

Innovating for Improvement

Parkinson's Advanced Symptoms Unit

South Tees Hospitals NHS Foundation Trust



About the project

Project title:

Parkinson's Advanced Symptoms Unit

Lead organisation:

South Tees Hospitals NHS Foundation Trust

Partner organisation:

Tees, Esk and Wear Valleys NHS Foundation Trust

South Tees Clinical Commissioning Group

Integrated Occupational Therapy Service

Parkinson's UK

Project lead/s:

Dr Neil Archibald

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Part 1: Abstract

Parkinson's disease (PD) affects one in 100 people over the age of 65 years and, in an ageing society, this number is anticipated to rise. Motor fluctuations, postural instability, gait freezing and falls, in addition to mood disturbance, psychosis and dementia, are key determinants of disability, quality of life and mortality.

Hospital outpatient clinics struggle to meet the often complex needs of these patients, leading to increased morbidity, caregiver stress and early nursing home placement. Patients with advanced PD are at high risk of hospital admissions and, once admitted, spend longer in hospital than age-matched controls.

In Teesside, our Parkinson's team has 1000 patients under its care. The service is led by two Parkinson's disease nurse specialists (PDNS), Zenita and Sue, supported by a neurologist, Dr Neil Archibald and a pharmacist, Viv Horton. Referrals are made to physiotherapy (physio) and occupational therapy (OT), as required.

We are typically able to offer two, 15-minute review appointments per year and, if issues arise in the intervening period, we squeeze people in as best we can. We think we do a pretty good job but our response time to problems can be long and, if we need to involve other specialties, months can pass before help is at hand.

If you are hallucinating, developing dementia, freezing multiple times per day and falling, you simply cannot wait that long. If you are a carer for that person, you cannot wait that long. If you are the team trying to help your patient, you cannot wait that long and, if you are the GP, you will probably end up admitting the patient to hospital.

We wanted to do better ... and with the help of the Health Foundation, we have done so.

The Parkinson's Advanced Symptoms Unit (PASU) is a novel outpatient service, run by South Tees Hospitals NHS Foundation Trust. It is staffed by a neurologist, PDNS, community psychiatric nurse, pharmacist, physiotherapist, occupational therapist and therapy assistant.

PASU offers flexible scheduling of patient slots, dependent upon clinical need. We do not pre-book appointments in advance, ensuring the service remains responsive to need.

We offer detailed assessments, usually by several members of the MDT, without the time pressures of a normal clinic environment. During clinic appointments, we use standardised physiotherapy, occupational therapy and mental health interventions.

Once a management plan has been agreed, patients are asked to keep in touch with the team by phone and email, and can be reviewed again as required. PASU team members also deliver interventions in the patient's own home. Home assessments

from the therapy team and CPN provide another opportunity to evaluate progress. These are often performed within 24 hours of attending PASU.

For many patients, PASU functions as a “one-stop shop” to address a specific clinical need. Others attend for a number of weeks, until their condition has stabilised. PASU allows for closer monitoring of higher risk patients, ensuring that treatment complications are minimised. It offers support not just for patients with motor complications, but also for those with dementia and psychosis.



FIGURE 1 - KEY COMPONENTS OF PASU MODEL

A rapid access, community-based, self-referral service for patients with advanced PD, addressing both physical and mental well-being, is a first in the UK.

As a team, we finally feel we can deliver timely interventions for complex problems, and feedback from patients and carers alike has been fantastic. PASU has helped streamline other parts of our service and, as a result, waiting times for other patients have reduced.

We have been assessing the impact of PASU using validated health outcome measures, as well as other key metrics, such as hospital admission/re-admission rates, carer stress and patient quality of life.

Defining the key healthcare metrics for the project has been very important. We decided early in the project to record data relevant to patients and carers, and that would provide evidence of “quality” and “impact”. Other metrics focus on whether our service can reduce the cost of healthcare, by reducing unscheduled care and complications in this high-risk group.

