

PRIORITY BRIEFING

The purpose of this briefing paper is to aid Stakeholders in prioritising topics to be taken further by PenCLAHRC as the basis for a specific evaluation or implementation research project. This paper was compiled in 2-3 days.

Would access to urgent clinic appointments reduce crisis incidence or hospital admissions in Parkinson's patients?

Question ID: 4

Question type: Intervention

Question: Would access to urgent clinic appointments reduce crisis incidence or hospital admissions in Parkinsons patients?

Current problem: Of course many patients do not require review this frequently, but there are currently few opportunities for them to be reviewed quickly if things do suddenly deteriorate.

Population: Patients with diagnosed Parkinsons who are suffering a significant deterioration in their condition.

Intervention: Access to urgent clinic appointments for medical review initiated by the patient.

Control: Routine appointments that are often more than 6 months apart

Outcome: Reduce crisis situation at home, or prevent hospital admission if condition suddenly deteriorates, e.g. prevent increase in falls or loss of function by rapid review of medication.

*Please note that the details included in the box are from the original submission and have been edited where necessary for clarity and precision

Parkinson's Disease: Parkinson's disease is a progressive neurological condition. People with Parkinson's disease lack dopamine because some nerve cells in their brain have died. Without dopamine, movements become slower and the loss of nerve cells in the brain causes the symptoms of Parkinson's disease to appear. The main symptoms of Parkinson's disease are tremor, rigidity and slowness of movement. As well as affecting movement, people with Parkinson's disease can find that other issues, such as tiredness, pain, depression and constipation, have an impact on their day-to-day lives. The symptoms someone has and how quickly the condition develops will differ from one person to the next. There's currently no cure for Parkinson's disease and the cause is unclear. Parkinson's disease doesn't directly cause people to die, but symptoms do get worse over time. The symptoms can be controlled using a combination of drugs, therapies and occasionally surgery. As Parkinson's disease progresses, an increased amount of care and support may be required, although many people maintain a good quality of life with limited care or treatment.

Patient-initiated appointments: Many patients do not require review as frequently as every six months, but there are currently few opportunities for them

to be reviewed quickly if things do suddenly deteriorate. Appointments to see a specialist consultant would be given to patients on their request as soon as possible (ideally within 48 hours) as opposed to standard clinician-led follow-up appointments. Service provision would move from a clinician driven and inflexible follow up service for people with Parkinson's disease to one where people are seen when they request help and in a timely fashion. These appointments aim to improve immediate service responses to patients needing ongoing but fluctuating Parkinson's disease care.

The Health Problem:

In the UK approximately 127,000 people are diagnosed with Parkinson's disease (1/500) with an annual incidence of 4-20 per 100,000. Parkinson's disease affects men and women, although men are statistically slightly more likely to develop it than women. The risk of getting Parkinson's disease increases with age. Most people with Parkinson's are aged 50 or over but younger people can be affected too (1/20 is under the age of 40). In the South West region there are approximately 10,500 people with Parkinson's disease and 28 specialist Parkinson's disease nurses (six specialist nurses cover Devon and Cornwall). There are at least 15 support groups spread through Devon and Cornwall. Parkinson's nurses work in hospitals, residential care homes and in the community. They run nurse-led clinics in hospitals and the community and can also run telephone clinics or have dedicated times when people can call (though these are infrequent- possibly only monthly). This is designed to allow a quick response without the need for a clinic appointment, however, nurses cannot deal with urgent medication changes and in this situation would need urgent access to a consultant.

Of 6,179 of patients with Parkinson's disease admitted to hospitals in the UK in 2009/10 10-11% died within 90 days of the treatment/admission (HES). One important part of the Parkinson's disease care service is the specialist nurse. Parkinson's nurses deliver expert, accessible care for people with Parkinson's disease at all stages of the condition but not all areas of the country have them and there is a shortage. A Parkinson's disease charity (www.parkinsons.org.uk) estimate that on average a nurse can save £43,812 in avoided consultant appointments, £80,000 in unplanned admissions to hospital and £147,021 in days spent in hospital per year.

The reported costs of Parkinson's disease in Europe average at 7,600 Euros per patient per year ranging from 2,500 to 13,000 Euros and these costs increased with increasing severity. In this report indirect costs accounted for a greater amount of the costing than direct costs, with drugs accounting for 50% of the latter.

Guidelines:

NICE Guidelines (2006) state that treatment and care should take into account patients' individual needs and preferences. People with Parkinson's disease

should have the opportunity to make informed decisions about their care and treatment. Guidelines generally support six-12 month reviews.

National Service Framework for long term conditions (2005) states that there should be a person-centred service to improve the coordination of services and address many of the key issues service users and voluntary organisations have identified. These include information and the need for a holistic, integrated, interdisciplinary approach to care planning, review and service delivery involving a range of agencies. They also state that there should be enough flexibility to allow for both planned reviews and unplanned reviews when a person's condition suddenly deteriorates or their circumstances change (e.g. due to the illness of a carer).

NHS Priority:

Regional

SW SHA Priorities framework 2008-11 (please note this has not yet been updated for 2012)

Local

- CPCT want to promote patients to manage their own illness wherever possible and to promote patient choice (and RCAT)
- DPCT aim to promote rapid access to assessment and treatment as well as self-management and care
- Plymouth Hospital also aims to promote responsive and flexible out-patient services

QIPP

- Optimising urgent care pathways.

