

# Parkinson's, dementia and psychiatry meeting

NNAG event write up

19th July 2018



# Document control

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<b>Document Title</b>	NNAG event write up
<b>Job No</b>	
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<b>Date</b>	26 <sup>th</sup> September 2018

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[The Strategy Unit](#), hosted by Midlands and Lancashire CSU, has been employed by the Neurological Alliance to provide programme management for the National Neuro Advisory Group. This document has been produced as part of this package of work. Please direct any queries to Lucy Hawkins, Senior Consultant, [lucy.hawkins4@nhs.net](mailto:lucy.hawkins4@nhs.net).

# Executive summary

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NHS England's National Neuro Advisory Group (NNAG), The Neurological Alliance and the UK Parkinson's Excellence Network held a meeting on the 19<sup>th</sup> July 2018 in order to identify what good care looks like for people affected by Parkinson's, dementia and mental health issues. This write up summarises presentations and discussions from the event, it highlights the key issues faced for this patient cohort and identifies a number of recommendations as to how services could be improved.

Parkinson's is a progressive neurological condition which develops due to the loss of dopamine producing cells in the brain. There is on-going research into what causes the loss of these cells, but current thinking suggests a combination of genetic and environmental factors. Parkinson's often presents physical manifestations such as tremors and shakes, lethargy and balance problems. However, depression and anxiety, hallucinations, sleeping difficulties, memory problems and dementia are also all common features of the disease as it progresses.

Many Parkinson's patients have complex mental health conditions that do not conform to simple diagnostic categorisation, as a result it is difficult to assess how best to support them; there is a risk that patients are 'bounced' between services resulting in very disjointed care. A common contributing factor cited was insufficient availability of time in regular clinics to support the most complex patients, which increased healthcare access elsewhere. In addition, historical ways of working means that communication and the sharing of information between specialties and trusts compounding the fragmentation of care.

The following recommendations were developed to tackle the challenges faced:

- More research to better understand both the range of conditions and how and where these are best treated
- Normalising multidisciplinary working to improve communication and ensure appropriate expertise.
- Ensuring sufficient time of clinician with the patient and their carer to explore and address needs.
- Better sharing of information between organisations and professionals through improved electronic communication and shared records.
- Exploring the use of technology and innovative solutions such as virtual clinics to deliver services cost-effectively.
- Management support for teams in developing business cases for service improvement.

Following the event, the UK Parkinson's Excellence Network have committed to setting up a mental health hub as part of its on-going programme of work and to provide support to teams and organisations looking to develop business cases to enable service changes. The NNAG will also be looking at how the recommendations from the day can be taken forward and are establishing a workstream to improve mental health provision for all neurological conditions.

We hope that this document will provide useful guidance to professionals, commissioners and policy makers.

# Event description

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The National Neuro Advisory Group (NNAG) exists to seek alignment between programmes in NHS England, the Department of Health's Arm's Length Bodies and system partners, such as charities relevant to people with neurological conditions, and to guide the strategic development of work to improve outcomes for people living with neurological conditions. One of the aims of NNAG is to bring together all the different professionals that need to work together to achieve improvement in neurology services including clinicians, patients, commissioners and academics.

As part of the NNAG's wider scheme of work several condition specific groups have been identified to lead the development of pathways to complement the revised neurosciences specification.

These groups have been identified by conditions that share similar challenges in ensuring access and equity of care, as well as where pathways between services could be improved. The groups are as follows:

- Neuromuscular
- Headache and migraine
- Epilepsy
- Neurorehabilitation
- Parkinson's, dementia and psychiatry

A number of workshops have been established by these groups in order to facilitate the improvement of services nationally through the sharing of good practice and identification of areas where more work is needed. Different models of care will work in different parts of the country but equity in the standard of care is the goal.

This report concerns itself with the third of these workshops that focused on Parkinson's, dementia and psychiatry and was held on the 19<sup>th</sup> July 2018. It summarises each of the presentations, and feedback from group discussions, including the challenges identified and solutions already in place, as well as identifying the key actions to be taken forward.

The presentations have been kindly made available by the speakers and may be used to support the further exploration of the themes and outcomes of the day.

# 1. Introduction

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Parkinson's is a progressive neurological condition which develops due to the loss of dopamine producing cells in the brain. There is on-going research into what causes the loss of these cells, but current thinking suggests a combination of genetic and environmental factors.

