for COPD [chronic obstructive pulmonary disease] that they have helped us focus in on the needs of our population, rather than just going on averages and incidences of a typical group of people.”

201. Dr Chris Clough explained that plans were already underway within the Department of Health to develop a national minimum dataset for long-term neurological conditions in England. However, he commented that, although this was initially due to be ready for 2010, they were likely to encounter some delays as responsibility was being handed over to another body, the Information Standards Board for Health and Social Care.

202. Liz Wolstenholme commented that a register of people with conditions such as Parkinson's disease, presumably held jointly between health and social care services, could take a more proactive role in identifying potential service users and help improve the commissioning of services across the patient pathway:

“...if there was a register of people with neurological conditions and somebody made a phone call every year to see how you were then that would feel very caring because somebody knows about you, because often you feel quite alone.”

203. On the practicality of this suggestion, with her background working at the interface between health and social care in the Department of Health, Liz Wolstenholme commented:

“I feel despair, having spent all my life at the health and social care interface, in hearing that things are still as bad as they ever were and I think we ought to look for simple mechanisms that actually deliver something rather than another anguished round of trying to make joint planning better.”

204. A number of witnesses highlighted the importance of involving people with Parkinson's disease in commissioning and planning services that are responsive to their needs. Janet Lewis commented:

“The need for us to engage with our patients and to understand the needs of our population are paramount.”

205. The PDS commented:

“It is imperative that health and social care commissioners and service-users work together to look systematically at local needs and redesign services to deliver responsive, holistic, high quality care.”

206. A number of witnesses commented that guidance was produced for commissioners and planners on developing services for neurological conditions. Dr MacMahon commented:

“In a sense, commissioners were not quite sure how to commission services to fulfil the aims of both the NSF and the NICE guidance. Commissioning also is very much in its infancy in these areas, particularly chronic neurological disease, particularly diseases that affect older people and particularly something like Parkinson’s [which] crosses so many different boundaries from neurology, geriatrics, into the rehab services you have already been speaking about and then on to mental health and palliative care. It is a very complex area to expect commissioners in their infancy to try and produce a package that would fulfil and tick all the boxes.”

207. A range of witnesses including commissioners, the RCN and PDNSA, spoke of the need to provide evidence of cost-effectiveness of interventions for people with Parkinson’s disease, for commissioners to use. The Inquiry received a range of evidence highlighting how good services for people with Parkinson’s disease can deliver cost savings, for example the PDS evidence included as an appendix a document for commissioners setting out the cost-effectiveness of Parkinson’s disease nurse specialists. It would appear that more guidance for commissioners on this would be a powerful tool for service improvement.
208. Barbara Howe outlined how beneficial evidence on cost-effectiveness and clinical effectiveness of services would be for commissioners:

“I think what would help to get these services delivered… is to actually take to PCTs something to show them that, if you do this, if you invest in this, not only is it much better for the patient [which obviously is your first achievement] but you will gain something else later; there will be a pay-back. If you work with the patient groups and you tailor the services in the way that they advise, you will tick some of the world class commissioning boxes when people come round.”

209. Richard Glasspool, Chair of the PDNSA, recommended that organisations such as the Royal Colleges, the PDS and his own organisation, should work together to generate more evidence of the cost-effectiveness of Parkinson’s disease nurse specialists.

**Conclusion**

210. For services to respond to the needs of people with Parkinson’s disease, services need to be commissioned and planned across organisational and geographical boundaries. While there has been evidence to the Inquiry highlighting the cost-effectiveness of many elements of Parkinson’s disease care, it would appear that this is not being presented effectively to commissioners and planners.

**Recommendations**

211. Governments in England, Wales and Northern Ireland should put in place national registers for people with neurological conditions, to provide commissioners and planners with data on the populations of individuals with Parkinson’s disease in their area.

212. Parkinson’s disease services should be jointly commissioned and planned across health and social care and should respond to the holistic needs of people living with the condition.

213. Funding should be made available for all those clinically eligible for deep brain stimulation in England, Wales and Northern Ireland.

214. The Welsh Assembly Government’s forthcoming implementation plans to take forward the recommendations of the Welsh Neuroscience External Expert Review Group must consider the interface between health and social care for people with Parkinson’s disease and other neurological conditions.

