

**Report to:** SINGLE COMMISSIONING BOARD

**Date:** 14 February 2017

**Officer of Single Commissioning Board** Clare Watson, Director of Commissioning

**Subject:** **EVALUATION OF THE PARKINSON'S DISEASE SPECIALIST NURSE POST**

**Report Summary:** Parkinson's disease is a neurodegenerative movement disorder which commonly occurs in the later years of life. The consequence of inadequate management of the condition can result in poor control of symptoms with medication and side-effects, high levels of disability, mental health problems and increased carer burden, all of which lead to increased dependency on health and social care services

Parkinson's UK pump primed a Parkinson's Disease Specialist Nurse to work in Tameside and Glossop for 18 months. The nurse has been working with the Community Neuro Rehab Team (Community Neuro Rehab Team) and has a wide range of duties in order to support people with a diagnosis of Parkinson's Disease.

An evaluation of the post has been conducted with the aim that the Single Commission will to continue to commission the post if the evaluation shows that the Parkinson's Dedicated Nurse Specialist has had a positive effect on the economy as a whole.

**Recommendations:** The Single Commissioning Board are asked to:-

- (1) Review the evaluation report and Equality and Quality Impact Assessments.
- (2) Agree to continue to commission the Parkinson Dedicated Nurse Specialist as part of the Community Neuro Rehab Team, with the overall aim to support patients and carers in the community and achieve the following outcomes:
  - Ensure a sustained reduction in the number of avoidable admissions,
  - Achieve a reduction in length of stay when an admission occurs,
  - Community Neuro Rehab Team will be the main point of contact for Parkinson's Disease patients and their carers as their condition progresses,
  - Provide training to other health professionals so they can support the long term management of the patient.
- (3) Acknowledge that the funding for the Parkinson Dedicated Nurse Specialist will be covered within the block contract from 2017/18 onwards.

**Financial Implications:** Parkinson's nurse is already included in the signed ICO contract for 2017/18 (funded from the S75). Therefore no funding decision required with regard to this report. However the report presents some interesting data for information which may be used by the Integrated Care Organisation in the future to direct the work of Parkinson's Nurse to best effect.

**(Authorised by the statutory Section 151 Officer & Chief Finance Officer)**

<b>Legal Implications: (Authorised by the Borough Solicitor)</b>	The Funding is accounted for. If it was decided not to continue this would on the face of it represent a saving. However, what needs to be taken into account when making such an evaluation is whether costs will show themselves further up the system and indeed whether they will be greater. To assist in making this determination it is important to consider the equality impact assessment and the health inequalities seeking to reduce.
<b>How do proposals align with Health &amp; Wellbeing Strategy?</b>	<p>The Parkinson Dedicated Nurse Specialist role aligns with the H&amp;WB strategy by:</p> <ul style="list-style-type: none"> <li>• Providing a clear pathway for medical professionals to support the identification and management of people with Parkinson's Disease.</li> <li>• Providing easily accessible support in the community which will increase independence and reduce ill health</li> </ul>
<b>How do proposals align with Locality Plan?</b>	<p>The service is consistent with the following priority transformation programmes:</p> <ul style="list-style-type: none"> <li>• Enabling self-care</li> <li>• Neighbourhood-based management</li> </ul>
<b>How do proposals align with the Commissioning Strategy?</b>	<p>The service contributes to the Commissioning Strategy by:</p> <ul style="list-style-type: none"> <li>• Empowering people to identify the symptoms and manage their own care</li> <li>• Encourage neighbourhood teams to work with the Parkinson Dedicated Nurse Specialist to provide holistic support</li> <li>• Support primary care to manage people who are on their register</li> </ul>
<b>Recommendations / views of the Professional Reference Group:</b>	PRG agreed with the recommendations.
<b>Public and Patient Implications:</b>	The Parkinson Dedicated Nurse Specialist supports people who have been diagnosed with Parkinson's and also their carers. Removing the service could have a negative impact on the patients, carers and the wider health economy.
<b>Quality Implications:</b>	<p>A quality impact assessment has been completed and is attached (Appendix B). If the service is not commissioned it could have an impact on the patients and their carers.</p> <p>The full evaluation documents are collated together and available from Samantha Hogg. These include further details around the quality of the service and include a personal review by the Parkinson Dedicated Nurse Specialist.</p>
<b>How do the proposals help to reduce health inequalities?</b>	The incidence of Parkinson's increases with age. By identifying people early and by supporting and managing people appropriately, it will ultimately improve the length of time that a person is able to control their symptoms.

**What are the Equality and Diversity implications?**

It is anticipated that the proposal to continue to commission the Parkinson Dedicated Nurse Specialist will not have a negative effect on any of the protected characteristic group(s) within the Equality Act. However, removing the service could have a negative impact. An Equality Impact assessment has been completed and is attached (**Appendix A**).

**What are the safeguarding implications?**

It is anticipated that there would be no safeguarding implications.

**What are the Information Governance implications? Has a privacy impact assessment been conducted?**

Information governance is a core element of the NHS. The Tameside and Glossop Integrated Care NHS Foundation Trust, GP Practices and neighbourhood teams would have IG policies in place and they would be expected to adhere to these.

**Risk Management:**

By having the Parkinson Dedicated Nurse Specialist in post, it is expected that there would be a reduction in risk as more people would be supported locally.