Parkinson's often presents physical manifestations such as tremors and shakes, lethargy and balance problems, however, depression and anxiety, hallucinations, sleeping difficulties, memory problems and dementia are also all common features of the disease as it progresses.

Historically, in the treatment of Parkinson's there has been a significant divide between neurology, geriatric medicine, dementia and psychiatry services. This originates from separating the disease by brain, mind and body and then planning and commissioning healthcare services accordingly. However, this separation is now understood to be detrimental as patients often have complex needs which require a joined-up, patient centred, approach to care.

Whilst progress is being made, in many parts of the country care provision for people with Parkinson's remains fragmented. A meeting specifically targeted at Parkinson's was therefore selected as it was deemed to be an area where solutions can be relatively simple, and there is knowledge of progress.

It was also anticipated that discussions and recommendations from the meeting could be generalisable to other neurological conditions. In particular, Motor Neurone Disease (MND), Progressive Supranuclear Palsy (PSP), Multiple System Atrophy (MSA), as well as in early onset / atypical dementia clinics.

## 2. Summary of presentations

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This section summarises the presentations from the day and key discussions following each. Please read the following summaries in conjunction with the corresponding slide pack.

### 2.1 The future of dementia care

#### *Dr Catherine Mummery*

Dr Cath Mummery began the day by focusing on the future of dementia care. Her presentation demonstrated how our understanding of dementia is changing. Due to the ambition from the 2013 G7 Dementia summit, to have a cure or disease modifying treatment by 2025, there is currently a lot of investment in research in this area, and approximately 580 on-going trials worldwide. She raised the point that when we are looking at how to improve and join up services we need to make sure we are also thinking about future proofing services.

Dementia is one of the biggest health challenges we are facing at the moment, with the cost of dementia to the UK being calculated at more than £23 billion. There have been significant improvements in recent years in terms of public awareness, diagnosis and post diagnostic care. But, dementia is still thought of as an incurable disease of old age.

Dr Mummery demonstrated that delaying symptoms by 5 years is not only better for the individual but would halve the prevalence of the disease, hence providing significant societal savings. There have already been a number of task force documents<sup>1</sup> published around prevention, these have shown that by reducing risk factors we can make a big difference on the prevalence of the disease.

In addition to this, she explained that through current trials we have learnt a lot about diagnosis and what sort of treatments we should be looking to test. One significant finding has been the use of bio-markers to support diagnosis. Cerebrospinal fluid (CSF) markers and neuroimaging enable specific diagnosis at an early stage. Developments in functional imaging have also revealed that pathology precedes symptoms by up to 20 years. This is important as it demonstrates that Alzheimers is a mid-life disease, by the time of symptom onset it is already advanced, so we need to diagnose early to enable treatments to be given that prevent further decline.

Dr Mummery concluded by illustrating that if a successful treatment for dementia is identified this will have a huge impact on the way that we run services. We will have to start thinking of it as a treatable mid-life disease rather than an end of life disease. We are going to need to diagnose early and we are going to need capacity to do that. We will need to develop selection criteria in

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<sup>1</sup> Alzheimer's Society (2018) *A roadmap to advance dementia research in prevention, diagnosis, intervention and care by 2025*, International Journal of Geriatric Psychiatry; 33:900-906.  
Rossor and Knapp (2015) *Can we model a cognitive footprint of interventions and policies to help meet the global challenge of dementia*, The Lancet; 386 (9997):1008-1010.  
Livingston et al. (2017) *Dementia prevention, intervention, and care*, The Lancet; 390 (10113): 2673-2734

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order to identify who is given the treatment and what the outcomes of success are, and we will need to consider the cost effectiveness of emergent drugs in terms of whole system savings.

## **2.2 What does good look like? South Tees Hospitals NHS Foundation Trust**

### ***Dr Neil Archibald***

Dr Neil Archibald described the journey of the Parkinson's Advanced Symptom Unit (PASU) at South Tees Hospitals NHS Foundation Trust. He explained that the PASU was set up as a response to the challenges faced by the complexity of the patients being seen and the limited time available to see them. The initial pilot was run with a grant of £75,000 from The Health Foundation, and the service has now been running for 4 years.