215. Governments in England, Wales and Northern Ireland should work with other stakeholders to produce guidance for commissioning and planning Parkinson’s disease services, including data on cost-effectiveness and how these services can help achieve better outcomes for patients.

**Workforce and training issues**

216. Evidence to the Inquiry suggests there are key areas of services for people with Parkinson’s disease in which significant workforce development and training is required. These include:

- training in the management of the mental health aspects of the condition for all health and social care professionals involved in Parkinson’s disease care, and the development of specialist mental health services for people with Parkinson’s disease
- training of the general health and social care workforce including therapists, and the development of more therapists with a special interest in Parkinson’s disease
- improved access to specialists with an interest in Parkinson’s disease
- comprehensive access to Parkinson’s disease nurse specialists in every part of England, Wales and Northern Ireland.

217. The range of workforce and training issues that were highlighted to the Inquiry by professionals and people living with the condition suggests the need for a strategic level review of all services involved in the care of people with Parkinson’s disease.
218. Dr Clough, neurology adviser to the Department of Health, commented that the need for a neurology workforce review had been identified when the NSF for Long-term (Neurological) Conditions was developed. Dr Clough said:

“...we did try to get some resource[s], to look at what is the workforce you need to deliver the NSF, and that has largely been abandoned. We do not know what workforce we would need to deliver the NSF.”

219. While the Welsh Neuroscience External Expert Review Group identified that the workforce involved in all aspects of care for people with long-term neurological conditions needs to be increased, the focus of the review was confined to health services. Further work is needed to examine what training and workforce development is required within social care services and care homes.

Specialists
220. A range of professionals spoke of the need to increase the number of specialists throughout the UK. For instance Professor Carl Clarke said: “We need to at least maintain and preferably expedite the expansion in consultant services for PD patients.”

221. Dr Graham Venables, President of the ABN, commented that the number of neurologists in post had considerably increased over recent years. He commented:

“The numbers have gone up. Certainly in my time they have almost doubled in numbers from 300 to just over 600 bodies in post.”

222. However, the ABN called for further neurology specialist posts to be created, so patients are able to gain timely access to an appropriately trained specialist.

223. Dr Paul Morrish commented in his evidence that, although more neurology posts had been created, the demand was outstripping this increase in capacity due to an increase in referrals. Dr Morrish commented that:

“The creation of new neurology posts has been like adding an extra lane to the M25; it has attracted more referrals from areas already relatively well served.”

224. Dr Morrish concluded that to meet this extra demand GPs should be trained in Parkinson’s disease and be more involved in the specialist care of this group. However, Professor David Burn outlined to the Inquiry that in his view GPs should play an increased role in the management of more common conditions such as migraine, to free up specialists to play a role in the diagnosis and management of more complex conditions such as Parkinson’s disease.

225. Other clinicians including Dr Doug MacMahon and Dr Peter Fletcher, Chair of the Movement Disorders Section of the BGS, emphasised the importance of the specialists’ role in the management of Parkinson’s disease. Dr Fletcher also highlighted that Parkinson’s disease nurse specialists are well placed to help manage the caseloads of specialists, through nurse-led clinics.

Parkinson’s disease mental health expertise
226. Dr Graham Venables, President of the ABN, identified the need for “substantial training and investment” to develop appropriate mental health assessment services for people with Parkinson’s disease:

“There are trainee neuropsychologists out there who have the skills to do it, but in most departments there are not enough individuals because that same department would be stretched, coming from a neurology perspective at least, in providing services for people with head injury, with stroke, with multiple sclerosis, people with adjustment disorders, relating to many of those things, and then the more specialist work-ups for epilepsy surgery, for example, which take a huge amount of time. I think there would be a very, very significant resource issue there to provide not only the initial assessment but two or five years down the line a repeat assessment. I am not saying that you need a consultant neuropsychologist to do that but the more basic grades have to be supervised, and it is a whole career structure and empire that has yet to be developed on an on-going basis.”
Nurse specialists

227. A number of submissions referred to the need for expanding the Parkinson’s disease nurse specialist workforce; for example Professor Carl Clarke commented:

“There must be an acceleration in the expansion of the UK Parkinson’s nurse specialist service which should be led by the NHS, not the Parkinson’s Disease Society.”

228. Sue Thomas, Policy Adviser at the RCN, stated that an “ideal position” would be for every person with Parkinson’s disease to have access to a Parkinson’s disease nurse specialist, but that this was difficult to achieve in some more rural areas. The RCN would however “like to see at least a critical mass of nurses” and “we certainly need more than there are at the moment”.

