

Evaluation report summary

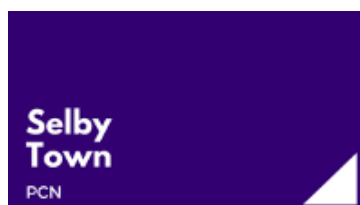
Parkinson's Nurse Specialist

February 2021



Impact of Parkinson's Nurse Specialist on:

- people diagnosed with Parkinson's, their carers and family
- primary and secondary care



BACKGROUND

In 2018, the NHS Vale of York Clinical Commissioning Group (CCG) Executive team agreed to support a Parkinson's UK (PUK) proposal for funding for a community-facing Parkinson's Nurse Specialist. The funding was to come from PUK for two years, with the project being evaluated for onward resourcing. The funding arrangements were confirmed and a PNS has been in post since July 2019.

THE PARKINSON'S NURSE SPECIALIST

The Parkinson's Nurse Specialist (PNS) cares for people who have been diagnosed with Parkinson's Disease (PD) and supports their family and carers who are affected by the condition. The PNS:

- has specialist experience, knowledge and skills in Parkinson's, and plays a vital role in giving expert care to people with Parkinson's.
- can assist people to improve quality of life by referring them to the appropriate care services and therapies.
- liaises with GPs and hospital consultants and any other healthcare professional regarding a person's needs.
- advises people on adjustment of medication following discussion with medical colleagues.

We have had a community Parkinson's Nurse Specialist post, funded by the Parkinson's UK charity, since June 2019, covering the South Hambleton and Ryedale (SHaR), Tadcaster and Rural Selby, and Selby Town Primary Care Network (PCN) areas.

The need for the PNS

As part of the evaluation, a comparative analysis of the population needs of this patient cohort was made against the same patient cohort covered by York city PCNs. A summary of this analysis is shown below:

- SHaR PCN has the highest number of Parkinson's patients both in absolute numbers and as percentage of population over 65
- Tadcaster and Rural Selby PCN has the highest number of Parkinson's patients under 65, and the highest percentage of Parkinson's patients under 65
- SHaR PCN have the joint highest cognitive burden among Parkinson's patients with York Medical Group
- The average distance to hospital for Parkinson's patients in York Medical Group is 2.84 miles
- The average distance to hospital for Parkinson's patients in SHaR is 18.28 miles.

The population needs analysis indicates that there are potentially areas of health inequality within the area that the PNS post covers, particularly around distance to service provision, access to transport and associated levels of morbidity. The post is designed to address these localised issues.

ENGAGEMENT PROCESS

To evaluate the impact of this post on Parkinson's patients, SHaR PCN has been targeted because the post started there in August 2019, before the COVID-19 pandemic, resulting in more valuable data being recorded.

Although the engagement process has been challenging due to pressures related to COVID-19 and the vaccination programme, the patient response rate was high from those GP practices that were able to take part.

The questionnaire was distributed by GP practices on behalf of the CCG. The evaluation for this post sought feedback from all the involved stakeholders:

- ✓ Patients
- ✓ Carers
- ✓ GPs
- ✓ Secondary Care:
 - Consultants
 - Nurse Specialists
- ✓ Care Homes

Unfortunately, no response was received from care home managers. The Evaluation Team's assumption was that this was due to COVID-19 pressures. Only 10 responses were received from GPs and two from York Teaching Hospitals NHS Foundation Trust consultants, plus one from a Parkinson's Nurse in Neurology who works closely with the PNS. Also, the PNS has been asked to provide additional evidence in a format of a comments log and case studies.

101 patient questionnaires were distributed from GP practices by post. The responses were collated using the SurveyMonkey website. A total of 47 responses were received, representing a 46.5% response rate. 82% of the responses were completed by the person diagnosed with Parkinson's and 18% by a family member or a carer.

To supplement the survey, out of 47 responses 21 patients provided their contact number and agreed to be contacted for further conversation to get a more meaningful understanding of their experience; 18 of these patients were successfully contacted.



THE EVALUATION

Feedback was received from all apart from care homes. It showed, importantly, that not all Parkinson's patients are the same. They vary greatly in their requirements according to the progression of their condition and their social situation, complicated further by the fact that they are older and, as such, are more likely to have social and clinical issues beyond Parkinson's. This requires care to be patient-centred. The feedback received indicated that was the central approach of the current PNS:

- For many people the PNS is a very important source of professional support. She gives advice on lifestyle, medication, local support groups and general day-to-day support. Many find the PNS friendly, approachable and easy to access.
- People report feeling confident knowing that expert advice is available locally.
- The PNS works collaboratively with GPs and the consultants across neurology and care of the elderly. She also links with the wider neurology multi-disciplinary team.
- An important role of the PNS has been to improve self-management and limit any deterioration of symptoms.
- With COVID-19 social distancing and preventative measures in place, many patients' mental health has been negatively affected – for example, with experiencing hallucinations or anxiety. The PNS has been able to offer support and advice to those patients.
- The PNS role has become integral to delivering expert, accessible care for people with Parkinson's at all stages of the condition.
- By providing care in local settings, whether at home, care homes or in nurse-led clinics, the PNS keeps care closer to home and provides support for patients and carers.