Traditional Parkinson's clinics provide patients with a 15-minute face to face appointment every 6 months with either a Consultant or Parkinson's nurse. PASU is a community based rapid access multidisciplinary service that runs in parallel to the normal clinics for patients with more complex needs.

PASU clinics run every Wednesday morning with a neurologist, Parkinson's nurse specialist, pharmacist, physio, occupational therapist and mental health specialist. The therapy team also have an additional 1.5 days per week to do home visits for patients and work closely with other community teams so that they can pick up issues quickly and refer in when needed. The PASU team also meets for 1 hour per week to feedback on cases, action plan and educate themselves as a group.

In the clinic patients have a 60-minute appointment, during which a team assessment is undertaken, and they are given education around their condition and prescription guidance. The patients then have a community therapy assessment which involves visits from different team members to support with any adjustments that need to be made and education and training for both patients and carers.

Dr Archibald explained that the impact so far has been: a reduction in emergency admissions (3%), a reduction in length of stay (38%), a reduction in hip fractures (50%), a reduction in nursing home admissions (50%), a reduction in psychiatric admissions (they have had 0 in last 2 years), a reduction in prescribing costs (£40,000 per year) and an overall reduction in healthcare costs (approx. £1million savings).

He concluded with feedback gathered as to why they think it works: there are a team of people who want to provide the best service for their patients, and they have the time to do it properly.

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## **2.3 What does good look like? Derby Teaching Hospitals NHS Foundation Trust**

### ***Lisa Brown and Clare Johnson***

Lisa Brown and Clare Johnson from Derby Teaching Hospital's explained how their integrated multidisciplinary Parkinson's service has developed over the years. The model has been driven by the team and evolved organically within the resources that they have available to them, and some internal business cases. Now, all patients receive the same care whether they are under a neurologist or geriatrician.

The service is overseen by a Consultant Neurologist or Geriatrician specialising in movement disorders, care is co-ordinated by Parkinson's nurse specialists and they have a multidisciplinary rehabilitation unit with specialist therapists. They have a weekly multidisciplinary Parkinson's clinic, and once per month this becomes an advanced Parkinson's clinic when the team are joined by a Palliative Medicine Consultant. This clinic has enabled advanced care planning and more support for people to die at home, the savings from which have funded the Palliative Medicine Consultant input.

The team has 1 day per week of a Clinical Psychologist and they host Old Age Psychiatry trainees who want to learn more about Parkinson's. This has enabled the forming of links with the Mental Health trust and they are currently looking at formalising this link through funding some Consultant Psychiatrist time. They have also developed a step-up step-down mental health pathway, where all therapists have a basic level of skills in mental health support with the psychologist and psychiatrist providing increased input as required.

They explained how one of their key successes has been the multidisciplinary approach to developing a Cognitive/Mental Health and Wellbeing pathway. This pathway provides guidance for all grades of staff to aid the on-going support and therapy provided to the patient, but also a guide to follow in order to seek further support when cases get more complex. Patients and carers were also involved in the development of the pathway.

The Derby team believe that their success has been due to an integrated, holistic, multidisciplinary team approach. One stop shop style services are beneficial as you can solve problems far more quickly when you're in the same room.

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## **2.4 What does good look like? Cardiff and Vale University Health Board**

### ***Sandra Mahon and Tracy Williams***

Sandra Mahon and Tracy Williams from Cardiff and Vale University Health Board explained how they have had to develop a new service within the existing financial envelope.

They described the journey that the team took after identifying that the original model of referring Parkinson's patients with dementia out to the memory clinic was not working. Particular triggers that highlighted the need for change were: a poor attendance rate at memory clinic, an increasing number of telephone contacts due to carer strain, multiple medication changes in a short period of time and deteriorating cognitive assessment scores.

They looked to re-design the service with what they had and began by running small focus groups with patients to discuss what they wanted from the service in terms of dementia diagnosis and treatment. The resounding feedback from patients was the need for time.

They also benchmarked with other services nationally as well as locally, working closely with the local memory clinic to ensure that the same standard of service was delivered by each team.