Existing Research:

Published research

No published systematic reviews have been found in this area. However, a systematic review has been recently conducted by PenCLAHRC looking at the effectiveness of patient initiated clinics (appointments) for managing the care of people with long term chronic or recurrent conditions. In this review, no studies on Parkinson's disease were identified, which suggests there is not much published literature on the provision of patient initiated clinics in this patient group.

The conditions that were identified in this review as having tried patient initiated clinics were rheumatoid arthritis, breast cancer and irritable bowel syndrome. The review concluded that there were potential cost and time savings in using a patient initiated appointment system and that the system was largely acceptable to patients and clinicians and appeared to do no harm to the patients.

In the literature searches conducted for this briefing, we identified two papers that discussed the potential for the provision of patient-initiated care in patients with Parkinson's disease. One study looked at hospital admissions of patients with Parkinson's disease, in particular their reasons for admission, over a six year period. They found that one of the most common reasons for hospitalisation was motor and psychiatric complications which could be dealt with in the community. As a result an 'open door' policy at the Parkinson's disease clinic was introduced to try and reduce hospitalisations and improve management of symptoms¹. However, no data was recorded on the effectiveness of the 'open door' policy¹.

In the second study a year's worth of telephone calls to a specialist nurse was analysed to determine the nature of complaint, the determination of the actual cause by the nurse, time taken, result of the call, whether the patient called back (and the number of times that this happened), the average length of the calls per day and per week and the outcome of the call. The specialist nurse dealt with frontline telephone calls from patients with movement disorders². The paper reports that patients with Parkinson's disease accounted for 80% of the calls to the specialist nurse and that the nurse was able to resolve most of the calls on their own, however, it does not discuss how patients received an urgent appointment if they needed one.

Ongoing research

No ongoing research in this area could be found to date.

Feasibility:

A number of Parkinson's support groups run in Devon and Cornwall which may be able to provide input towards any research or implementation plans.

References:

- 1) Klein, C., T. Prokhorov, et al. (2009). "Admission of Parkinsonian patients to a neurological ward in a community hospital." *Journal of Neural Transmission* **116**(11): 1509-1512.

Hospitalization is a significant factor contributing to health care costs related to management of Parkinson's disease (PD) patients. We reviewed reasons for admission of PD patients to our Neurological Department over a 6-year period. Thereafter, we applied an "open door" policy to try to diminish the number of hospitalizations. Case records including patient data, disease duration, staging, reasons for admission, and motor, mental and general medical status of PD patients admitted to the Neurology Department over a 6-year period were reviewed. Out of 1,920 admissions, 143 were PD patients. All PD admissions were through the emergency department (non-elective). Motor complications were the reason for admission in 37%, psychosis in 24%, general medical problems in 14%, and a combination of motor and psychiatric in 25%. Drug-induced psychosis was the most significant cause of repeated and prolonged admissions (29% of patients). As motor and psychiatric complications are the commonest causes for admission, improved community-based care to "fine tune"

medication appeared to be a priority. After analyzing our results, we instituted an "open door" policy, where patients are free to come to the Parkinson's clinic without appointment. This policy should improve control of PD symptoms and diminish hospitalizations.

- 2) Hall, L., A. South, et al. (2011). "Telephone based nursing management of movement disorders patients - Maximizing health utility." *Movement Disorders* **26**: S351-S352.

Objective: 1. Determine the nature of calls received by the clinic nurse 2. Understand outcomes and cost savings to the health care system. Background: The increasing volume and complexity of patients seen in the movement disorders clinics requires a team approach. With infrequent follow-up visits (every six to nine months in most clinics), the clinic nurse specialist plays a critical role in providing continuing care, often over the telephone. Such intervention can not only reduce patient stress by dealing with problem issues on the phone, but also reduce doctor and emergency room visits. This can translate into immediate cost savings for the patient (reduced travel), the health care system and at the same time improve quality of care. Methods: 132 charts were evaluated from telephone calls made during the year ending September 2010. All calls were evaluated in terms of the nature of complaint, the determination of the actual cause by the nurse, time taken, result of the call, whether the patient called back and the number of times that this happened. The average length of the calls per day and per week was evaluated and the outcome of the call was recorded. A cost based analysis of the time spent by the nurse versus the dollar value of the visit to the emergency room or the family doctor is calculated. Results: The most numerous calls were related to questions such as medication, side effects, and increased parkinsonian symptoms. Only 10% required discussion with the consultants. The nurse returned calls and generally within one day for > 80% of the problems. Over 1/3rd of patients were calling from >100 km distance. Most importantly, when an average annual cost savings is estimated, the presence of a nurse and the subsequent phone service saves between \$30 to \$35,000 dollars annually. Conclusions: Since PD accounts for 81% of the calls and approximately 52% of the calls are patient initiated, it appears to be that patients are quite capable of calling and asking for help. The outcome data shows the nurse's role is multi-faceted including routine tasks such as renewals to complex counselling. The nurse is able to resolve almost all calls on her own and this is substantially faster than when advice is needed from the physician. This service thus results in a much better health utility index and realizes a substantial cost saving to the publically funded health care system.