**Access to Information :**

The background papers relating to this report can be inspected by contacting Samantha Hogg, Commissioning Development Manager by:



Telephone: 07342 055 999



e-mail: [Samantha.hogg@nhs.net](mailto:Samantha.hogg@nhs.net)

## **1.0 BACKGROUND**

- 1.1 Parkinson's disease is a neurodegenerative movement disorder which commonly occurs in the later years of life. It is estimated that 27.5 per 10,000 people over the age of 65 will develop Parkinson's disease. Therefore in Tameside and Glossop there will currently be over 450 people living with Parkinson's disease. Additionally, prevalence is expected to rise by an increase of 27% nationally by 2020.
- 1.2 The consequence of inadequate management of the condition can result in poor control of symptoms with medication and side-effects, high levels of disability, mental health problems and increased carer burden, all of which lead to increased dependency on health and social care services
- 1.3 Based on the population of Tameside and Glossop, it is estimated that there are currently around 440-480 people living with Parkinson's disease. Most GPs will have an average of 4 or 5 people on their caseload

## **2.0 PURPOSE OF THE ROLE**

- 2.1 The aim of the Parkinson's Nurse Specialist (PNS) is to improve services for people with Parkinson's disease in Tameside and Glossop through the appointment of a PNS as part of local service redesign.
- 2.2 Providing support to people with Parkinson's in hospital or care homes costs much more than other forms of care. Although most patients want to stay at home, the reality has been that community services have not been available to make this happen. Parkinson's nurses can help people to stay at home. It has been estimated that by developing and funding community based services for people with Parkinson's the savings and health costs would be around £56 million, or comparative to 30% of the money spent supporting people in care homes.
- 2.3 The role of the PNS is outlined below, and their role would sit within the integrated Community Neuro rehab Team (Community Neuro Rehab Team):
  - Care coordination for people with Parkinson's Disease and complex needs;
  - Provide clinical monitoring, symptom control and medicine management as well as health promotion and wellbeing;
  - First point of contact for information and signposting once triage has commenced in the integrated service;
  - Support and advice when a person with Parkinson's Disease is admitted to hospital/respite to ensure continuity of their care plan;
  - Expert patient and other self care group education and support sessions;
  - Practice supervision for case managers involved with people with Parkinson's disease on their caseload;
  - Specialist advice and support for other professionals working with an individual patient about specific symptoms/issues;
  - Provision of training to other health and social care professionals and non-qualified staff about PD and its management.

## **3.0 FUNDING**

- 3.1 The post has been pump primed by Parkinson's UK for 18 months. The Parkinson Dedicated Nurse Specialist started in December 2015 and the non-recurrent funding from Parkinson's UK will cease in June 2017.

- 3.2 Parkinson's UK agreed to provide the grant on the proviso that the future funding of the post would be provided by the CCG if the objectives of the service could be met following an evaluation of the service. This report includes the evaluation data.
- 3.3 The grant provided by Parkinson's UK is £12167.40 per quarter, with an annual cost of £48669.60 annual cost. This excluded any on-costs.
- 3.2 If was felt that the most suitable place for the Parkinson Dedicated Nurse Specialist to work was with the Community Neuro Rehab Team. Therefore the Parkinson's nurse payments have been paid to Tameside and Glossop Integrated Care NHS Foundation Trust.

#### 4.0 AUDIT OF WORK (AUGUST 2016)

- 4.1 The audit was undertaken to review the type of work undertaken by the Parkinson Dedicated Nurse Specialist. This information is taken from a snapshot in August 2016.
- 4.2 The work was broken down into a number of functions which included administration, patient time, education and meetings. Of all of these functions, phone calls were the most common (50% of all tasks), with home visits (22%) and administration (19%) being a close second and third (see figure 1). The majority of the contacts were made with patients or their carers/family (82%) followed by other professionals (12%) and the patients GP (5%).

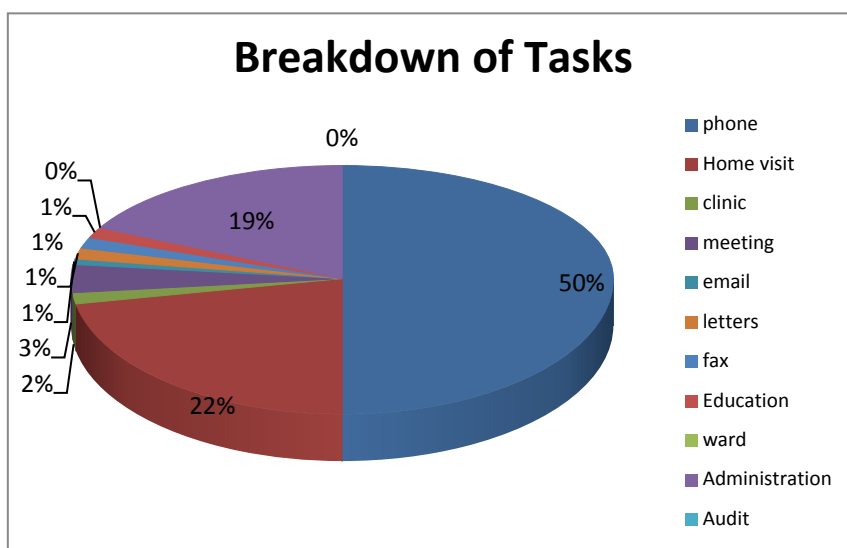


Figure 1: Breakdown of Tasks undertaken by the Parkinson Dedicated Nurse Specialist during August 2016

- 4.3 The reasons for consultation (e.g. phone, home visit, clinic appointment) varied; along with initial contact (23%), advice, support and information covered 53% of the queries. Some of these people then went on to need a home visits/clinic appointment with the nurse (38%), or required a change to their medication (15%); although the majority needed information (43%).