Now the Parkinson's / dementia patients are kept within the Parkinson's service. In parallel to the normal 6 monthly Parkinson's clinic there is a multidisciplinary Parkinson's / dementia clinic with a Consultant and a Nurse once every 3 months. In this clinic appointments are 45 minutes and the Consultant and Nurse see the patient and the carer together, they develop an individualised care plan and provide information on their condition and medication. They have also started to use technological solutions for patient monitoring, including the use of wrist worn movement recording devices (Parkinson's KinetiGraph™ watches). Alongside the Consultant and Nurse in the clinic there are representatives from the Alzheimer's Society and Parkinson's UK available at the clinic to signpost to community support.

This has now been running for 3 years and feedback from patients has all been positive. The service is cost neutral, it has saved time by preventing overruns in the normal Parkinson's clinics and has improved access to support from voluntary sector organisations.

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## 2.5 What is the problem? A carer's story

Despite the examples of good practice above there are still problems and challenges faced in the care of this patient cohort. M until recently was the primary carer for G, G and M have been married for more than 50 years, they have 3 children and G was a stay at home mum while M travelled the world setting up a business.

G had a history of what the family called 'wiggly toe syndrome' where she would regularly be convinced she had something wrong with her, but the doctors would always reassure her it was nothing.

When she started to feel lethargic and noticed that her writing was deteriorating G was convinced that she had Parkinson's, but the GP wasn't sure. She had lots of tests and only ended up seeing a Neurologist to try and rule out Parkinson's. It turned out she did have it.

After diagnosis she was given medication and they had 5-6 years of very little problem at all. Then she started to wake up in the night saying she couldn't breathe. The Consultant said it was probably anxiety, but she found that it was cured by the Parkinson's medication. She was referred to a Psychiatrist for the anxiety who prescribed another drug to go into the medication mix.

Her dependence on medication increased and she became obsessive. Her breathing problem got worse, she had increasingly difficult nights and the symptoms of tiredness and lethargy worsened. The differences between when she was on and off medication were stark. She was listed as a candidate for deep brain stimulation to try and help with the symptoms.

However, whilst preparing for the operation she had a severe psychotic episode and ended up as an inpatient for 3 months with 1:1 care. The doctors looking after her didn't really know what was going on, was it anxiety or depression, dementia, psychosis?

After 3 months as an inpatient 1:1 care was still required so she was moved to a care home under the continuing healthcare programme. There she saw a Psychiatrist who specialised in Parkinson's and under his care her behaviour has progressively improved.

She is still in a care home today but content, she is able to go out with carers support and has a caring family looking after her.

### **Lessons:**

G's story is not uncommon, patients with Parkinson's can present with a range of symptoms due to the complex nature of the condition. The result of this is patients being bounced from professional to professional due to concerns around mis-diagnosis and poor communication between specialties. This could be improved by a multidisciplinary co-ordinated approach being taken to

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ensure that the right expertise is in the room, and to improve communication between patients, their families and all professionals involved in their care.

## **2.6 The UK Parkinson's Excellence Network**

### ***Daiga Heisters***

After taking some time out in groups to discuss the key challenges and how they could be overcome, we heard from Daiga Heisters, Head of the UK Parkinson's Excellence Network on what they are doing.

The Excellence Network seeks to improve patient care through: Increasing the voice of service users and putting them in control, equipping professionals to influence services, building an expert workforce and working together for change.

More information on the Excellence Network can be found [here](#).

## **2.7 All Party Parliamentary Group on Parkinson's, Mental health matters too**

### ***Laura Cockram***

To finish the day Laura Cockram, Parkinson's UK, summarised the findings of the All Party Parliamentary Group (APPG) on Parkinson's report published in May 2018, the full report can be found [here](#).

The APPG chose to focus the report on support for people with Parkinson's who experience anxiety and depression as these symptoms are the most common and can have a significant impact on quality of life.

The key findings from the report echoed challenges discussed at the meeting:

- There is a historical divide between the commissioning and delivery of physical and mental health services, this leads to poor continuity of care and the onus is often put on the patient to pass on information in consultations.
- There are communication barriers between departments and across trusts leading to difficulties accessing patient notes and ensuring continuity of patient centred care.
- There is a shortage of mental health professionals with the knowledge and skills to meet the specific needs of people with Parkinson's. Depending on the age of the patient and nature of the mental health problems specialist care may be provided by working age adult, or old age psychiatry teams.