“It may not be that everybody can have a PD nurse specialist themselves, but certainly there could be enough nurses within geographical areas to be able to cascade education down to the generalist workforce so that we could upskill nurses so they were sufficiently specialist in order to manage complications and then know when to refer on to the specialist nurse themselves. It may be that there have to be solutions like a neurology nurse in areas where we physically cannot have a PD nurse specialist, but there should at least be that critical mass of numbers that would give patients access.”

229. A range of witnesses commented about lack of cover for Parkinson’s disease nurse specialists when they go on holiday, sick leave, and so on; however there was a consensus amongst respondents that the answer to this did not lie in general neurology nurses.

230. Sue Thomas, from the RCN, commented:

“I do not think a neurology nurse is the answer to increasing the whole of the [nurse specialist] workforce, it has to depend on local need. If we were to have a neurology nurse in Inner London she would not be able to cope with the multiplicity of neurological conditions, they would get burnt out very quickly.”

231. Professor Burn commented:

“The idea about the seven day week and the cover is going to come. Extending the hours beyond nine to five has already arrived in many areas and it needs to be implemented. I would be more in favour of trying to provide, if we needed to do that, more of a generic, cross covering out of hours. I would vigorously like to defend the idea of a specialist nurse in Parkinson’s disease remaining just that, rather than a team of neurology nurses who have shared skills in Parkinson’s disease, MS etc. I have seen how well somebody can do – and two other colleagues to boot subsequently – dealing with one area of specialism. It is such a complicated, happening area that we would dilute the standard and the quality of care by expecting them to take on more... I personally would be very much against the idea of trying to generalise a nurse’s training to take on several areas of, say, neurological disease.”

Therapists

232. Dr Nick Miller, University of Newcastle, identified a need to develop the speech and language therapy workforce, commenting on the need for:

“Training up a body of Speech Language Therapists who are actually specialists in Parkinson’s disease; so who are totally cognisant of the latest evidence basis and are able to deliver it in an expert fashion.”

233. A model for increasing the knowledge base of therapists through a core of regional experts was identified by Bhanu Ramaswamy, speaking about the Dutch model, Parkinson’s Net:

“The Society in the Netherlands actually trained up some therapists and they act as regional experts; so on the whole people come to them from the point of diagnosis and they can be followed through purely initially on a consultation basis at the beginning to understand where their responsibilities lie; how they can maintain activity; where they can look towards preventing future problems. Then as the condition progresses they actually come back and they are utilising the services more at that point. That would be an example of something that has worked, pushed through by the Society that trains up their staff.”

General health and social care workforce

234. Submissions point to the need to increase training for the non-specialist workforce including GPs, ward staff, and social care workers including domiciliary and care home staff; and suggest barriers to increased training include lack of time available for Parkinson’s disease nurse specialists to provide this role and lack of protected time for training in Parkinson’s disease.
235. A range of evidence to the Inquiry highlighted the important role that Parkinson's disease nurse specialists play in educating the general health and social care workforce about Parkinson's disease. However, evidence from the RCN and PDNSA commented on the restrictions of nurse specialists’ time to provide this educational role:

“I think the barriers are time-related. These nurses have got very busy clinical caseloads. The NICE guidelines recommend that nurses should have a caseload of about 300 patients, Richard said that he has 420 and I know some PD nurses that have caseloads of 700 patients, and in a day’s work they have problems doing their clinical caseload let alone educating people… They need protected time to undertake educational activities and that needs to be recognised by their management so that they can take on that educational role. In terms of the people that they educate, which includes health and social care staff, it is allowing people protected time away from their own jobs to undertake education.”

236. Richard Glasspool, PDNSA, also identified staff turnover as a critical barrier to the education of ward staff and care home staff:

“...One of the things that we are probably not going to be able to get away from is staff turnover in homes or secondary care wards. You can go in one month and do the training but within 12 months up to 50 per cent of the staff have turned over so those skills have gone with those individuals, hopefully to another home.”

