Wiltshire Council

Health and Wellbeing Board

26 September 2019

Subject: Specialist Parkinson's Nurses to Enhance Neurology Nursing Provision for Wiltshire residents

Executive Summary

A review of specialist Parkinson's nurse provision in the County has highlighted a service gap for North Wiltshire patients. The Paper identifies the issues, highlights the service in the rest of Wiltshire and recommends a preferred option to enhance this service to deliver improvements in provision and greater equity of access.

Proposal(s)

It is recommended that the Board note proposals to enhance Parkinson's nurse provision in the GWH Community Neurology Team; and support the next steps to agree the recommended way forward and commission enhanced service with the support of Parkinson's UK.

Reason for Proposal

Identification of service variation for North Wiltshire residents accessing Parkinson's nursing care and support.

Ted Wilson

Community and Joint Commissioning Director

Wiltshire CCG

Specialist Parkinson's Nurses to Enhance Community Neurology Nursing Provision for Wiltshire residents

Purpose

The purpose of this paper is to examine the current provision for patients with Parkinson's disease in Wiltshire, identify any service gaps and consider options for improving provision across the County.

Background

Current guidelines recommend that people with Parkinson's disease should receive specialist review at least every six months, whatever the stage of their condition, usually provided by a consultant and Parkinson's disease nurse specialist (PDNS). A recent Parkinson's UK national audit of patient experience, found that 60% have not seen the community nurse within the last year and some regions have a limited specialist service, although in the South West most CCGs have a PDNS.

Current Provision

In Wiltshire, the CCG commissions its adult community provider, Wiltshire Health and Care (WH&C) across the County to provide generic neurological community nursing and therapy support. These neurologically trained nurses support patients with a wide range of neurological conditions. Specialist nurses, exclusively for specific diseases such as Parkinson's are not provided across Wiltshire, however, Swindon CCG have approximately two years ago invested, with the support of Parkinson's UK, a dedicated Parkinson's specialist nursing team linked to the GWH neurology team. Swindon are therefore able to offer a seamless specialist service to its patients, across primary and secondary care, who suffer from Parkinson's disease, whilst Wiltshire patients who are GWH facing, do not have that continuity of care. This has resulted in complaints and criticisms from patients, Parkinson's UK, councillors and local MPs in North Wiltshire, who are critical of this fragmented and inequitable neurology service, whilst Swindon residents receive an effective "one stop" service for all their medical and specialist nursing needs.

WH&C provides a wide range adult community services for Wiltshire within a 'block activity' contract. Within this contract there is a service specification to provide support within the community to those with neurological conditions. WH&C currently provide eleven community teams, based in three localities in the county. Each locality has a neurology nurse and therapists within each team (Occupational Therapists and Physiotherapists) who run clinics in the community and offer some home based support. Most of their work is with Multiple Sclerosis and Parkinson's patients. In addition, there are neuro-physiotherapists in the acute hospital outpatient departments.

WH&C have increasingly been challenged to meet the growing demand across Wiltshire for an effective neurology service with a limited resource (3.6 FTE) and without any specialist Parkinson's provision as these patients are supported for the duration of their lives. WH&C have recently appointed a speech and language therapist to the post in the North. In South Wiltshire a Band 6 nurse sees patients with a diagnosis of Multiple Sclerosis which enables the Community Neurology Lead to concentrate on all the remaining caseload; Salisbury Hospital Foundation Trust (SFT) have a PDNS within their hospital as part of their Consultant Neurology Team, whilst the Royal United Hospital in Bath (RUH) also provides dedicated PDNS service as part of the neurology team. Nevertheless, the Great Western Hospital (GWH) provides a PDNS service for Swindon residents only, but not for Wiltshire

residents who are referred to the community neurology service at Chippenham Hospital led by a neurology advanced practitioner trained Speech and Language Therapist.

Due to the high level of demand for these clinicians in North Wiltshire, the service is delivered within an outpatient model with limited time available for home visits. The Neurology Lead aims to review each patient six monthly, an appointment that will complement a Consultant review. The Neurology Lead will use this time to review the patient's symptoms, sign post for support and refer to other services as required. Patients are provided with the means to contact the practitioner if they need additional input prior to the next appointment. These staff are imbedded in the Community Teams therefore should a patient's needs change rapidly they can quickly facilitate a review by the community team to address this changing need.