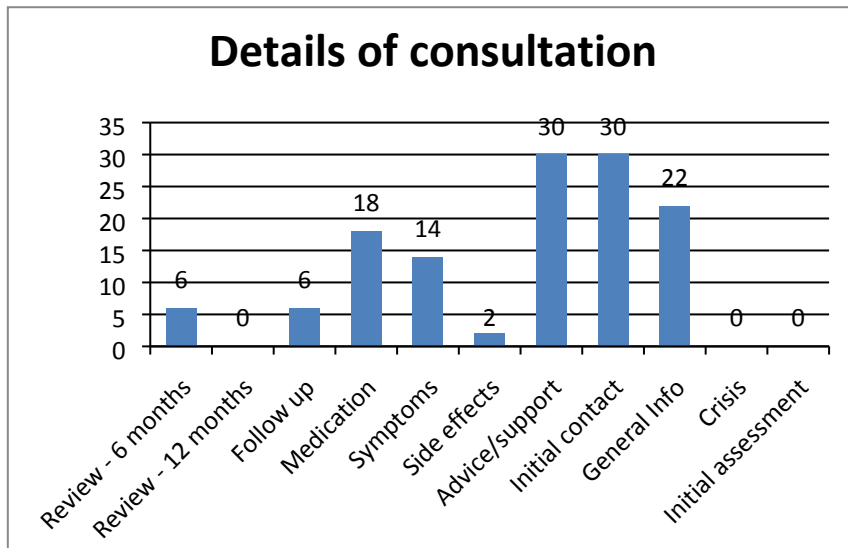


Figure 2: The Breakdown of the consultations undertaken in August 2016

4.4 If the Parkinson Dedicated Nurse Specialist had not been available, the outcomes highlighted in figure 3 would have been likely. The consultant would have been the main point of contact for a large number of people (40%), with the need for a GP appointment either at home or in surgery (24%) or another health professional contact (27%) also common.

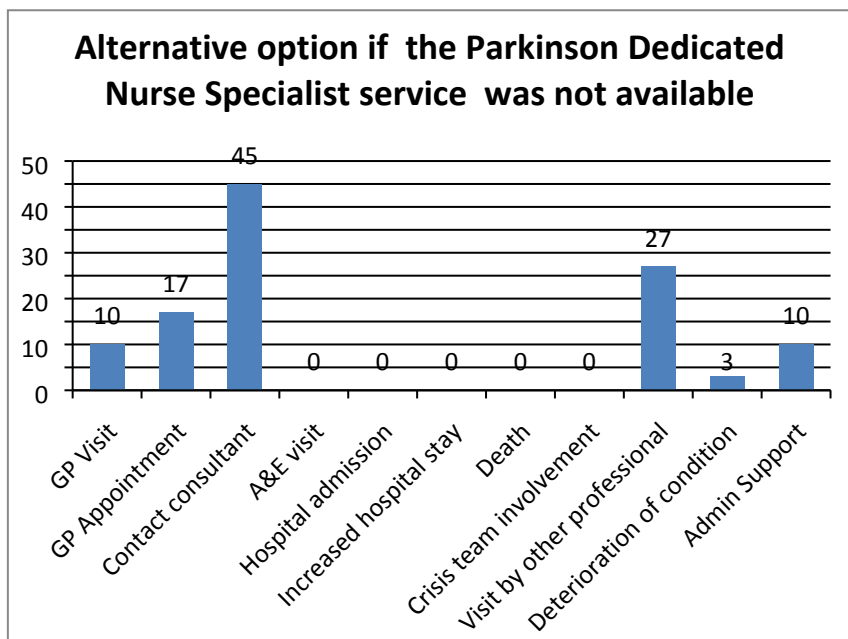


Figure 3: Alternative option if the Parkinson Dedicated Nurse Specialist role did not exist in Tameside and Glossop

## 5.0 ACCESS TO SUPPORT FOR PEOPLE DIAGNOSED WITH PARKINSON'S DISEASE

5.1 The Parkinson Dedicated Nurse Specialist started identifying patients and taking referrals from December 2015. There has been a marked increase in the number of patients who have access to specialist support since the Parkinson Dedicated Nurse Specialist has been in post.

*Table 1: Number of referrals to Community Neuro Rehab Team for support with Parkinson's Disease*

	2014	2015	2016 *	2015 – 2016 Difference
No. Parkinson's Patients accessing Community Neuro Rehab Team	25	60	105	+75%

\* January – October 2016

- 5.2 The Parkinson Dedicated Nurse Specialist will be the point of contact in Community Neuro Rehab Team, but there are also MDT sessions arranged for Occupational Therapists, Speech and Language Therapists, Psychologists and Physiotherapists to provide further specialist support to people diagnosed with Parkinson's disease.
- 5.3 The support from the Parkinson Dedicated Nurse Specialist and Community Neuro Rehab Team is available at home or in a clinic setting and there has been some in reach to the hospital to support discharge.

## 6.0 ADMISSIONS AND ADVICE

- 6.1 Using pseudonymised data, the patients who have been reviewed by the Parkinson Dedicated Nurse Specialist in 2016 were tracked through the system and their Non-Elective Admission in 2016 was compared to previous years. There has been a decrease in the number of non-elective admissions which can be seen as 2016 progresses.

*Table 2: The number of non-elective admissions for people who have had contact with the Parkinson Dedicated Nurse Specialist during 2016.*

Month	2014	2015	2016
Jan	35	35	32
Feb	34	30	20
Mar	25	32	22
Apr	23	25	19
May	28	25	13
Jun	18	39	17
Jul	18	32	19
Aug	32	24	16
Sep	20	29	13
Oct	25	33	12
Nov	14	25	
Dec	30	32	
<b>Total</b>	<b>302</b>	<b>361</b>	<b>183</b>
<b>Apr - Oct Total</b>	<b>258</b>	<b>304</b>	<b>183</b>
<b>Difference</b>		<b>46</b>	<b>-121</b>
		<b>17.8%</b>	<b>-39.8%</b>

- 6.2 When comparing the activity in terms of bed days and actual costs for some of the specific Primary Diagnoses from SUS data, we can see some large reductions, of which some would specifically correlate with the work of the Parkinson Dedicated Nurse Specialist.