237. Sue Thomas, from the RCN, pointed to the lack of prioritisation of training in Parkinson’s disease:

“We have some wonderful anecdotal comments from nurses who have been in doing training, but the nurses that have come to be trained are having to go and give care during the training sessions. They are popping in and out of the training session to go and take somebody to the toilet or to give them their meal. That is not acceptable and I think we need to be able to provide education and we also need it to be recognised that there has got to be time for that, both from the trainer and the person that is being trained.”

238. Richard Glasspool added:

“Unfortunately, Parkinson’s disease does not sit under the remit of mandatory training, so managers and staff alike are going to do their mandatory training because they are required to do that and some of the ancillary stuff like extra training on Parkinson’s disease perhaps is not taken with the same interest.”

239. The need for training in primary care Parkinson’s disease was raised in a range of evidence. Many individuals commented that they felt their GP did not understand Parkinson’s disease. The ABN commented:

“We have previously highlighted concerns about the level of neurological expertise within primary care. Few practices have doctors with additional training in neurology and fewer still have the expertise to diagnose and manage people with PD. We continue to urge that vocational training in primary care include adequate training in neurology, and better awareness of neurological conditions in general.”

**Conclusion**

240. There are some key areas of the health and social care workforce where shortages have been identified in the number of appropriately trained professionals working with people with Parkinson’s disease.

241. There is strong evidence that many of the general health and social care professionals involved in the care of people with Parkinson’s disease do not have appropriate training and awareness about the condition.

**Recommendations**

242. Governments in England and Northern Ireland should each review the neurology and social care workforce to inform national and regional workforce planning decisions.

243. The Welsh Assembly Government should review the social care workforce involved in the care of people with neurological conditions as part of their implementation plans to take forward the recommendations of the Welsh Neuroscience External Expert Review Group.

244. At a local level, health and social service managers should take into account the needs of people with Parkinson’s disease in their training strategies.

245. Awareness of neurological conditions should be part of the training and revalidation cycle of GPs.
Conclusions and recommendations

Inequalities in service provision

Conclusion
246. It is clear there are major inequalities in access to the full range of services for people with Parkinson's disease and carers. We conclude that there are systemic problems throughout England, Wales and Northern Ireland with many areas falling below those standards set out in the NICE guideline, and in some areas significantly below. We also conclude that the NSF for Long-term (Neurological) Conditions is not being implemented in many areas in England.

247. Although assessments of carers' needs is being undertaken to comply with regulations, too often no action is being taken and no funding follows. We question the cost efficacy of this approach.

Recommendations
248. Commissioners, planners and health service managers responsible for services for people with Parkinson's disease across England, Wales and Northern Ireland should audit their services against the NICE guideline.

249. Local Authorities and Primary Care Trusts in England should also audit their services against the NSF for Long-term (Neurological) Conditions.

250. Where services are found to be below the standard set out in the NICE guideline and, in England, the quality requirements of NSF for Long-term (Neurological) Conditions, plans should be made to improve services in line with these standards.

Preventative services and early intervention

Conclusion
251. The value of therapy and social care services in the management of Parkinson's disease is not being recognised by many health and social care professionals making referrals to, and delivering, these services. This can result in early decline in an individual's condition, and impact on the carer's health. This has implications on quality of life and cost effectiveness of health and social services. There is strong evidence that the current provision of services at a later stage or after long waits is a false economy.

Recommendations
252. Professional and patient organisations should raise awareness amongst professionals who make referrals of the benefits of a preventative approach to services for people with Parkinson's disease.

253. Commissioners and planners of health and social services should consider the long-term cost implications of providing services that only respond to those with high end needs, and the benefits of a more preventative approach for Parkinson's disease services.
Information, self care and knowing how to access services

254. Information provision is a key component of quality health and social care services. However it is clear that many people with Parkinson's disease and carers are not receiving the information and signposting that they need. This demonstrates that many services are not meeting standard of care set out in the NICE guideline, and, in England, the quality requirements of the NSF for Long-term (Neurological) Conditions, covering information provision.

255. There is strong evidence that people are not being signposted to social services in particular. Parkinson’s disease is a progressive condition, requiring more and more complex interactions with health and social care over time. Therefore it is important that people with Parkinson’s disease and carers receive information about what to expect, how to manage their condition and how to access the full range of services they may need as their condition develops.

Recommendations

256. All health and social care professionals working with people with Parkinson's disease and their carers should take responsibility for ensuring individuals’ information needs are met as a key aspect of their role, including signposting people to other relevant services. In particular health professionals working with people with Parkinson's disease and carers should ensure they provide information about how to access social care services wherever relevant.