Notwithstanding this, the Wiltshire patients facing GWH do have a more limited and fragmented service than Swindon patients, which is perpetuating a two tier service and subsequent complaints and criticisms of a post code service for those suffering from Parkinson's disease. A GWH Community business case is enclosed which would address this inequity and provide a seamless service for Wiltshire residents who have Parkinson's disease who are referred to the GWH Neurology Team.

Demand on GWH Community Neurological Nursing Team

Table 1 below illustrates the activity since April 2017 on the community neurology team. The reduction in this activity is correlated by the loss of a neurology nurse in North Wiltshire, which took six months to replace.

Table 1: Activity of neurology patients for the community teams

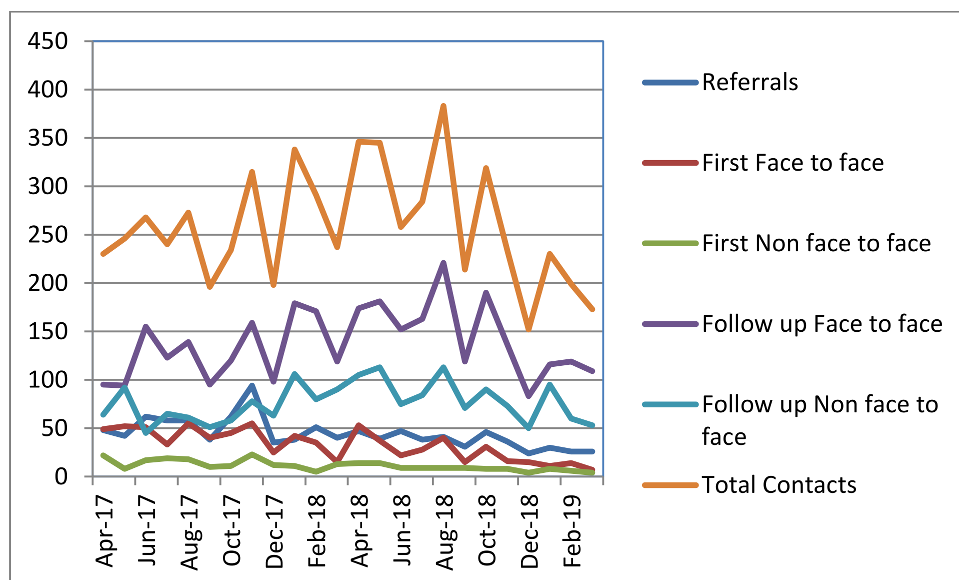
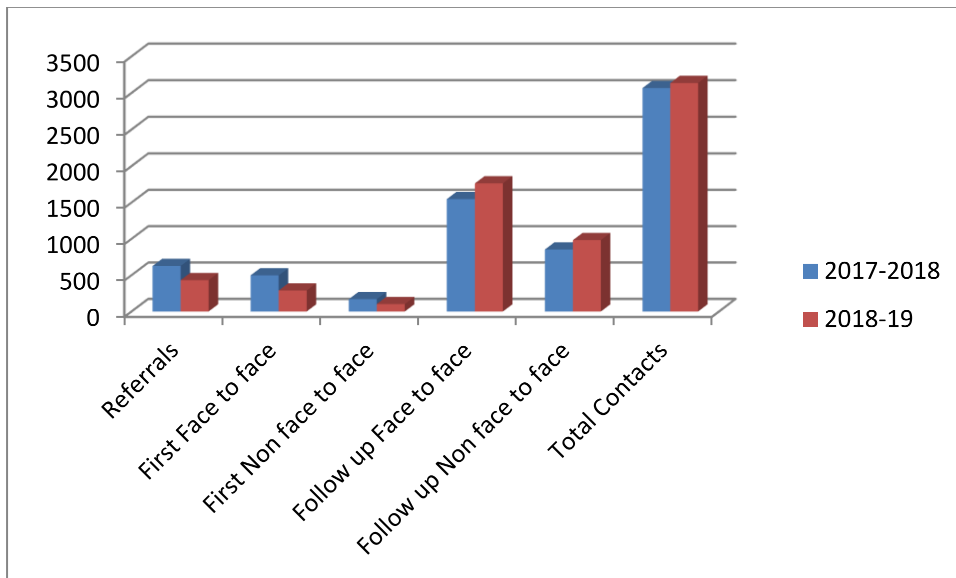


Table 2: Last two year totals by referral type and totals



In table 2 above initial referrals and first appointments either face to face or non-face to face are all lower in the most recent year of analysis, however, follow ups have increased which has resulted in a higher total contacts figure for 18/19 compared to the previous year.