Part 2: Progress and outcomes

How does it work?

Patients can self-refer, or be sent for assessment by any member of the local healthcare team. Patients with complex needs, contacting the PD helpline, are offered an appointment in PASU. Referrals also come from clinicians within the region and community teams (GPs, matrons, physiotherapists).

Since opening our doors in September '15, we have seen 150 patients. We do not pre-book appointments in advance, ensuring the waiting time for assessment remains short. The average time from referral to review is 10 days. Previously, our response time for an MDT assessment was 120 days.

Triaging complex patients into the PASU service has increased the efficiency of the parallel "routine" Parkinson's clinic. We have been able to offer 10 additional appointments per month in this clinic, reducing our waiting time from 6 months to 4 months.

On arrival, visitors to the clinic are asked to fill in baseline questionnaires looking at self-rated quality of health (LTC 6; EQ-5D-5L) and caregiver stress (caregiver strain index). These are reassessed, following our interventions, to quantify impact. During clinic appointments, we use standardised physiotherapy, occupational therapy and mental health interventions.

Once a management plan has been agreed, patients are asked to keep in touch with the team by phone and email, and can be reviewed again as required. Home assessments from the therapy team and CPN provide another opportunity to evaluate progress - 50% of patients attending PASU will have a home assessment, usually within 7 days of attendance (if urgent – within 24 hours). Feedback from these visits is given to the MDT the following week.

Typical PASU appointment (in numbers)

- appointment length – 2 hours
- team members involved – 3
- therapy team home follow-up – 3 visits
- therapy assistant home follow-up – 8 visits
- home physio/OT assessment – 90 minutes
- home therapy assistant visit – 60 minutes
- therapist telephone liaison (per patient) – 90 minutes

Additional qualitative impacts include:

- Taster sessions for social and exercise opportunities.

- Facilitating ongoing engagement in community resources - in line with our remit of empowering self-management in the future. The most notable outcome from this aspect of PASU is the “Tremorloes” choir, for patients and carers affected by Parkinson’s.
- An education programme for people affected by Parkinson’s disease dementia, offering tips on management of symptoms, whilst allowing patients and carers to meet others affected by a similar problem.
- We have also just run the first educational session for carers, with excellent feedback.

Multiple healthcare professionals have also attended for additional training through PASU. These include:

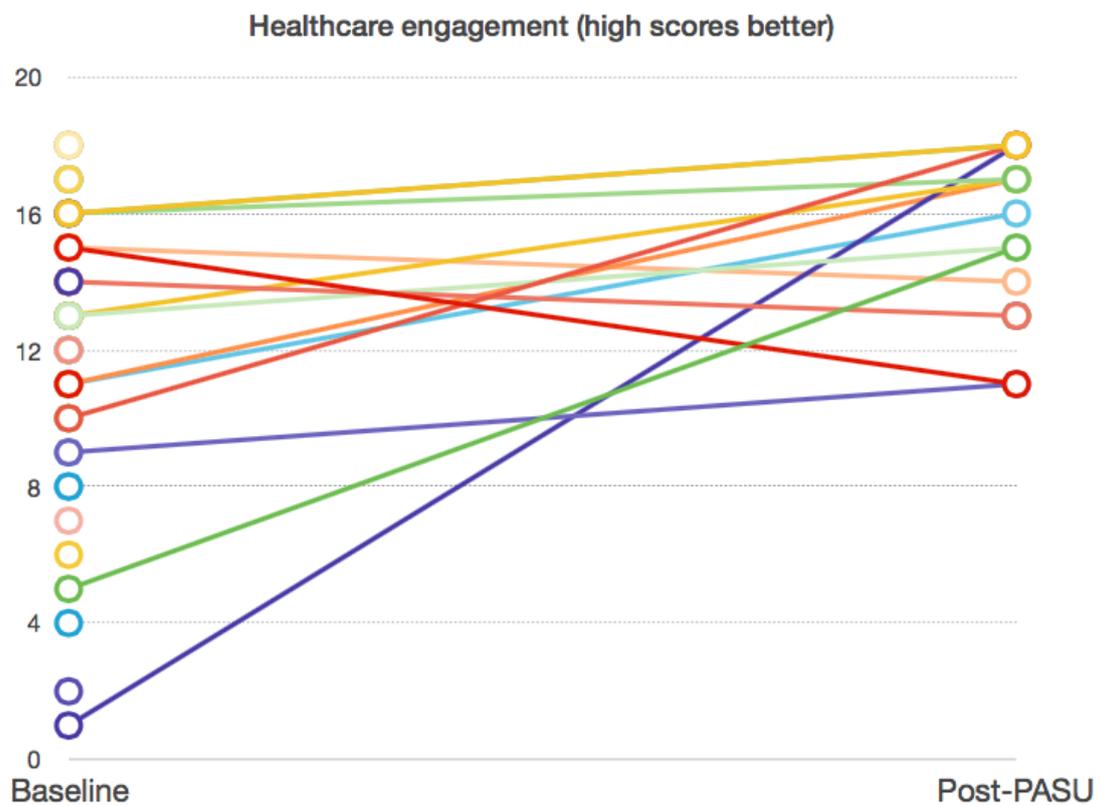
- Care of the Elderly doctors
- Palliative care clinicians
- Pharmacists
- Physiotherapist students
- Nursing students
- Community Psychiatric Nurses