*Table 3: 2015 and 2016 bed days and the related expenditure for people with a diagnosis of Parkinson's Disease*

	Bed Days			Spend		
	2015 (12 mths)	2016 * (12 mths)	Increase/ (Decrease)	2015 (12 mths)	2016 * (12 mths)	Increase/ (Decrease)
Bronchopneumonia, unspecified	519	214	(305)	124,371	53,189	(71,182)
Unspecified acute lower respiratory infection	52	24	(28)	16,853	4,184	(12,669)
Parkinson's disease	146	28	(118)	31,650	4,218	(27,432)
Pneumonitis due to food and vomit	245	97	(148)	66,151	18,817	(47,334)
Open wound of scalp	129	18	(111)	26,476	6,775	(19,701)
Congestive heart failure	85	-	(85)	23,561	-	(23,561)
Tetany	29	4	(25)	16,069	4,619	(11,450)
Disorientation, unspecified	144	5	(139)	23,434	3,901	(19,533)
<b>Total</b>	<b>1349</b>	<b>390</b>	<b>(959)</b>	<b>23,434</b>	<b>95,703</b>	<b>(232,862)</b>

(\* = 10 months data used to forecast the position at 12 months)

- 6.3 Looking at these specific Primary Diagnoses with Tariff costs applied, an element of the monetary savings are identified. It has to be highlighted that some of these costs would then offset the demand in the community, and the costs are not a cashable saving for the Single Commission due to the block contract agreement for 2017/18.
- 6.4 The financial information indicates ~£500k saving from 2015 to 2016 (FYE). However, with the increased requirement of community services, this would indicate there is a potential of the activity saving between £250k to £500k.
- 6.5 Further work will be required to develop pathways for people who have been admitted to hospital. The Parkinson Dedicated Nurse Specialist has made an effort to contact ward staff once she is aware that a patient has been admitted. The Parkinson Dedicated Nurse Specialist may be able to train some Parkinson's champions on the wards to help support people who have been admitted. There would need to be further work undertaken with the Urgent Care team to support patients to remain in their own home.
- 6.6 The Parkinson Dedicated Nurse Specialist has supported the hospital pharmacists with the medication requirements of inpatients with a diagnosis of Parkinson's Disease and has developed a safety bulletin for the hospital to use. This has helped to ensure the optimum



dose of medication is provided at the correct time to reduce the likelihood of the person “going off” and losing their independence. If a person does not receive their medication at the right time (which is often not at the usual medication times on the ward), the person is more likely to stiffen and may need help to go to the toilet, may have difficulty swallowing, and in the worst cases, they may become completely frozen.

## 7.0 REDUCTION IN MEDICAL APPOINTMENTS AND CONTACTS

7.1 Using the review undertaken in August, it is estimated that there would have been 45 less consultant contacts, 17 less GP contacts, and 10 less GP home visits. Assuming this is a typical month, there would be 540 less consultant contacts (which could then lead to appointments), 204 GP contacts, and 120 less GP home visits in a year. Using the cost of the Parkinson Dedicated Nurse Specialist vs clinician as a rough guide, the savings could be:

*Table 3: Assumptions about time saved by having a Parkinson Dedicated Nurse Specialist in post*

	<b>Annual contacts</b>	<b>Saving</b>
Consultant contacts	540	£11,070
GP contacts	204	£816
GP home visits	120	£1,440
<b>Total saving</b>		<b>£13,326</b>

7.2 Even though this is a potential saving, it is not a guaranteed cashable saving available within the system as these would have been additional requirements. However, it does represent the reduction in need for appointments and better management of patients.

7.3 The Parkinson Dedicated Nurse Specialist is able to identify suitable patients for Apo-morphine, undertakes the planning and Apo-morphine challenge at a local level. This has been undertaken in Tameside in a GP Practice and the patient was then followed up at home. If there was no Parkinson Dedicated Nurse Specialist, consultants would have to refer to Salford Royal to the Advanced Therapies clinic for assessment and potential admission. This demonstrates integrated local working with GP, Consultant and patient to ensure cost savings, and reduction in stress for patients by not going in to hospital.

## 8.0 AWARENESS RAISING AND WORKING WITH COLLEAGUES

8.1 The Parkinson Dedicated Nurse Specialist has delivered training to GPs, nurses, Community Neuro Rehab Team, hospital Pharmacists, Willowood Hospice, and the hospital SALT team.

8.2 There have also been meetings held with the local mental health team and meetings with the IV and Urgent Care teams. The Parkinson Dedicated Nurse Specialist has also met with practice managers, set up a stand at the hospital for Parkinsons awareness week and has presented at the Indian Community Centre.

8.3 The Parkinson Dedicated Nurse Specialist has also attended the PDSNA National Conference.

## 9.0 FEEDBACK FROM SERVICE USERS, CARERS, COLLEAGUES

### Service Users and Carers

- 9.1 Twelve patients/carers from the Tameside and Glossop Parkinson's Disease support group completed questionnaires. Overall they felt that the Parkinson Dedicated Nurse Specialist service had been useful as they were able to ask for advice without having to try to contact their consultant. Also the Parkinson Dedicated Nurse Specialist nurse has also been able to help when appointments with the consultants have been a delayed or when the follow up appointment with the consultant is not yet due.
- 9.2 Some patients struggle to access support from the consultants and others make a GP appointment in order to ask for an appointment with the consultant. This is no longer required as the Parkinson Dedicated Nurse Specialist can provide support. Someone also felt that the support of the Parkinson Dedicated Nurse Specialist had helped them to remain living at home.
- 9.4 At least 5 of these patients have to visit their consultant in Oldham or Salford. This level of travel can be challenging for some people with a diagnosis of Parkinson's Disease.