Addressing the Provision Gap

Parkinson's UK has identified Wilshire as one of the areas where there is a shortage of specialist PD nurses, specifically in the north of the county. Since the inception of CCGs, eleven posts had been part funded by Parkinson's UK in the south west. All eleven had been taken on by the CCGs after the initial funding period (usually 18-24 months).

The key focus of service gap in Wiltshire CCG relates to GWH facing Wiltshire patients who do not receive a specialist neurology nursing service as Swindon patients. Consequently, patients do not currently feel well supported and do not receive equitable care. Non-elective admissions and particularly length of stay are key issues with this patient group. Due to the nature of the disease, length of stay is often high as patients may not receive their optimum medication regime, when an in-patient. The PDNS would also be a point of information and advice for patient carers and offering carer support. This disease is a lifelong condition and therefore all patients will continue to receive support until their death.

The two main options to address the provision gap would be to augment the existing PDNS service within GWH or provide a specialist PDNS within the community. The do nothing option is considered for its implications and comparison.

Options:

Option 1 – Do nothing

Retaining the status quo by continuing the provision of generic neurology services provided by WH&C under the 'block' contract

Advantages:

- No additional cost

Disadvantages:

- Lack of specialist nursing support for patients with Parkinson's disease.
- Lack of equity with patients from neighbouring CCGs
- Potential increased acute admissions and lengths of stay
- Potential reputational damage
- Ongoing public concern and complaints

Option 2 – Work with WH&C to ensure service levels are improved within current structure

Advantages:

- No change required to infrastructure
- Could be implemented immediately
- Performance and quality could be monitored under existing contract
- Would not commit CCG to forward spending outside of contract

Disadvantages:

- Limited improvement likely
- Would not address inequity of provision with Swindon residents
- No provision of specialist nursing care as would be delivered by a single condition specialist within a neurology team

Option 3 – Commission specialist support for existing GWH Neuro team (preferred option)

Advantages:

- Seamless and equitable specialist service for Swindon and Wiltshire residents referred to GWH Neurology Team
- Improved ongoing care and support to existing neurology patients
- Improved economies of scale within Neurology Team to meet existing and future demand
- Consistency across CCG areas
- WH&C would work closely with GWH Neurology Team to ensure access to timely wider community services eg Physiotherapy
- Supportive of BSW strategy
- Potential non recurrent financial support from Parkinson's UK (2 years)

Disadvantages:

- Additional recurrent investment required
- Dependent on available specialist nurses

Recommendation

Option 3 would provide an optimum equitable and seamless service for all Wiltshire patients with Parkinson's disease referred to the GWH Neurology Team.

Specifically this would include:

- A condition specialist to support the medical and nursing needs of all patients under one well established and dedicated neurology team;

- Outreach clinical appointments in the community including home visits;
- Prompt access to ongoing therapy support in the local community;
- A critical mass of GWH specialist nursing staff to ensure that assessments and regular reviews are undertaken seamlessly irrespective whether the patient has a Swindon or Wiltshire GP.

Next Steps

To agree recommendation and commission enhanced service with the support of Parkinson's UK.

Appendix One: PDNS Service Benefits (Parkinson's UK)

The objectives of the PDNS will be to:

- Reduce unplanned admissions for the Parkinson's disease cohort
- Reduce length of stay for the patient cohort
- Reduce the need for patients to attend outpatient clinics
- Provide support to patients and their families or carers to improve experience
- Help integrate Health and Social care around the patient
- Educate health and social care professionals about Parkinson's Disease

The role of the Parkinson's Disease Nurse Specialist will be to:

- Be the first point of contact for information and signposting, co-ordinating care for people with Parkinson's disease.
- Provide clinical monitoring, symptom control and medicine management as well as health promotion and wellbeing.
- Lead and provide a specialist resource for patients with Parkinson's disease, their relatives and carers, members of the general public, health professionals, statutory and voluntary bodies.
- Work in partnership and act as a conduit in the care of individuals with Parkinson's disease between a variety of services and settings, including primary care and secondary care (e.g. GP surgeries and inpatient wards).
- Develop the knowledge of individuals with Parkinson's disease, their relatives and carers, members of the general public, health professionals, statutory and voluntary bodies about the management and symptoms associated with Parkinson's disease.
- Actively facilitate and participate in improving and enhancing the delivery of the care given to individuals with Parkinson's disease.
- Identify the "hidden" patients who are not well known to clinicians in primary or secondary care settings. This will involve working in traditionally hard to reach communities.
- Liaise with local nursing and residential homes to ensure all Parkinson's disease patients have access to specialist care and advice.
- Work towards becoming a nurse prescriber to enable medication reviews and alterations.