Quality metrics

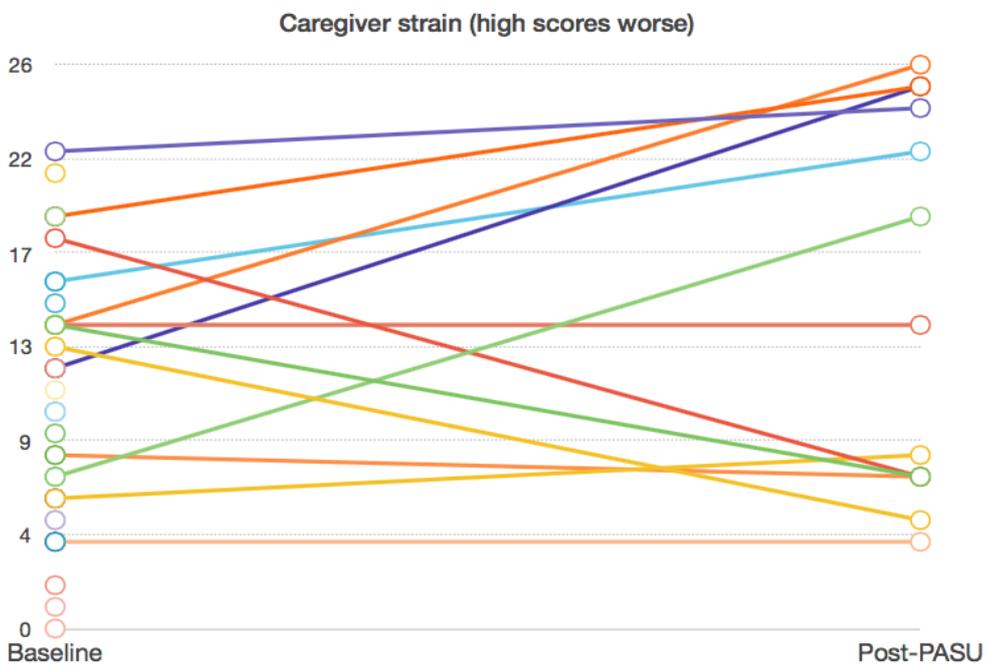
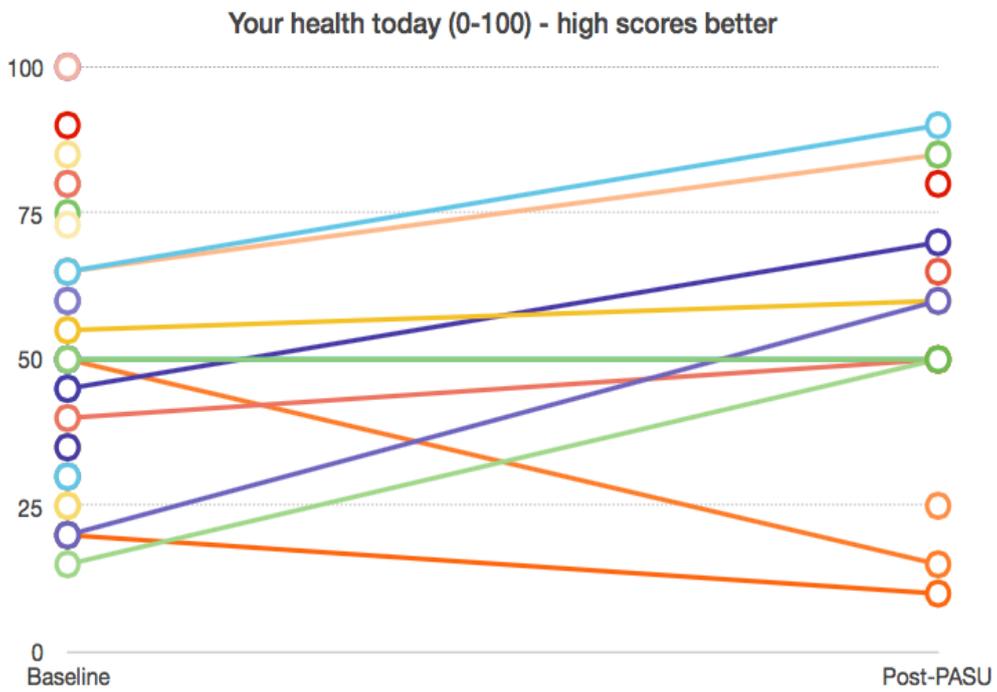
We have been careful to choose metrics that have direct relevance to clinical practitioners, and have avoided using complex and time-consuming research tools. All are free to use, quick to complete, familiar to practitioners and widely available. We hope this approach will help others to judge the external validity of our findings.