### Primary care

- 9.6 Four GPs responded to a survey. Three had previously been unable to gain specialist Parkinson's advice, and suggested that having someone to speak to quickly about medication and admission avoidance is helpful. They also felt it was important for someone to help support the whole Parkinson's pathway for the patient, GP and consultant. All practices suggested they would be willing to share practice data to identify patients who have not had a follow up so they could be supported by the Parkinson Dedicated Nurse Specialist.

### Consultants

- 9.8 Four consultants from a range of Hospitals completed questionnaires. Their responses were outstandingly positive; all felt that the Parkinson Dedicated Nurse Specialist had provided support which had reduced the need for extra consultant appointments and had supported a reduction in hospital admissions.

**"Prior to the Parkinson Dedicated Nurse Specialist taking up her post it was commonplace for the patients from Tameside and Glossop area to call with problems and request or require an earlier outpatient appointment. They had no local nurse specialist to call instead and I had no-one to refer the queries on to. It got to the point where I was contemplating stopping taking new referrals from that area as it was plain that the clinic burden was too great. The Parkinson Dedicated Nurse Specialist was known to me from her previous Parkinson Dedicated Nurse Specialist experience and her impact was immediate. I haven't had to bring a single patient back to clinic earlier in the last ten months since she has been in post as the Parkinson Dedicated Nurse Specialist."**

**Dr Jason Raw, Consultant Physician, Pennine Acute NHS Trust.**

## 10.0 PATIENT WELLBEING

- 10.1 As part of the Initial appointment, all Parkinson's patients are asked to identify an area they would like to improve and this is logged using the Canadian Occupational Performance measure (COPM). A small audit of 15 patients has shown that all 15 have made

improvements in their COPM score. The tasks the people wanted to achieve included transferring from bed/chair/car, showering, dressing, sleeping and eating/drinking.

- 10.2 The Parkinson Dedicated Nurse Specialist has also been working with a Physiotherapist and a technical instructor and has set up new accessible activities. Line dancing was one of these activities and the 6 week course had 8 participants. The group provided positive feedback.

## **11.0 NICE GUIDELINES**

- 11.1 NICE Clinical Guideline 35 and R77 are being met.

## **12.0 FUTURE COMMISSIONING**

- 12.1 The Parkinson Dedicated Nurse Specialist is knowledgeable about the progression of Parkinson's Disease and is skilled in supporting people to manage their care. The Parkinson Dedicated Nurse Specialist has worked closely with colleagues in Community Neuro Rehab Team and this has become a mutually beneficial partnership; therefore it would be beneficial for the post to remain in Community Neuro Rehab Team. There will be an aspect of in-reach and training for secondary care colleagues, however, the main focus would be to provide support in the community.

- 12.2 With this in mind, it would be anticipated that the Parkinson Dedicated Nurse Specialist (as part of Community Neuro Rehab Team) would:

- Achieve a sustained reduction in the number of avoidable admissions,
- Achieve a reduction in LOS when an admission occurs,
- be the main point of contact for Parkinson's Disease patients and their carers as their condition progresses,
- Provide training to other health professionals so they can support the long term management of the patient.

- 12.2 Almost a fifth of the tasks undertaken by the Parkinson Dedicated Nurse Specialist is administration. A large proportion of this could be completed by an administration assistant so that the Parkinson Dedicated Nurse Specialist could spend more time spent with patients. The future commissioning of the Parkinson Dedicated Nurse Specialist would recommend that more time is spent undertaking clinical work and less undertaking administration duties.

## **13.0 HOST EMPLOYER**

- 13.1 The post is currently situated with Community Neuro Rehab Team which is part of Tameside and Glossop Integrated Care Foundation Trust. The Community Neuro Rehab Team have found that the Parkinson Dedicated Nurse Specialist has provided additional knowledge and expertise and therefore it is proposed that the Parkinson Dedicated Nurse Specialist would remain as part of Community Neuro Rehab Team.

## **14.0 RECOMMENDATIONS**

- 14.1 As set out on the front of the report.

<b>Subject / Title</b>	Continuation of the Parkinson's Disease Specialist Nurse Service
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<b>Team</b>	<b>Department</b>	<b>Directorate</b>
Transformation	Commissioning	Single Commissioning Function

<b>Start Date</b>	<b>Completion Date</b>
01.09.16	19.01.17

<b>Project Lead Officer</b>	Samantha Hogg
<b>Contract / Commissioning Manager</b>	Alison Lewin
<b>Assistant Director/ Director</b>	Clare Watson

<b>EIA Group</b> (lead contact first)	<b>Job title</b>	<b>Service</b>
Samantha Hogg	Commissioning Development Manager	Commissioning
Elizabeth Hartley	Parkinson's Disease Specialist Nurse	Community Neuro Rehab Team (TGICFT)
Rebecca Ward-Dooley	Area Development Manager	Parkinson's UK
Cheryl Madeley	Clinical Pathway Lead	Tameside and Glossop Integrated Care NHS Foundation Trust (TGICFT)

**Tameside & Glossop Single Commissioning Function  
 Equality Impact Assessment (EIA) Form  
 PART 1 – INITIAL SCREENING**