257. Commissioners and service planners should specify, as a key requirement, the need for services to provide information and signposting, and ensure services fulfil this role through monitoring.

Integrated services

Conclusion

258. Evidence to the Inquiry indicates that services are commissioned and planned in segments rather than across the full patient pathway, pointing to a lack of integration between services.

Recommendations

259. Commissioners and service planners should work to develop service specifications for integrated models of service delivery which reflect the holistic needs of people with Parkinson’s disease.

260. Governments in England, Wales and Northern Ireland should work with patient and professional groups to develop a blueprint for Parkinson’s disease services for commissioners and service planners.

Training and awareness of Parkinson’s amongst professionals

Conclusion

261. There is a large body of evidence demonstrating major shortfalls in the general health and social care workforce regarding the knowledge and skills needed to care for people with Parkinson’s disease.
Recommendations

262. Service managers should ensure that all professionals involved in the care of people with Parkinson's disease are able to take up education and training opportunities in the condition, including those provided by the PDS.

263. All GPs and care home professionals should take up education and training opportunities available to them through the PDS.

Other areas of inequalities

Conclusion

264. Evidence has highlighted particular concerns about how far people with Parkinson's disease from black and minority ethnic groups and people living in care homes have access to appropriate health and social care services.

Recommendations

265. Commissioners and service planners must ensure that people from black and minority ethnic communities are involved in the development and review of services to ensure these meet their needs, working through community groups as appropriate.

266. Commissioners and service planners should ensure that services are signposted effectively to black and minority ethnic communities and that uptake of services by these groups is monitored.

267. Commissioners and service planners must ensure provision is made for full access to appropriate services for people with Parkinson's disease in care homes.

Inspection and monitoring of NICE and the NSF

Conclusion

268. 2010 will mark the half way point of the NSF for Long-term (Neurological) Conditions' ten year implementation period. Evidence to this Inquiry has highlighted major concerns that this strategy is not considered a priority at a local and Government level and implementation has been extremely inconsistent.

269. The NICE guideline sets out evidence-based good practice for Parkinson's disease services, against which health service managers, commissioners and clinicians can measure their performance and accordingly develop services. However, this Inquiry has seen evidence that services in many areas do not yet meet these standards, and there is a lack of impetus behind implementation. The fact that the NICE guideline is not mandatory and that there are no financial incentives for implementation has been particularly highlighted.

Recommendations

270. The Government should conduct a review of the NSF for Long-term (Neurological) Conditions to measure progress made towards implementation at this half-way point, against its 11 quality requirements for health and social care.

271. The Welsh Assembly Government should outline a clear timetable for implementation of the recommendations of the Welsh Neuroscience External Expert Review Group and how it intends to monitor outcomes.

272. The regulators across England, Wales and Northern Ireland should introduce measures to ensure services and commissioning and planning processes are monitored in relation to their adherence to the NICE guideline and that there are stronger drivers for implementation.

273. Consideration should be given to seeking mechanisms to ensure stronger incentives are in place to encourage implementation of the NICE guideline.
Leadership for improving Parkinson’s services

**Conclusion**

274. There is evidence of a lack of leadership for development and implementation of policy on neurology services at a national level. Evidence points to the positive impact that local clinical champions can have on service improvement in line with the NICE guideline and NSF for Long-term (Neurological) Conditions.

**Recommendations**

275. There should be clearer lines of responsibility for neurological policy and implementation of guidelines with national leadership at government level in England, Wales and Northern Ireland.

276. Professionals and commissioners involved in the care of people with Parkinson’s disease should identify local leads to drive forward service improvement across both health and social care.

**Impact of other policies**

**Conclusion**

277. Evidence to the Inquiry highlighted that Government policies on waiting time targets, Payment by Results in England and frameworks for eligibility criteria for social care services were having unintended consequences on the delivery of services for people with Parkinson’s disease and their carers. It is also clear that policy making around carers’ services was not always having the desired effect.

**Recommendations**

278. Governments in England, Wales and Northern Ireland must have regard to the impact of new policies on services for people with long-term neurological conditions such as Parkinson’s. This includes the setting of new Payment by Results tariffs (England) and eligibility criteria for social care.

279. In addition, the setting of targets and policy milestones, for example, waiting time targets, must accommodate the needs of people with progressive conditions for ongoing management and support.