Data collection is still ongoing, but analysis of our 6-month data is now available.

Data collected at first attendance, and follow-up, demonstrates that the PASU delivers a high-quality service. There has been an increase in engagement in healthcare (LTC-6), showing that we are providing patients with the tools they need to manage their own condition. This data is illustrated for each patient/carer, rather than as an “average”, and allows trends to be explored, whilst recognizing that every individual’s response to treatment is different.



We have also seen improvements in quality of life, as measured by the EQ-5D and “Your Health Today” questionnaires.



Caregiver strain is a complex issue. Whilst some carers report significant reductions in stress following attendance at PASU, for many others, paradoxically, levels have increased. We would like to explore this further but suspect that, by allowing our carer group the opportunity to articulate their stress, we are seeing raised awareness of the issue.

Work is underway in PASU to try to support carers better – individual carer assessments; caregiver education events; emergency health care plans etc.

Part 3: Cost impact

The financial scale of the problem

Patients with advanced PD are at high risk of unplanned hospital admissions and, once admitted, spend longer in hospital than age-matched controls. It is known that patient mortality and morbidity for frail elderly patients increases with length of stay, whilst their confidence and ability to return to their usual place of residence decreases.

As the condition progresses, admission to 24-hour nursing care becomes more likely. Interventions that can maintain independence and safety, and improve carer quality of life, defer or avoid this admission and the consequent financial burden on the health economy.

One of the motivations of PASU is to try and reduce the amount of crisis admissions to hospitals, respite care and long-term nursing care. Unscheduled care is extremely costly, both to hospital trusts and commissioning bodies. For example, over 2014/15, the total bill for Parkinson's disease admissions in South Tees was £1.7m, with complications such as urinary tract infection (£181k), pneumonia (£147k) and hip procedures (£132k) proving particularly costly.