Main drivers for service improvement

The PDNS service is strongly aligned to delivering the following outcomes for Parkinson's disease:

- Reduced avoidable emergency hospital admissions
- Reduced A&E attendances
- Reduced length of stay in hospital
- Reduced number of delayed discharges
- Increased number of people able to live at home following discharge from Intermediate Care and Reablement
- Reduced permanent admissions to nursing care and residential care
- Reduced readmissions to hospital
- Reduced patient waiting times for non-urgent care
- Reduced safety incidents linked to uncoordinated multi-disciplinary working
- Increased amount of health and social care activity delivered in the community
- Increase in staff satisfaction and reduction in staff turnover
- Increase in the number of people supported to die in their place of choice

National NHS Strategic Plan

	Domain 1	Domain 2	Domain 3
	Securing additional years of life for people with treatable mental and physical conditions	Improving health related quality of life for people with long term conditions	Reducing avoidable time in hospital Increasing elderly people living independently at home on discharge
Domain 4	Increasing positive experience of hospital care Increasing positive experience of care outside hospital		
Domain 5	Significant progress on eliminating avoidable deaths		

The role of the PDNS works towards:

- Domain 2: Improving health related quality of life for people with long term conditions
- Domain 3: Reducing avoidable time in hospital; Increasing elderly people living independently at home on discharge
- Domain 4: Increasing positive experience of hospital care; Increasing positive experience of care outside hospital

National Context

NICE guidance for Parkinson's Disease diagnosis and management states:

"1.1.1.6 People with PD should be offered an accessible point of contact with specialist services. This could be provided by a Parkinson's disease nurse specialist".

1.9.1 Specialist Nurse Interventions

1.9.1.1 People with PD should have regular access to the following:

- Clinical monitoring and medication adjustment
- A continuing point of contact for support, including home visits, when appropriate
- A reliable source of information about clinical and social matters of concern to people with PD and their carers

Which may be provided by a Parkinson's Disease Nurse Specialist.

The Parkinson's Disease Society provided evidence that a PD nurse can reduce consultant neurologist outpatient time by 40%, assuming responsibility for monitoring and adjusting medication, and reducing (re)admission rates by 50%. The total cost saving would be in the region of £6 million in England alone." - RCP Association of British Neurologists – Local adult neurology services for the next decade 2011.