**Commissioning and service planning**

**Conclusion**

280. For services to respond to the needs of people with Parkinson’s disease, services need to be commissioned and planned across organisational and geographical boundaries. While there has been evidence to the Inquiry highlighting the cost-effectiveness of many elements of Parkinson’s disease care, it would appear that this is not being presented effectively to commissioners and planners.

**Recommendations**

281. Governments in England, Wales and Northern Ireland should put in place national registers for people with neurological conditions, to provide commissioners and planners with data on the populations of individuals with Parkinson’s disease in their area.

282. Parkinson’s disease services should be jointly commissioned and planned across health and social care and should respond to the holistic needs of people living with the condition.
283. Funding should be made available for all those clinically eligible for deep brain stimulation in England, Wales and Northern Ireland.

284. The Welsh Assembly Government’s forthcoming implementation plans to take forward the recommendations of the Welsh Neuroscience External Expert Review Group must consider the interface between health and social care for people with Parkinson’s disease and other neurological conditions.

285. Governments in England, Wales and Northern Ireland should work with other stakeholders to produce guidance for commissioning and planning Parkinson’s disease services, including data on cost-effectiveness and how these services can help achieve better outcomes for patients.

Workforce and training issues

Conclusion

286. There are some key areas of the health and social care workforce where shortages have been identified in the number of appropriately trained professionals working with people with Parkinson’s disease.

287. There is strong evidence that many of the general health and social care professionals involved in the care of people with Parkinson’s disease do not have appropriate training and awareness about the condition.

Recommendations

288. Governments in England and Northern Ireland should each review the neurology and social care workforce to inform national and regional workforce planning decisions.

289. The Welsh Assembly Government should review the social care workforce involved in the care of people with neurological conditions as part of their implementation plans to take forward the recommendations of the Welsh Neuroscience External Expert Review Group.

290. At a local level, health and social service managers should take into account the needs of people with Parkinson’s disease in their training strategies.

291. Awareness of neurological conditions should be part of the training and revalidation cycle of GPs.
Glossary of terms

The below definitions are used for the purposes of this report.

**Commissioning** – the process of deciding what services or products are needed, funding them and ensuring that they meet requirements.

**Deep brain stimulation (DBS)** – a surgical technique in which a medical device is implanted into the brain and connected to a small unit implanted in the chest. When the unit is switch on mild electrical impulses are sent to targeted sites in the brain through the device to stop or reduce Parkinson’s symptoms. This technique is only suitable for a subsection of people with Parkinson’s who are assessed as being clinically eligible.

**Dietetics** – a health care profession concerned with diet and nutrition.

**Medical specialist** – in the context of Parkinson’s care, this may be a neurologist, a consultant in elderly care medicine with a special interest in movement disorders or a general practitioner with a special interest in Parkinson’s.

**Multi-disciplinary team** – a group of health and social care workers who are members of different disciplines, each providing specific services to the service user. In relation to Parkinson’s services, a full multi-disciplinary team should include medical specialists, nurse specialists, physiotherapists, occupational therapists, speech and language therapists, dietetics, clinical psychology, palliative care professionals and social workers.

**Occupational therapy** – a profession concerned with promoting health and well-being through occupation or participation in the activities of everyday living. Occupational therapists have experience in assisting people with disabilities to manage the practical aspects of everyday living, through maximising their current abilities, supporting them to retain independence for as long as possible and developing coping strategies with individuals to enable them to deal with future problems.

**Palliative care** – the active holistic care of patients with progressive conditions. It includes management of pain and other symptoms and provision of psychological, social and spiritual support. The goal of palliative care is achievement of the best quality of life for patients and their families.

**Parkinson’s disease nurse specialist** – a nurse with a specialist knowledge and experience in caring for people with Parkinson’s. Key responsibilities including making and receiving referrals to other health care professionals, managing caseloads, providing information, education and support to people in their own homes, in clinics and in hospitals, and prescribing and monitoring medicines for, and treatments to, people with Parkinson’s.

**Payment by Results** – the funding system in England for paying NHS Trusts (bodies responsible for providing acute or hospital services). In this system, payment is linked to activity, and each different type of activity has a fixed tariff attached to it. It is designed to reward efficiency and support patient choice.