<p><b>1a.</b></p>	<p><b>What is the project, proposal or service / contract change?</b></p>	<p>Parkinson’s Disease (PD) is a neurodegenerative movement disorder which commonly occurs in the later years of life. The consequence of inadequate management of the condition can result in poor control of symptoms with medication and side-effects, high levels of disability, mental health problems and increased carer burden, all of which lead to increased dependency on health and social care services</p> <p>Parkinson’s UK pump primed a Parkinson’s Disease Specialist Nurse (Parkinson Dedicated Nurse Specialist) to work in Tameside and Glossop for 18 months. The nurse has been working with the Community Neuro Rehab Team (Community Neuro Rehab Team) and has a wide range of duties in order to support people with a Diagnosis of Parkinson’s Disease.</p> <p>An evaluation of the post has been conducted with the aim that the Single Commission will to continue to fund the post if the evaluation shows that the post has had a positive effect on the economy as a whole.</p> <p>The proposal is that the service will continue to be funded; however, this EIA will look at the impact of the proposal not being accepted and what would happen if the service is discontinued.</p>
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<b>1b.</b>	<p><b>What are the main aims of the project, proposal or service / contract change?</b></p>	<p>The role of the Parkinson Dedicated Nurse Specialist is outlined below, and their role would sit within the Community Neuro rehab Team (Community Neuro Rehab Team):</p> <ul style="list-style-type: none"> <li>• Care coordination for people with Parkinson’s Disease and complex needs</li> <li>• Provide clinical monitoring, symptom control and medicine management as well as health promotion and wellbeing</li> <li>• First point of contact for information and signposting once triage has commenced in the integrated service</li> <li>• Support and advice when a person with Parkinson’s Disease is admitted to hospital/respite to ensure continuity of their care plan</li> <li>• Expert patient and other self care group education and support sessions</li> <li>• Practice supervision for case managers involved with people with Parkinson’s disease on their caseload.</li> <li>• Specialist advice and support for other professionals working with an individual patient about specific symptoms/issues.</li> <li>• Provision of training to other health and social care professionals and non-qualified staff about PD and its management</li> </ul> <p><b>This Equality Impact Assessment will highlight what would happen if this role is no longer available.</b></p>
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<b>1c. Will the project, proposal or service / contract change have either a direct or indirect impact on any groups of people with protected equality characteristics?</b>				
<b>Where a direct or indirect impact will occur as a result of the project, proposal or service / contract change please explain why and how that group of people will be affected.</b>				
Protected Characteristic	Direct Impact	Indirect Impact	Little / No Impact	Explanation
Age	X			The prevalence of Parkinson’s Disease increases with age.
Disability	X			Parkinson’s Disease is a neurodegenerative movement disorder which will not improve. It is a long term

				condition which could lead to permanent disability
Ethnicity	X			Parkinson's UK are undertaking research in the UK, but research from the USA suggests people from white ethnic backgrounds are more likely to develop PD
Sex / Gender	X			Parkinson's UK are undertaking research in the UK, but research from the USA suggests males may be slightly more likely to develop PD
Religion or Belief			X	
Sexual Orientation			X	
Gender Reassignment	X			As with Sex/Gender, there could be some impact if the Parkinson Dedicated Nurse Specialist service was not available.
Pregnancy & Maternity			X	
Marriage & Civil Partnership			X	
<b>NHS Tameside &amp; Glossop Clinical Commissioning Group locally determined protected groups?</b>				
Mental Health	x			Certain mental health problems, like depression and disturbances are complications of Parkinson's disease and/or its treatment.
Carers	x			People with Parkinson's may deteriorate more rapidly and this may put extra pressure on their carers
Military Veterans			x	
Breast Feeding			x	
<b>Are there any other groups who you feel may be impacted, directly or indirectly, by this project, proposal or service / contract change? (e.g. <i>vulnerable residents, isolated residents, low income households</i>)</b>				
<b>Group (please state)</b>	<b>Direct Impact</b>	<b>Indirect Impact</b>	<b>Little / No Impact</b>	<b>Explanation</b>

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Wherever a direct or indirect impact has been identified you should consider undertaking a full EIA or be able to adequately explain your reasoning for not doing so. Where little / no impact is anticipated, this can be explored in more detail when undertaking a full EIA.

1d.	Does the project, proposal or service / contract change require a full EIA?	Yes	No
		x	
1e.	What are your reasons for the decision made at 1d?	There would be an impact on people with Parkinson's disease if the service was no longer funded. It is not necessarily discrimination, but there would be a gap in support which could be detrimental to the health and wellbeing of those diagnosed with Parkinson's and those who care for someone with Parkinson's.	

## **PART 2 – FULL EQUALITY IMPACT ASSESSMENT**

2a. Summary
<p>Historically patients with a diagnosis of Parkinson's disease, Parkinsonism or Atypical Parkinson's in the Tameside and Glossop area have been referred to consultants across Greater Manchester (GM). The point of contact for patients for support, early review and crisis intervention was either through their GP or consultants secretary. This group of patients can present with complex needs and multiple pathology. Carers can be under strain. Early referral to the community neuro rehab team Community Neuro Rehab Team can support people with a new diagnosis and promote well-being. However referrals to this service is dependent upon a good knowledge of local services. Parkinson's patients known previously to Community Neuro Rehab Team are able to self-refer back as required. Before the Parkinson Dedicated Nurse Specialist was in post, there were no set community clinics in place and Parkinson's patients who needed assessment for Apo-morphine would be referred to Salford Royal which could lead to hospital admission.</p> <p>An 18 month pump primed community post was agreed with Parkinson's UK and Tameside and Glossop CCG. The appointment required an autonomous nurse who has had exposure to caring for people with Parkinson's, non-medical prescriber and community practitioner. Nurses who take on this specialist role often need to have sufficient knowledge and experience to be immediately up and running due to the short period in which evidence is required to show an impact. Parkinson's nurses', who are based within a well-established functioning Community Neuro Rehab Team, enhance the service for both patients and Community Neuro Rehab Team by increasing the number of referrals and providing patients with timely access to the multi-disciplinary team.</p> <p>The Parkinson Dedicated Nurse Specialist has now been in post for 12 months and an evaluation</p>



has been completed. This has shown that the Parkinson Dedicated Nurse Specialist (as part of the Community Neuro Rehab Team) has had a positive impact on hospital admissions, has received a lot of positive feedback from patients and clinicians and has set up local services which have reduced the need for travel/admission.