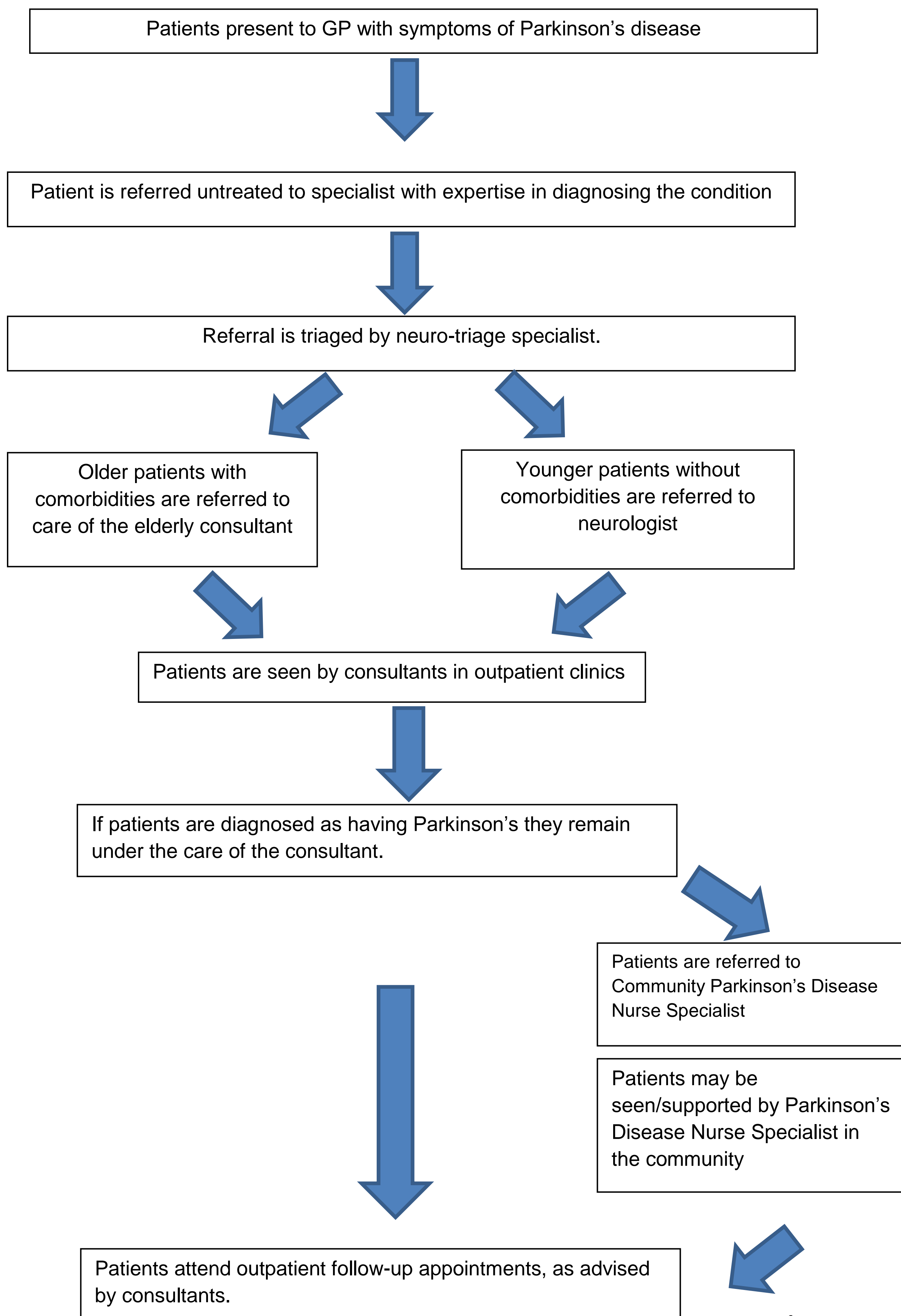
Key Desired Outcomes – Quality outcomes

Outcome	Beneficiary-(ies)	National / Local	How?
Reduced non-elective admissions for patients with Parkinson's disease	Patients/Provider/Commissioner	Local	Improved management of condition and medication to prevent deterioration resulting in emergency admissions.
Reduce consultant follow up appointments	Patients/Provider	Local	Nurse-led clinics will free-up consultant clinic time.
Increased staff knowledge in regards to care of Parkinson's Disease through provision of education	GPs, community and primary care healthcare staff	Local	PDNS to educate health and social care professionals about PD along the patient's care pathway. This should lead to more appropriate secondary care referrals and reduced outpatient appointments.
Increased patient independence and confidence	Patients	Local	Improving self-management and maintenance of independence at home through education and support.

Predicted Outcomes

Outcome, metric, expected change	Rationale	Source / method of measurement and reporting
Reduced non-elective admissions for patients with Parkinson's disease where PD is primary diagnosis	Better case management and patient and carer support should lead to a reduction in non-elective admissions for the patient cohort.	Through contract performance metrics
Reduced consultant follow-up appointments	The PDNS should offer clinics for PD patients, reducing the need for consultant follow-up appointments	Through contract performance metrics
Increased patient reported satisfaction	Without access to specialist care, patients are currently highly dissatisfied. The PDNS should support patients, their families and carers and increase patient reported satisfaction.	Patient satisfaction surveys and audits.

Appendix Two: Patient Pathway for Parkinson's Disease



Swindon Community Health Services

Extension of Swindon Parkinson's Specialist Nursing Service

1.0 Background

The Swindon Parkinson's Specialist Nursing Service is a specialist service within the Swindon area providing multi-disciplinary care to those patients with Parkinson's Disease or Parkinsonism's and their family members / carers.

The Service was developed with stakeholder involvement from the voluntary, acute and community settings and provides a service both within the acute and community pathways.

Referral into the service comes immediately following diagnosis and is provided to all patients receiving care from the SCHS cohort of GP's.

SCHS has been approached by the Wiltshire CCG in order to review the possibilities of extending the specialist nursing service to serve those patients with GP's in North Wiltshire areas that are also under the care of the Elderly Care and Neurology Team based at Great Western Hospital (GWH).

2.0 Current Position

Current Service provision promotes self-management and care as its key values and is itemised below:

- **Diagnosis:**

  Diagnosis is given by the Consultants (Neurologists and Elderly Care Physicians) within the Department of Medicine for the Elderly (DOME) at GWH as well as by Consultants in surrounding areas, eg, Oxford.