Although not specifically "coded" for, many other admissions are due to caregiver strain, hallucinations, delirium and dementia.

Costs are spread between hospital trusts, local commissioners and local authorities.

	Cost (£)	Who pays?
Acute medical care	2400	CCG
Acute hip fracture care	8600	CCG
A&E attendance	150	CCG
Acute psychiatric admission	10,740	CCG
Respite care	500/week	Local authority
Nursing home admission	615/week	Local authority (£500) CCG (£115)
EMI nursing home admission	650/week	Local authority (£500) CCG (£150)

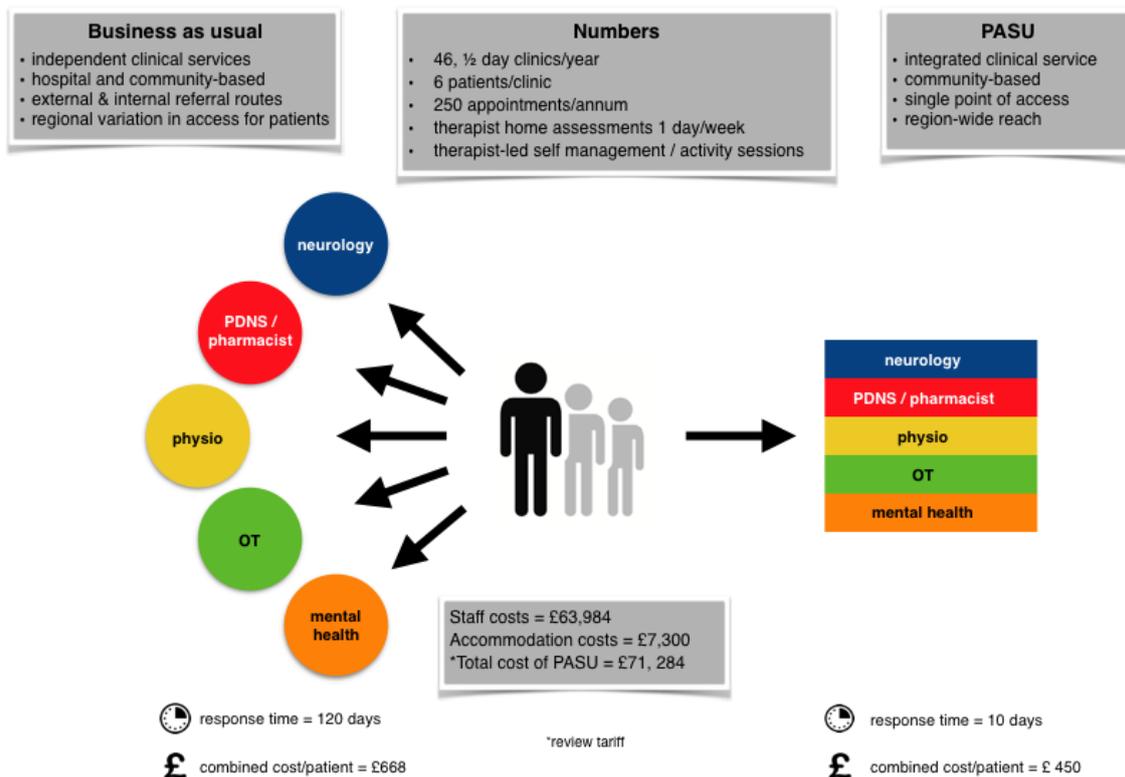
The cost of “business as usual”

The current service costs, met by local commissioners, can be measured by looking at the individual components of “business as usual”.

- Neurology multi professional review appointment, two 15 minute slots @ £130
- Physiotherapy appointment @ £45 (via block contract)
- Occupational therapy appointment @ £45 (via block contract)
- Mental health @ £318 (tariff for Mental Health Services for Older People assessment)

In total, this service model costs the commissioners up to £668 - if all members of the team are required – as well as building in considerable delay as the patient progresses through it.