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The report makes the following recommendations to tackle the challenges faced:

- Taking a holistic, person centred approach to care with joined-up mental and physical health services.
- Improve data collection on mental health (and dementia) prevalence for people with Parkinson's to help with designing and delivering better services.
- Fund more research into effective mental health interventions for people with Parkinson's.
- Build understanding of the specific needs of people with Parkinson's, sharing best practice and fostering collaboration between physical and mental health professionals.
- Update the NICE guideline on Parkinson's to reflect effective evidence-based interventions for the treatment of depression and anxiety in people with Parkinson's.
- Carers and family members should be supported in addressing their own mental health concerns by professionals and signposted to appropriate voluntary sector (Parkinson's UK) support services.

These recommendations will direct the work of Parkinson's UK around mental health for several years.

**Progress since the report launch:**

- Meeting with NHS England on encouraging Clinical Commissioning Groups (CCGs) to consider including Parkinson's in Improving Access to Psychological therapies long-term condition services.
- Meeting with the National Institute of Health Research to improve signposting of funding announcements and discuss how we can increase research on anxiety and depression in people with Parkinson's.
- Parliamentary meeting with MPs to prepare them to exert pressure on their CCGs around integrating physical and mental health services for people with Parkinson's.

# 3. Themes from group discussion

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## 3.1 Main challenges faced

- The organisational structure of the NHS, often acute and mental health services are in different trusts and are commissioned separately which makes integrating care between them difficult. The same is true for social care services, and links between health and social care are still poor.
- Many Parkinson's patients have complex mental health conditions that do not conform to simple diagnostic categorisation, as a result it is difficult to assess how best to support them; there is a risk that patients are 'bounced' between services resulting in very disjointed care.
- It is difficult to access specialist advice without going back to GP for another referral, some services, such as neuropsychology, are not available in different areas, and there are long waiting lists for certain specialties.
- There is not enough time available in clinic to support the most complex patients, this can lead to poor symptom management and increased healthcare contact in other forms, such as telephone appointments and increased admissions.
- Confidentiality agreements mean that letters don't go to everyone involved in the care of a patient unless explicitly stated that they should, this can prove a challenge to communication. This is compounded by each organisation using different clinical systems that aren't linked to one another.
- Overall communication between professionals in different specialties is poor.
- More research is needed to better understand the range of conditions and how and where these are best treated.

## 3.2 What is needed to improve services

- Normalising multidisciplinary working to improve communication and ensure appropriate expertise.
- Access to appropriate mental health professionals including neuropsychologists, and psychiatrists with experience in working with people with Parkinson's.
- A shared basic set of skills for all multidisciplinary team members with clear step-up and step-down pathways when specialist support is required, joint learning events would help facilitate this.
- Earlier diagnosis of dementia in Parkinson's patients, including identification of people at risk. This will ensure that suitable cognitive strategies can be implemented, and that families and individuals have a clear understanding of their condition.
- Better sharing of information between organisations and professionals through improved electronic communication and shared records.
- Exploring the use of technology and innovative solutions such as virtual clinics to deliver improved services cost-effectively.
- Management support for teams in developing business cases for service improvement.

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### **3.3 What the target outcomes could be**

- Improved patient reported quality of life
- Improved symptom control
- Reduced waiting times for review, diagnosis and treatment
- Reduced emergency admissions
- Reduction in unscheduled healthcare utilisation, both medical and psychiatric
- Reduced falls and hip fractures
- Reduced nursing home admissions
- Reduction in healthcare costs overall e.g. prescribing or appointments

## 4. Actions

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The following actions were identified with general consensus on the day:

- This document to be shared with Getting It Right First Time (GIRFT) Neurology, Geriatric Medicine and Mental Health leads, NHS RightCare and other relevant professionals. Lucy Hawkins, Senior Consultant at The Strategy Unit will take the lead on this with the document to be finalised and shared by October 2018.
- In light of the recent health funding announcement and development of the NHS 10 year plan with as Mental Health a priority area, learning from this event should be incorporated into organisational plans and responses to this proposal in order to provide a joined up approach.
- Parkinson's UK has offered support in campaigning for service improvement and to teams or organisations looking to develop business cases to enable service changes. Interested organisations or teams should contact the UK Parkinson's Excellence Network.
- UK Parkinson's Excellence Network to set up a mental health hub as part of its on-going programme of work. Katie Goates, Professional Communications and Engagement Programme Manager at Parkinson's UK, to take the lead on this and work with clinical champions and have this set up by September 2018.
- NNAG to set up a working group of relevant stakeholders to take the Parkinson's, dementia and psychiatry work forward – setting an agenda for change based on the discussions above and working with NHS England to see these changes taken forward. A lead for this will be identified at the net NNAG meeting, October 2018.