The 18 month funding will cease in June 2017. It is recommended that the service continues, however, this EIA considers what would happen if the service was to stop.

## 2b. Issues to Consider

1. PD is a long-term condition and therefore meets the statutory definition of disability under the Equality Act 2010. Regular reviews are required as each person's needs will vary greatly. As the condition progresses, medication issues become more critical, and so regular adjustments are required. Also, the amount of care needed to support people in the community will increase. Parkinson's Disease will increase over time due to the aging population. It is anticipated it could increase by as much as 27%.
2. The aim of the PD nurse is to support people to better manage their condition in a holistic way which is also in line with the local commissioning strategy. By removing the nurse, there would be a gap which could then have a negative effect on those diagnosed with PD and also those who care for someone with PD.
3. Parkinson's UK have now set up Parkinson Dedicated Nurse Specialist service in all of the GM areas, therefore by removing the service, T&G would be the only area not to have a specialist nurse.
4. The financial information indicates ~£500k saving from 2015 to 2016 (FYE). However, with the increased requirement of community services, this would indicate there is a potential of the activity saving between £250k to £500k
5. There has been engagement with patients, carers, consultants, the Community Neuro Rehab Team and Primary Care. All felt that there was a need for a service which would co-ordinate care for patients. The consultant has found that it is particularly important as the clinic would not be continuing to take on patients without the support of the Parkinson Dedicated Nurse Specialist. Engagement included:

Audience	Approach	Key Findings
Patients & Carers	Sept 16= twelve people – Questionnaire given out to the local Parkinson's support group	<ul style="list-style-type: none"> <li>• Overall they felt that the Parkinson Dedicated Nurse Specialist service had been useful as they were able to ask for advice without having to try to contact their consultant. Also the Parkinson Dedicated Nurse Specialist nurse has also been able to help when appointments with the consultants have been a delayed or when the follow up appointment with the consultant is not yet due.</li> <li>• Some patients struggle to access support from the consultants and</li> </ul>

		<p>others make a GP appointment in order to ask for an appointment with the consultant. This is no longer required as the Parkinson Dedicated Nurse Specialist can provide support. Someone also felt that the support of the Parkinson Dedicated Nurse Specialist had helped them to remain living at home.</p> <ul style="list-style-type: none"> <li>• At least 5 of these patients have to visit their consultant in Oldham or Salford. This level of travel can be challenging for some people with a diagnosis of Parkinson's Disease</li> </ul>
Consultants from GM Hospitals	Sept 16 = four consultants – Questionnaire	<ul style="list-style-type: none"> <li>• Their responses were outstandingly positive; all felt that the Parkinson Dedicated Nurse Specialist had provided support which had reduced the need for extra consultant appointments and had supported a reduction in hospital admissions</li> </ul>
Primary Care	Oct 16 = four clinicians – online questionnaire available for 4 weeks	<ul style="list-style-type: none"> <li>• They felt it was important for someone to help support the whole Parkinson's pathway for the patient, GP and consultant.</li> </ul>

6. The Parkinson Dedicated Nurse Specialist has provided training to staff from a number of clinical backgrounds. This has helped to improve awareness of medications, awareness of the Parkinson's pathways and the impact of Parkinson's on the person's life.
7. The Parkinson Dedicated Nurse Specialist will ensure that appropriate and timely referrals are made to essential services (such as other therapies or social care)

## 2c. Impact

This EIA evidences that a lack of a Parkinson Dedicated Nurse Specialist would impact upon patients across a number of protected characteristic groups. If the nurse was no longer available there could be:

- An increase in admissions (locally it appears to have reduced hospital admissions by 50%),
- An increase in consultant appointments/contacts (locally it is anticipated there would have been 540 more contacts) and GP appointments (204 clinic visits, 120 home visits)
- Consultants may have to cap patient waiting lists due to the high volume of contacts/appointments required (feedback from consultant)
- Less support for Carers (the Parkinson Dedicated Nurse Specialist will empower and educate patients and carers, including running courses and explaining about medication and symptoms)
- A reduction in working age people being able to work (this is twofold – one for the person diagnosed with Parkinson's and also their carer/family members).

Having a Parkinson Dedicated Nurse Specialist in post is good practice and will help the system as

a whole. Engagement suggests this post is important and if removed, there would be an impact on the people diagnosed with Parkinson's disease, who tend to be older and will require extra support from carers.

The Parkinson Dedicated Nurse Specialist has also helped the hospital staff to become more aware and responsive to Parkinson's patients and the Parkinson Dedicated Nurse Specialist is working closely with End Of Life colleagues with the aim to reduce avoidable admissions near the end of life.

**2d. Mitigations** (Where you have identified an impact, what can be done to reduce or mitigate the impact?)

<i>There would be an increase in the number of consultant / GP contacts if the nurse was not available</i>	<p><i>Due to the financial / funding constraints, it would be difficult to mitigate the impacts of not having a Parkinson Dedicated Nurse Specialist.</i></p> <p><i>There may need to be investment in self care / self management to encourage and equip people to manage their condition. This would link into the neighbourhood and healthy lives workstream.</i></p> <p><i>There may be a cap on referrals and so there would need to be thoughts about commissioning further consultant clinics.</i></p> <p><i>There may need to be further investment in formal carers</i></p>
<i>Increased admissions</i>	
<i>Poor self-care</i>	
<i>Increased hours for carers</i>	

**2e. Evidence Sources**

*McMahon (1999) Parkinson's Disease Nurse Specialist: An important role in disease management. Neurology, 57(7)*

*Parkinson's Nurses: Affordable, Local, Accessible, and Expert Care. A Guide for Commissioners in England (2011).*

<https://www.parkinsons.org.uk/sites/default/files/publications/download/english/englandnursereport.pdf>

*NICE Clinical Guideline 35 (June 2006). Parkinson's disease – Diagnosis and management in primary and secondary care*