There were also areas for improvement identified, which could easily be delivered with a few minor tweaks to the service provision, if the post was to continue beyond June 2021. Those tended to be around meeting patient expectations further than has been established, particularly:

- Communications about access between PNS and patients/carers
- More regular contact with patients
- Signposting to extra support available to patients
- Improving proactive approach
- Improving the link between patients and their GP practices.

The evaluation uncovered other issues around integration of service provision that were beyond its remit but may need further consideration elsewhere:

- Consideration of greater integration of the existing Parkinson's services across the patch covering Neurology and Care of the Elderly specialist services
- Integration of computer systems between primary and secondary care in order to improve communications
- There is a large proportion of the York population who have neither secondary nor community care PNS access – these mainly being those under the care of the Care of the Elderly consultant.

THE EVALUATION

The overwhelming conclusion from the evaluation was that the PNS post should continue. This clearly had the support of all the stakeholders contacted. It provides a focal point for integrating previously fragmented service provision. It also provides a conduit for patients accessing additional support that allows maintenance of independence and self-determination. More information can be found on our website at www.valeofyorkccg.nhs.uk/parkinsonsnurse

TYPICAL FEEDBACK FROM STAKEHOLDERS

An excellent resource that helps when we need it and we always appreciate her knowledge and experience

Very advantageous. Easy to contact. Very knowledgeable. She is a very good link to my Parkinson's Consultant

She can be accessed very quickly over the phone, she is available when I need to talk to her, sometimes I will leave a message and she will call back

Help with sourcing equipment via Social Services

Support with being newly diagnosed and started on PD meds

She is very easy to contact, if I start to worry about my symptoms I would get in touch

The Parkinson nurse provides a wealth of experience and a way of contacting other resources, navigating the NHS

IMPACT OF THE PNS ON PATIENTS, CARERS AND PRIMARY CARE

Overall we have received very positive feedback from both patients/carers and primary care - examples of the good practice shown by the PNS combined into seven themes:

GOOD PRACTICE



1 PNS supports with management of symptoms and medication

- She discusses with patients their symptoms and medication and 75% of patients confirmed that this is a priority for them.
- PNS provides expertise and is knowledgeable about Parkinson's disease and 88% of patients agreed strongly with that.

- GPs said the PNS has quick access to hospital team and provides detailed plans regarding patients' medication adjustments and review.
- Before the PNS was in post only 10% of GPs had good knowledge of PD; since in post 50% have good knowledge.

2 PNS is a first point of contact

- Patients typically said she is very approachable, easily to contact and non-judgemental.
- 80% described their relationship with the PNS as positive and close.
- 58% of patients reported that the PNS was their first point of contact for fast access to specialist care.

- 90% of GPs agreed that the PNS is their first choice that provides them with the most support to manage patients with Parkinson's.
- Comments include: *"Extremely responsive, easy to make contact with"*

3 PNS has access to a multi-disciplinary team

- 88% said PNS refers them to appropriate professionals.
- Some patients have side effects due to drugs, such as mobility problems, and she refers them to physio/OT.
- PNS has close working relationships with primary, secondary and social care colleagues.

- For GPs the PNS acts as a link and care coordinator between primary and secondary-care professionals.
- 100% of GPs confirmed that PNS encourage referrals to dementia services and to occupational therapy.

GOOD PRACTICE

For patients

Primary care colleagues

4 PNS provides person-centred approach to care

- She looks at the individual and what they need to fight the disease.
- 83% say their appointments they have with the PNS are purposeful. *"The PNS is caring, supportive and effective. Excellent relationship"*
- 96% said the PNS is very important in their Parkinson's care.

- 80% of GPs confirmed that PNS has made very good improvement to patients' care.

5 PNS supports families and carers

- 63% confirmed that PNS provides support and advice to their family/ carer in stressful situations. *"She listens to them when they're worried about someone with Parkinson's"*

- 100% of GPs feel that PNS is important in supporting their patients and family with Parkinson's.

6 PNS offers mental health support

- Many patients said that they are experiencing a negative impact of COVID on their mental health.
- Patients said: *"PNS provides emotional support and reassurance during these challenging times"*.
- *"Very comfortable, easy to talk to and listens to me."*

- There is an increased demand on mental health services and GPs are relying on the PNS.

7 PNS provides care closer to home

- Most Parkinson's patients are from rural areas, are frail and cannot travel.
- The PNS helps patients avoid coming to hospital by offering support in the community.
- Patients can be seen in the comfort of their home without unnecessary traveling to hospital and time pressure.

- *"Support and services close to home. Proactive monitoring. Proactive assessment of cognition and mental health"*

CONTACT US

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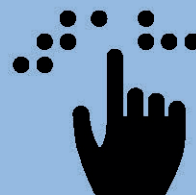
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