# 5. Appendices

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## Appendix 1 –Event agenda



Thursday 19<sup>th</sup> July 2018

### Agenda

13:00 Welcome and introductions

❖ Adrian Williams and Alistair Burns

Contact: [Adrian.Williams@uhb.nhs.uk](mailto:Adrian.Williams@uhb.nhs.uk) and [alistair.burns@manchester.ac.uk](mailto:alistair.burns@manchester.ac.uk)

13:15 The Future of Dementia Care

❖ Dr Catherine Mummery

Contact: [cath.mummery@nhs.net](mailto:cath.mummery@nhs.net)

13:35 What does good joined up care look like?

❖ Neil Archibald, South Tees NHS Trust

❖ Clare Johnson and Lisa Brown, Derby Teaching Hospitals NHS Foundation Trust

❖ Sandra Mahon and Tracy Williams, Cardiff and Vale UHB

14:35 So what is the problem?

❖ Adrian Williams et al.

❖ A carer's story

15:00 Tea and coffee break

15:15 What could we do better? (Table discussion)

❖ Please see questions on your table

15:50 UK Parkinson's Excellence Network: What's next 2018

❖ Daiga Heisters, Head of Excellence Network, Parkinson's UK

Contact: [dhesiters@parkinsons.org.uk](mailto:dhesiters@parkinsons.org.uk)

16:10 All-Party Parliamentary Group report

❖ Laura Cockram

Contact: [lcockram@parkinsons.org.uk](mailto:lcockram@parkinsons.org.uk)

16:30 Q&A / Discussion

❖ Feedback from focus groups

16:50 Closing remarks and agreed actions

❖ Adrian Williams and Alistair Burns

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## Appendix 2 – Event attendees

<b>Name</b>	<b>Organisation</b>
Aaron Sturrock	University Hospital Birmingham NHS Foundation Trust
Adrian Williams	NHS England / University Hospital Birmingham NHS Foundation Trust
Agata Sematovic	Sweet Tree Home Care Services
Alexis Cibrano	Sweet Tree Home Care Services
Alistair Burns	University of Manchester
Amanda Mobley	Newtown Hospital, Worcestershire
Amanda Thompsell	Faculty of Old Age Psychiatry
Andrea Lindahl	University Hospitals Coventry & Warwickshire
Andreia Ford	Bupa Cromwell Hospital
Andrew Paget	University College London Hospitals NHS Foundation Trust
Annette Andrew	Parkview Centre for Health & Wellbeing
Arshad Rather	University College London Hospitals NHS Foundation Trust
Ashwani Jha	Homerton Hospital, London
Bex Davenport	Manchester University NHS Foundation Trust
Carrie James	Royal Berkshire Foundation Trust
Catherine Mummery	University College London Hospitals NHS Foundation Trust
Cathy Barnes	900 The Crescent, Essex
Clare Johnson	Derby Teaching Hospitals NHS Foundation Trust
Daiga Heisters	Parkinson's UK
Debra Borsley	Airedale General Hospital
Duncan Lugton	Sue Ryder
Emma Teper	30 Felstead Street, London
Faith Insley	Sweet Tree Home Care Services
Gillian Lowes	Administrative Officer
Holly King	Central London Community Healthcare Trust
Ian McKeith	Newcastle University
Jennifer Foley	University College London Hospitals NHS Foundation Trust