- **Initial Review:**

  Patients are reviewed at the Newly Diagnosed Parkinson's Clinic by the Parkinson's Disease Nurse Specialist (PDNS), Specialist Physiotherapist and the Parkinson's UK Local Advisor. A comprehensive assessment is then completed with information and support being given re: the disease process as well as facilities available to them within the Swindon area. This assessment takes place within 8 weeks following initial diagnosis.

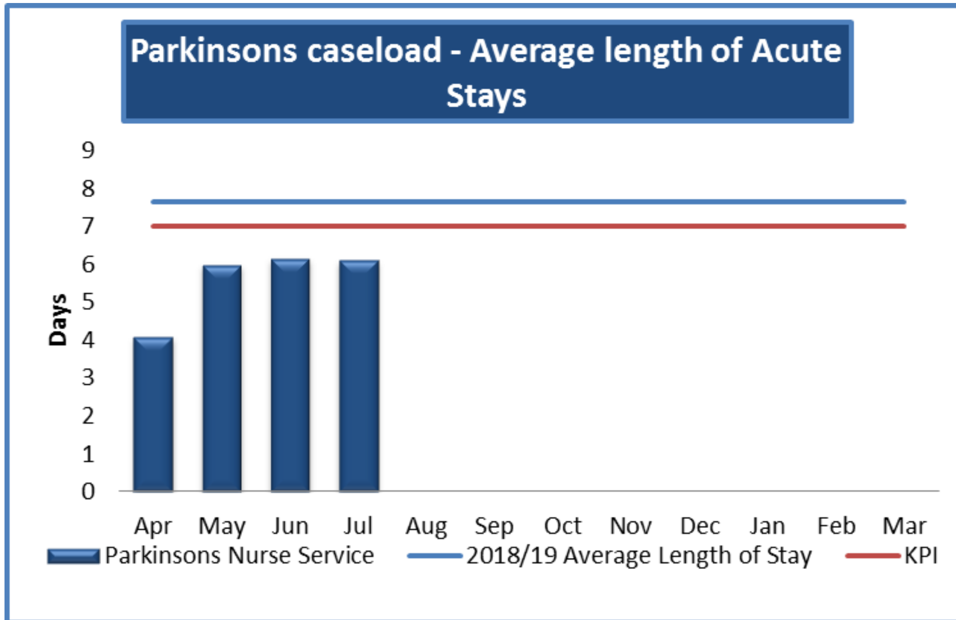
- **Follow up:**

  Patients are reviewed regularly within the clinic environment, and if not possible, within the home environment by the PDNS' acting as key worker in order to monitor their progress, altering medications as required, providing information on other services, and referring on to SLT, OT, Physio etc, as necessary. The timeframes of these appointments can be altered according to patient need and acts to reduce the number of emergency admissions to the acute sector.

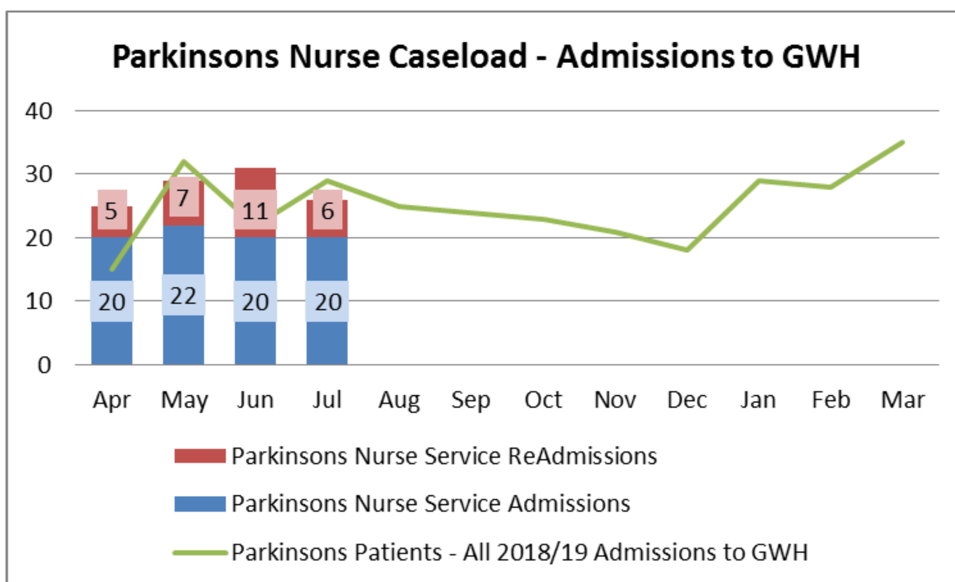
- **<u>Nursing / Residential Care Home patients:</u>**
  15% of the current PDNS caseload are living within Care Homes and these patients can find it difficult to attend Consultant / PDNS Clinics. PDNS clinics therefore take place in the Care Homes on an annual basis with further visits taking place as necessary.