*Questionnaires completed by patients, carers, consultants and primary care*

*Financial and activity figures prepared by Tameside and Glossop Single Commission*

*Audit of Parkinson Dedicated Nurse Specialist workload – August 2016 (then extrapolated to forecast for 12 months)*

**2f. Monitoring progress**

<b>Issue / Action</b>	<b>Lead officer</b>	<b>Timescale</b>
<i>A review of service offers for Parkinson's patients and carers if the Parkinson Dedicated Nurse Specialist funding is not extended</i>	<i>SH</i>	<i>April 2017</i>

<b>Signature of Contract / Commissioning Manager</b>	<b>Date</b>
<b>SHOGG</b>	<b>19.01.17</b>
<b>Signature of Assistant Director / Director</b>	<b>Date</b>

**Title of scheme: Continuation of the Parkinson's Disease Specialist Nurse Service**

**Project Lead for scheme: Samantha Hogg**

**Brief description of scheme:**

Parkinson's Disease (PD) is a neurodegenerative movement disorder which commonly occurs in the later years of life. The consequence of inadequate management of the condition can result in poor control of symptoms with medication and side-effects, high levels of disability, mental health problems and increased carer burden, all of which lead to increased dependency on health and social care services

Parkinson's UK pump primed a Parkinson's Disease Specialist Nurse (Parkinson Dedicated Nurse Specialist) to work in Tameside and Glossop for 18 months. The nurse has been working with the Community Neuro Rehab Team (Community Neuro Rehab Team) and has a wide range of duties in order to support people with a Diagnosis of Parkinson's Disease.

An evaluation of the post has been conducted with the aim that the Single Commission will continue to fund the post if the evaluation shows that the post has had a positive effect on the economy as a whole.

The proposal is that the service will continue to be funded; however, this QIA will look at the impact of the proposal not being accepted and what would happen if the service is discontinued.

The potential impact of not commissioning a Parkinson Dedicated Nurse Specialist include:

- An increase in admissions (locally it appears to have reduced hospital admissions by 50%),
- An increase in consultant appointments/contacts (locally it is anticipated there would have been 540 more contacts) and GP appointments (204 clinic visits, 120 home visits)
- Consultants may have to cap patient waiting lists due to the high volume of contacts/appointments required (feedback from consultant)
- Less support for Carers (the Parkinson Dedicated Nurse Specialist will empower and educate patients and carers, including running courses and explaining about medication and symptoms)
- A reduction in working age people being able to work (this is twofold – one for the person diagnosed with Parkinson's and also their carer/family members).

What is the anticipated impact on the following areas of quality? <a href="#">NB please see appendix 1 for examples of impact on quality.</a>						What is the <a href="#">likelihood</a> of risk occurring?	What is the overall <a href="#">risk score</a> (impact x likelihood)			
	Negligible 1	Minor 2	Moderate 3	Major 4	Catastro phic 5	1-5	Low 1-5	Moderate 6-12	High 15-25	Comments
<b>Patient Safety</b>		x				2	4			It is not anticipated that there would be any direct patient safety implications but there may be some indirect implications due to the condition not being as proactively and effectively managed.
<b>Clinical effectiveness</b>			x			2	6			There may be an increase in patients experiencing poor control of symptoms (e.g. due to medication/side-effects) which could lead to higher levels of disability, mental health problems and increased carer burden. By removing the Parkinson Dedicated

											Nurse Specialist, it could lead to an increase in admissions to hospital for Parkinson's patients.
<b>Patient experience</b>	x					4	4				There may be some complaints received if the service was not recurrently funded.
<b>Safeguarding children or adults</b>	x					2	2				It is not anticipated that the having no Parkinson Dedicated Nurse Specialist in post would lead to any safeguarding incidents.
<b>Human resources/ organisational development/ staffing/ competence</b>	x					2	2				There could be some effect as the Parkinson Dedicated Nurse Specialist runs training events and has supported other members of staff to appropriately manage patients
<b>Statutory duty/ inspections</b>	x					5	5				If there was no Parkinson Dedicated Nurse Specialist in post, it would be difficult to achieve

										NICE Guidelines
<b>Adverse publicity/ reputation</b>		x				2	4			There may be some negativity if there is no longer a service to meet the public's expectations
<b>Finance</b>		x				5		10		Removing the Parkinson Dedicated Nurse Specialist could lead to an increase in admissions to hospital for Parkinson's patients.
<b>Service/business interruption</b>					x	4			20	If funding the Parkinson Dedicated Nurse Specialist is not an option, then the local community service would not exist and this would have consequences for the patients and carers. There would potentially increase admissions, and increase the need for formal carers and GP appointments.



<b>Environmental impact</b>	x					1	1			It is not anticipated that there would be any effect on the environment.
<b>Compliance with NHS Constitution</b>		x				4		8		There would be some impact as removing the service would have an impact on some of the protected characteristics groups (see EIA) and there could be a question raised regarding value for money if patients have to contact consultants/GPs instead of a Parkinson Dedicated Nurse Specialist
<b>Partnerships</b>	x					3	3			It is anticipated that there could be some impact on partnerships but this would be kept to a minimum
<b>Public Choice</b>		x				3		6		Having no Parkinson Dedicated Nurse Specialist available would affect choice, particularly if there are Parkinson Dedicated Nurse

										Specialist nurses available in the other areas of GM.
<b>Public Access</b>		x				5		10		There would no longer be access to this service, however, the patients could still access care elsewhere

Has an equality analysis assessment been completed?	YES	If the funding for the Parkinson Dedicated Nurse Specialist was not put in place, there could be an negative impact on some of the protected characteristics groups
Is there evidence of appropriate public engagement / consultation?	Yes	Engagement with patients, carers, consultants and GPs has been undertaken.