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Jeremy Isaacs	St George's University Hospitals NHS Foundation Trust
Jerry Brown	ABN Cognitive group
Joe Korner	The Neurological Alliance
John-Paul Taylor	Newcastle University
Jonathan Bunday	Clarity Training
Josephine Arumugam	University College London Hospitals NHS Foundation Trust
Karen Hamilton	Neurological Nurse Specialists
Katharine McIntosh	The Neurological Alliance
Katherine Carpenter	BPS Division of Neuropsychology
Katie Goates	Parkinson's UK
Kirsten Turner	Neurological Nurse Specialists
Laura Cockram	Parkinson's UK
Lisa Brown	Derby Teaching Hospitals NHS Foundation Trust
Liz Williams	Parkinson's Specialist Practitioner
Lizzie Harrison	Berkshire HealthCare Foundation Trust
Lucy Hawkins	The Strategy Unit
Maddy Alemayehu	Home Instead
Matthew Jones	Salford Royal NHS Foundation Trust
Mehdi Salar Amoli and Mother	Imperial College London
Michael Karran	Alzheimer's Research UK
Michela Simoni	Sandwell and West Birmingham NHS Trust
Neil Archibald	South Tees Hospitals NHS Foundation Trust
Nicky Stapleton	The Health Centre - Hereford
Peter Smith	Talking Cures
Professor Martin Rossor	University College London
Rikki Lorenti	Sweet Tree Home Care Services
Rob Clarke	Integrated Neurological Services (Charity)
Sandra Cox	Parkinson's Nurse
Sandra Glynn	The Whittington Health NHS Trust
Sandra Mahon	Cardiff and Vale University Health Board
Sian Hurren	900 The Crescent, Essex
Soo Wong	Bupa Cromwell Hospital

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Susie Boorman

Neurological Nurse Specialists

Tracey Adey

Berkshire NHS

Tracy Williams

Cardiff and Vale University Health Board

Vicky Glynn

900 The Crescent, Essex

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## **Appendix 3 – Presentations**

Please see presentations attached

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## **Appendix 4 - Development of an Atypical Dementia Clinic in Birmingham**

Following the July event, a team from Birmingham have decided to try and implement some changes in their area. Below outlines their proposal which they hope to be able to develop further over the coming months. If you would like more information, or to be involved, please contact Dr Aaron Sturrock or Professor Adrian Williams (University Hospitals Birmingham NHS Foundation Trust) or Dr Michela Simoni (Sandwell and West Birmingham NHS Trust).

An important challenge for the development of local Parkinson's disease services is ensuring dementia clinics are accessible to all. As already discussed the role of a dementia clinic for Parkinsonian individuals extends beyond diagnosis to offering support and practical input managing the inevitable behavioural deterioration.

At the NNAG meeting an additional issue was raised; the existence of regional discrepancies in the provision of atypical and working age dementia services. This is a clear obstacle to universal support for individuals with dementia – for both those with and without Parkinson's disease.

The 2017 Public Health England data suggests that young onset (under 65s) dementia prevalence rate in West Midlands may be 1.5 times higher than average for England, and one of the highest rates nationally. There is a strong case therefore for developing an exemplary dementia service within the region, particularly for atypical dementias including young onset, and those with associated movement disorder.

In Birmingham, access to the dementia service for 'atypical' or 'complex' cases could be improved. At present many individuals are seen first in general Neurology clinics at University Hospital Birmingham (UHB), often being referred on to the subspecialist Memory Assessment Service (MAS) run by an experienced Psychiatrist for comprehensive neuropsychological input. Conversely where predominant movement disorder or non-neurodegenerative cause is suspected by the Psychiatrist the patient is usually referred onto Neurology. The MAS and UHB are geographically and logistically separated leading to communication issues, prolonged waiting times and significant delay in diagnostic processes. The patient journey simply to diagnosis becomes unnecessarily complicated.

To rationalise this process, we are looking to join up the services at the UHB site, in a consolidated neurology and psychiatry Atypical Dementia Clinic. This unit will aim to emulate the model used by existing neurodegenerative disorder clinics within Neuroscience Centres around the UK. It is planned that non-medical practitioners and nurses trained in administering neuropsychological testing, will work alongside two Neurology Consultants, and Psychiatrist in running the clinic. The aim would be to formulate a 'one stop shop' approach particularly useful for cases where there is a significant

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movement or psychiatric element, with a view to avoiding unnecessary duplication of work. In the near future we would aim to also access the expertise of a social worker, and neuropsychologist.

Other advantages of this Neurosciences centre-based model will be the ability to arrange on-site lumbar punctures to facilitate assessment of CSF biomarkers, as per the recent NICE Guideline, but also provide access to the state-of-the-art University of Birmingham imaging centre that will be useful in utilising the latest biomarker modalities, where appropriate. It is envisaged that this will also provide patients future access to involvement in research opportunities.

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