- **<u>In reach:</u>**

  All patients are highlighted on Medway and a daily report provides the PDNS' with details of admissions to the acute sector. In reach review within SWICC and GWH is undertaken by the PDNS' in order to assist in reducing the length of stay within the hospital environment.



Patients are then reviewed following discharge and seen at home as necessary, in order to ensure that the discharge is being appropriately managed and to reduce any further readmissions.



Other members of the MDT also receive the Inpatient Daily Report so that they can discuss with their acute Physio, OT or SLT colleagues the work that they have already done with the patient. This also assists in the reduction of the inpatient stay.

- **PDNS Helpline:**

  The Single Point of Access provides accessibility to specialist nursing support by giving a telephone point of contact for all in order to access the PDNS Service. This is used by the patients, carers, family members, GP's, acute and community staff members in order to obtain clinical advice and request further review. Response times are within 72 hours for over 90% of calls during the past year.

There are strong working relationships both within the team and without, to other colleagues such as Occupational Therapy, Physiotherapy and Speech and Language Therapy in order to support the person with Parkinson's. Communication is strong and is facilitated with regular MDT meetings as well as the team being able to work together within their own office area.

3.0 Going Forward

3.1 Proposed Area of Extended Parkinson's Specialist Nursing Service.

GP surgeries that are within the North Wiltshire area are listed below with their adult population cohorts. The figures have been taken from the NHS Digital GP population website which was last updated 1st May, 2019, and excludes all 0-9 & 10-19 age groups. The Parkinson's prevalence has been estimated using a 0.3% figure as identified by Parkinson's UK, 2019.

Cluster	Community team	GP surgery	Population
Calne	Calne & Corsham	NORTHLANDS SURGERY	10787
	Calne & Corsham	PATFORD HOUSE SURGERY PARTNERSHIP	8802
	Calne & Corsham	BEVERSBROOK MEDICAL CENTRE	7133
Chippenham	Chippenham	HATHAWAY SURGERY	15631

	Chippenham	ROWDEN SURGERY	16035
	Chippenham	JUBILEE FIELD SURGERY	4568
	Chippenham	LODGE SURGERY	8135
Corsham	Calne & Corsham	PORCH SURGERY	11371
	Calne & Corsham	BOX SURGERY	6915
East Kennet	Marlborough	KENNET AND AVON MEDICAL PARTNERSHIP	17628
	Marlborough	RAMSBURY SURGERY	9011
	Marlborough	BURBAGE SURGERY	3736
	Marlborough	OLD SCHOOL HOUSE SURGERY	3711
Malmesbury and Tolsey	Malmesbury and RWB	MALMESBURY MEDICAL PARTNERSHIP	15661
	Malmesbury and RWB	TOLSEY SURGERY	3503
Purton, Cricklade & RWB	Malmesbury and RWB	PURTON SURGERY	9911
	Malmesbury and RWB	TINKERS LANE SURGERY	8369
	Malmesbury and RWB	NEW COURT SURGERY	9964
	Malmesbury and RWB	CRICKLADE SURGERY	2700
Total Population			173571
0.3% Parkinson's prevalence			520.7

It must be noted that PDUK estimate the prevalence to increase to 0.32% by 2025 (Parkinson's UK, 2018, Clinical Practice Research datalink)

The table above shows the total population of Parkinson's patients within the North Wiltshire area. The extended service will care for those patients attending GWH outpatients and it is understood that these patients are based within the GP practices identified below (and shown in blue in the above table). There will be a limited number of GWH patients who will fall out of this catchment area and it is proposed that these will be cared for by the current Neurology Practitioner who will also continue to care for the remaining Neurology patients across the North Wiltshire area as well as those Parkinson's patients under the care of the Consultants based at RUH, Bath. It is thought that these Parkinson's patients will be mainly based within the Chippenham and Corsham areas.

The GP practices to be covered by the extended Swindon Specialist Nursing Service are therefore listed below:

Northlands Surgery, Patford House Surgery Partnership, Beversbrook Medical Centre, Kennet and Avon Medical Partnership, Ramsbury Surgery, Burbage Surgery, Old School House Surgery, Malmesbury Medical Partnership, Tolsey Surgery, Purton Surgery, Tinkers Lane Surgery, New Court Surgery, and Cricklade Surgery.