**Physiotherapy** – a health care profession concerned with the physical aspects of rehabilitation to maximise movement and the functional ability of a person and their role in society. In the context of a long-term condition such as Parkinson’s, physiotherapy is often regarded as an active and on-going process that should be kept under review.

**Practice-based commissioning (PBC)** – a Department of Health initiative designed to target financial drivers towards primary care and engage GP practices and other primary care professionals with the commissioning of services. Through PBC, front line clinicians are being provided with the resources and support to become more involved in commissioning decisions.

**Respite care** – the provision of short-term, temporary relief for carers from the responsibilities of caring.

**Self care** – the actions people take for themselves to maintain good health, including the role they play in managing their own long-term condition.

**Shared care guidelines** – guidelines on complex areas of treatment initiated in secondary care are then prescribed by a GP. The guidelines set out the process that needs to be followed for the GP to take on prescribing responsibility.

**Specialised commissioning** – the process of commissioning specialised services.
Specialised services – health services with low patient numbers but which need a critical mass of patients to make treatment centres cost effective. Of relevance to Parkinson’s, deep brain stimulation is categorised as a specialised service.

Speech and language therapy – health care profession involved in retaining, preventing and rehabilitating loss of function in relation to swallowing and communication through speech.

Acronyms

ABN – Association of British Neurologists
ADASS – Association of Directors of Adult Social Services
APPG – All Party Parliamentary Group
BGS – British Geriatrics Society
BAME – black and minority ethnic
CQC – Care Quality Commission
DBS – deep brain stimulation (see glossary of terms)
FACS – Fair Access to Care (eligibility framework for social service in England)
NICE – National Institute for Clinical Excellence
NSF – National Service Framework
PbR – Payment by Results (see glossary of terms)
PDNSA – Parkinson’s Disease Nurse Specialist Association
PDS – Parkinson’s Disease Society
RCN – Royal College of Nursing
ROTA – Race on the Agenda
SHA – Strategic Health Authority
Participants in oral evidence sessions and written evidence

Written evidence

The Inquiry received a total of 361 written submissions, including 331 from people with Parkinson’s and carers. Written evidence was provided by the following organisations and professionals, and Government representatives:

**Organisations:**
- Association of British Neurologists
- Association of Directors of Adult Social Services
- Belfast Health and Social Care Trust
- British Diabetic Association
- British Geriatric Society – Movement Disorder Section
- British Psychological Society
- Commission for Social Care Inspection
- Crossroads, Ipswich and District Branch
- Delivering Race Equality in Mental Healthcare Programme, National Mental Health Development Unit
- Healthcare Commission
- Medtronic Ltd
- Parkinson’s Disease Nurse Specialist Association
- Parkinson’s Disease Society
- Race on the Agenda
- Royal College of GPs
- Royal College of Nursing
- Southern Health and Social Care Trust
- The Princess Royal Trust for Carers and Crossroads Caring for Carers (joint submission)
- Wales Neurological Alliance

**Professionals and Government representatives:**
- Professor Carl Clarke, Professor of Clinical Neurology, Birmingham City Hospital
- Mrs Eileen Cooper, Senior Physiotherapist, The Fort Centre
- Dr Duncan Forsyth, Department of Medicine for the Elderly, Addenbrooke’s Hospital
- Mrs Annette Hand, Nurse Consultant, Jubilee Day Hospital, North Tyneside General Hospital
- Dr Professor Crispin Jenkinson, Professor of Health Services Research, Department of Public Health University of Oxford
- Professor George Kernohan, University of Ulster
- Dr Andrea Lindahl, Consultant Neurologist and Clinical Lead for Parkinson's disease, University Hospitals Coventry and Warwickshire
- Dr Doug MacMahon, Consultant Physician, Redruth
- Michael McGimpsey MLA, Minister for Health, Social Services and Public Safety, Northern Ireland Executive
- Dr Nick Miller et al, Institute of Health and Society, University of Newcastle
- Dr Paul Morrish, Consultant Neurologist, Gloucestershire Hospitals NHS Foundation Trust
- Dr Sandip Raha, Associate Specialist, Movement Disorder Clinic, Princess of Wales Hospital
- Bhanu Ramaswamy, Consultant physiotherapist in intermediate care, Derbyshire
- Dr Dorothy Robertson, Consultant, The Older People's Unit Royal United Hospital
- Dr Sudhir Singh, Department of Gerontology, John Radcliffe Hospital
Supplementary evidence