This costing model does not include any further follow up by the mental health or therapy services.



In order to provide the current service model, once the initial funding has finished, we needed to balance two key issues – the cost to the hospital in providing the staff for PASU and the cost to the CCG who will be paying for patients to attend. Most hospital services are funded by an agreed tariff for each patient seen. Discussions between our Trust and the local CCG (South Tees) led to an agreement for an enhanced tariff, covering the service costs, of £450 per patient episode.

At face value, this may seem high but, compared to the “business as usual” model, the tariff is a reduction of £218. Therefore, across a cohort of 276 patient episodes per annum, the cost of PASU would be £124,200, compared to up to £184,368 for the traditional service model.

As a regional service, the costs will be split across a number of different CCGs, spreading the financial burden for commissioners. Negotiations are ongoing with other CCGs to ensure that they, too, are willing to pay an enhanced tariff for their patients to be seen in PASU.

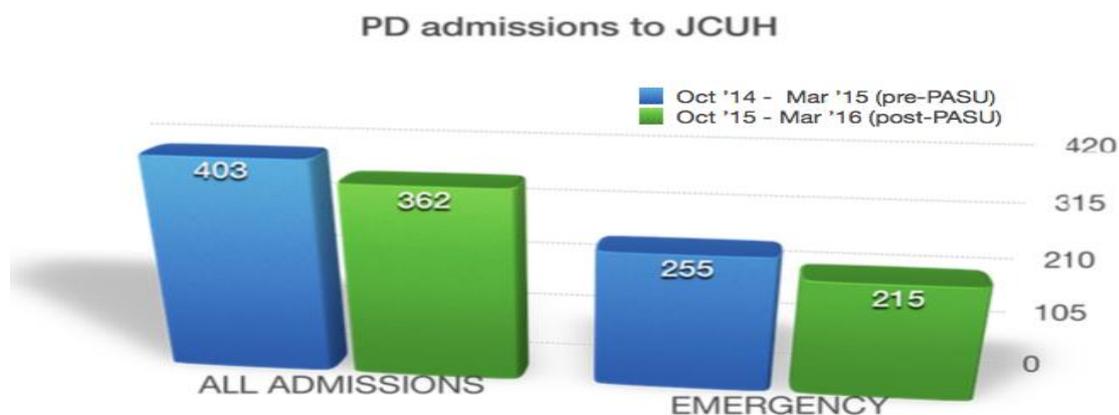
The financial impact of PASU

The PASU service has the potential to reduce costs of acute medical care, acute psychiatric care and nursing home admissions. It also allows community initiation of treatments that might otherwise occur as a “crisis” intervention or in the inpatient setting.

Data collection is ongoing, but figures from the first six months of the service are encouraging.

Reduction in admissions

In the first 6 months of the PASU initiative (Oct '15 – Mar '16), there has been a reduction in unscheduled admissions, to acute medical and surgical services, for patients with PD.



The overall trend for emergency admissions in South Tees NHSFT is down 6% over this time frame. In contrast, with respect to unplanned Parkinson’s admissions, we have seen a 16% reduction. This equates to 25 potential admissions avoided, with each costing, on average, £2,400 – a potential cost saving of £60,000.

Reduction in length of stay

Length of stay for PD patients is generally double that of their non-PD counterparts. Our data shows a modest reduction in length of stay (one day), totaling 215 bed days over the first 6 months of the project. This is obviously important for PD patients, but also improves patient flow in the hospital for all patients.



Impact on nursing home admissions

Our service currently provides care for 50 PD patients in long-term nursing care. The bulk of these admissions are due to declining mobility, dementia and psychosis and care-giver strain. The annual cost to the local authority, for this group of patients, is approximately £300,000 (£6000 per patient/annum). The approximate cost to the local CCGs is £75,000 (£1500 per patient/annum).