3.2 Proposed Increase in Staffing Levels

In order for a similar service to be provided to the proposed area of extension, funding would be required for the following staff:

Staff	WTE	Band
PDNS	1.0	Band 7
PDNS	0.6	Band 6
Administrative Assistant	0.3	Band 3

3.3 Other Requirements to be Considered.

- A clinic room (with Wi-Fi, desk and potential clinical support, e.g. in a GP practice) would need to be made available in the Marlborough, Malmesbury, Calne and Wootton Bassett areas once per fortnight in order to facilitate clinic care provision closer to the patients' homes.
- Office space for the new members of staff would be required.
- Financial costs: Costs of mileage and time to travel would need to be taken into consideration. Also stationery and printing costs. Equipment including: laptops, laptop bags and mobile phones for each individual; blood pressure monitors, tympanic thermometers, stethoscopes, pulse oximeters and boot bags for each PDNS.
- Introduction to other local services that are relevant to patient care would be necessary in order to understand the appropriate referral pathways. e.g, development of links with Adult Social Care in the Wiltshire area.
- The Swindon MDT works closely with the local Parkinson's UK Branch in order to identify with them how they can provide support for patients. Following an initial request for support in developing an exercise group the local Branch now provides classes in dance, tai chi, seated and standing exercise and walking football classes. These benefit the people with Parkinson's and their family members, improving physical function as well as maintaining their cognitive abilities. The work that the local branch does also assists in giving the Parkinson's Service the local information that is necessary to further develop and improve the service. Building on this established relationship, the PDNs working in North Wiltshire will work with the local PDUK Branches in the development of the new service to be provided.

3.4 Patient Benefits

- Reduction in waiting times to see the PDNS.
- Easier access to clinical support from the PDNS' via the Helpline.
- Improved ability to manage their own changing disease process.
- Care provided in the environment that is most suitable to their functional ability.
- Decreased admissions to hospital environment.

- Support by the PDNS team whilst in hospital.
- PDNS clinic held more locally to their home.

3.5 System Benefits

- Reduced admissions to hospital.
- Reduced length of inpatient stay.
- Follow up of complex patients / Care Home patients now currently regularly reviewed.
- Increased patient satisfaction.
- Decreased Consultant OPA's required therefore potential cost reduction on Follow Up payments or decrease in alternative waiting lists. It is understood that within the area above 191 patients attend GWH Parkinson's Consultant appointments, it is proposed that the number of OPA's for these individuals should decrease as they will be seen by the PDNS as an alternative, this will result in a cost saving to Wiltshire CCG or other waiting lists will be reduced as Consultants see other patients (not those with Parkinson's)

3.6 Additional benefits

- There will be strong links developed with the current Neurology Practitioner as they will be working alongside the PDNS' within North Wiltshire. This will allow for clinical supervision and support to occur with meetings to take place on a regular basis. The current Neurology Practitioner will have a potentially smaller and more manageable caseload enabling greater job satisfaction and further development of their own care provision.
- Liaison will take place with the Community Therapy teams in the appropriate areas to further discuss the care provision that is currently provided within Swindon in order to ascertain whether this could / should be replicated within the North Wiltshire area and whether this could be achieved within their current financial provision or whether a further business case would need to be put forward by Wiltshire Health and Social Care.

4.0 Next Steps

This paper has set out the current situation provided by the Swindon Parkinson's Specialist Nursing Service, has reviewed the areas local to Swindon to which it could be extended and the investment required to deliver sustainable long term improvements in clinical and organisational performance. It is for further review by the Wiltshire CCG. Following agreement it is thought that this service would take 3 months to commence, allowing for recruitment to posts to take place.

References:

1. NICE Guidance, Quality Standard 164

The recommendations in the QS164 standards are that all ‘Adults with Parkinson's disease have a point of contact with specialist services’ and that ‘Adults with Parkinson's disease are referred to physiotherapy, occupational therapy or speech and language therapy if they have problems with balance, motor function, activities of daily living, communication, swallowing or saliva’

The Service Extension proposed within this business case will achieve this for those patients identified above and the Swindon Service has already been positively audited against the QS164 standard.

2. NICE Guideline, NG71

This guideline covers diagnosing and managing Parkinson's disease in people aged 18 and over. It aims to improve care from the time of diagnosis, including monitoring and managing symptoms, providing information and support, and palliative care.

The Swindon Parkinson’s Service was reviewed against this guideline in 2017 and performed well.