Anonymous GP, Member of Primary Care Neurology Society (email)
Edwina Hart AM, Minister for Health and Social Services, Welsh Assembly Government (informal meeting with APPG panel members)

Oral Evidence Sessions

17 March 2009

**Group 1**
Steve Ford, Chief Executive, Parkinson’s Disease Society
Lucy Brazg, Chief Executive, Neurological Alliance
Liz Wolstenholme, person with Parkinson’s
Brian Lymbery, person with Parkinson’s

**Group 2**
Gordon Conochie, Joint Parliamentary Officer, Princess Royal Trust for Carers and Crossroads Caring for Carers
Denise Maule, carer of a person with Parkinson's disease

24 March 2009

**Morning session:**

**Group 1**
Dr Peter Fletcher, Chair, Movement Disorders Section, British Geriatric Society
Professor Graham Venables, President, Association of British Neurologists
Neil Bindemann, Executive Director, Primary Care Neurological Society

**Group 2**
Sue Thomas, Policy Adviser, Royal College of Nursing
Richard Glasspool, Chair, Parkinson’s Disease Nurse Specialist Association

**Group 3**
John Nawrockyi, Co-Chair of Disabilities Network, Association of Directors of Adult Social Services
Lucianne Sawyer, former carer and President, UK Home Care Association

**Afternoon session:**

**Group 1**
Dr Nick Miller, speech and language therapist and lecturer, Institute of Health and Society, University of Newcastle
Bhanu Ramaswamy, Consultant physiotherapist in intermediate care and post graduate lecturer, Sheffield Hallam University
Gary Robjent, Head of Public Affairs and Policy Development, Chartered Society of Physiotherapy

**Group 2**
Dr Paul Worth, Consultant Neurologist, Norfolk and Norwich University
Dr Doug MacMahon, Consultant Physician, Cornwall Health NHS Trust
Professor David Burn, Professor of Movement Disorder Neurology, Institute for Ageing and Health, Newcastle University
Dr Paul Morrish, Consultant Neurologist, Gloucestershire Hospital NHS Foundation Trust
31 March 2009

**Group 1**
Irene Falloon, carer of a person with Parkinson’s
Jack Glenn, person with Parkinson’s
Dr David Craig, Consultant in Elderly Care, Belfast Health and Social Care Trust

**Group 2**
David Thomas, person with Parkinson’s
Dr Sandip Raha, Associate Specialist, Movement Disorder Clinic, Princess of Wales Hospital, Bridgend

21 April 2009

**Group 1**
Sally Reed, Head of Strategic Commissioning (Physical Disability and Sensory Impairment), Adult Social Care, East Sussex County Council
Barbara Howe, Director of Specialised Commissioning, London Specialised Commissioning Group
Janet Lewis, Assistant Director Commissioning and Quality, East and North Hertfordshire PCT and West Hertfordshire PCT

**Group 2**
Dr Chris Clough, Neurology Adviser, Department of Health


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4. Dr Nick Miller, Dr Diana Jones, Dr Katherine Deane, Emma Noble, National survey of speech language therapy provision for people with Parkinson's disease: therapists' practices, patients' and carers' perspectives, University of Newcastle and University of Northumbria (January 2009)
5. Parkinson’s Disease Society, Members’ Survey
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8. Professor George Kernohan, Do people with Parkinson's disease (PD) need palliative care?, University of Ulster (provisional findings)
9. Parkinson’s Disease Society, Members’ Survey
10. Dr Nick Miller et al National survey of speech language therapy provision for people with Parkinson's disease
12. Neurological Alliance etc al, Taking control
13. Professor George Kernohan, Do people with Parkinson's disease (PD) need palliative care?
14. Dr Nick Miller et al National survey of speech language therapy provision for people with Parkinson's disease
15. Dr Nick Miller et al National survey of speech language therapy provision for people with Parkinson's disease
16. Parkinson’s Disease Society, Scoping exercise to consider how the Society could best support appropriate therapy provision for people with Parkinson’s (2007)

Panel members

APPG Members who have participated in this Inquiry:

Lord Brooke of Sutton Mandeville
Jeremy Browne MP
Baroness Finlay of Llandaff
Baroness Gale (Chair)
Anne Milton MP
Madeleine Moon MP
Lord Walton of Detchant