It was hoped that the PASU interventions would reduce admissions to long-term nursing care amongst our patient group.

In the baseline collection period (Oct '14 - Jun '15), we saw 8 PD patients from our caseload move in to nursing care. During the PASU period (Oct '15 - Jun '16), we have, so far, seen 7 nursing home admissions.

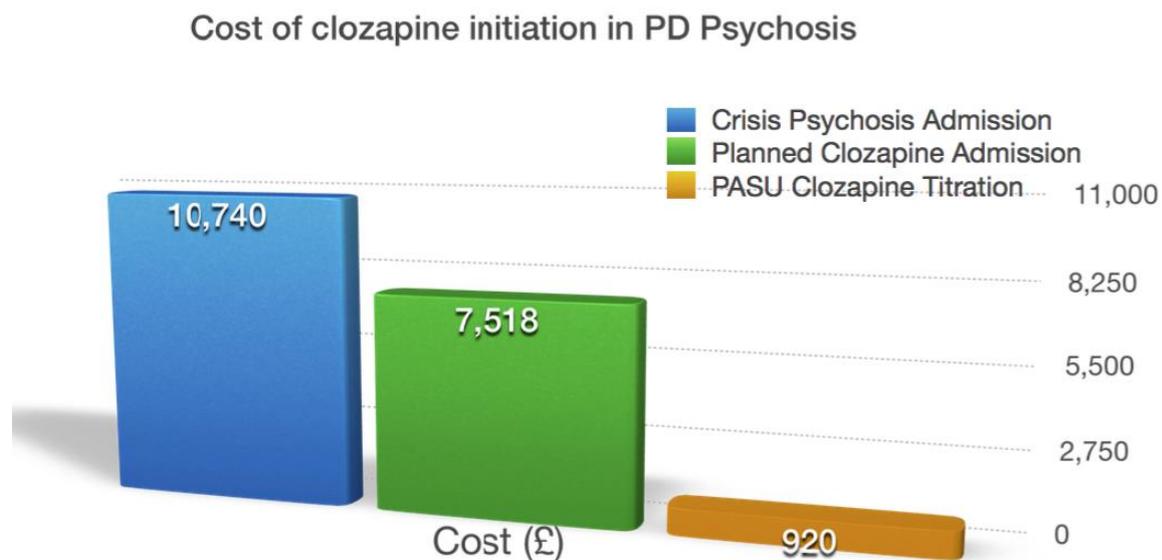
We have, therefore, been unable to show a reduction in nursing care home admissions attributable to the PASU intervention.

Impact on Mental Health services: clozapine initiation

Improving mental health is a key component of the PASU clinic, and setting up the first clozapine service in the North East of England has been a major outcome from the project. clozapine is the only NICE-approved, evidence-based therapy for psychosis in Parkinson's disease, yet access is restricted in the UK, largely due to "organisational" barriers.

Because of the cross-speciality nature of the PASU service, we have been able to shift clozapine initiation from a "crisis" intervention to a "planned" one. Initially, we admitted patients for treatment but, as the service has developed, we have been able to shift this into the community, using the PASU as a point of coordination.

To date, we have 6 clozapine patients on our caseload; 4 of these have commenced outpatient treatment. This service model offers a potential cost saving to commissioners of £9,820 per patient (£39,280 in total) when compared against initiation during a mental health crisis, and £6,598 per patient (£26,392 in total), when compared against a planned inpatient initiation and titration.



Reduction in elective admissions: apomorphine initiation

Interventions that would have previously required admission to the ward, such as apomorphine infusion initiation, can now be started from within a day case setting. Waiting times for this intervention have fallen from 8 weeks to 2 weeks, with a cost reduction to commissioners of £1040 per patient (previously £1400 for a 7 day admission; now £360 for a 3-day, day case initiation). We have now initiated 12 patients on apomorphine in this setting, providing an actual cost saving of £12,480.

Summary of financial benefits accrued

Over nine months September 2015 to May 2016 inclusive,

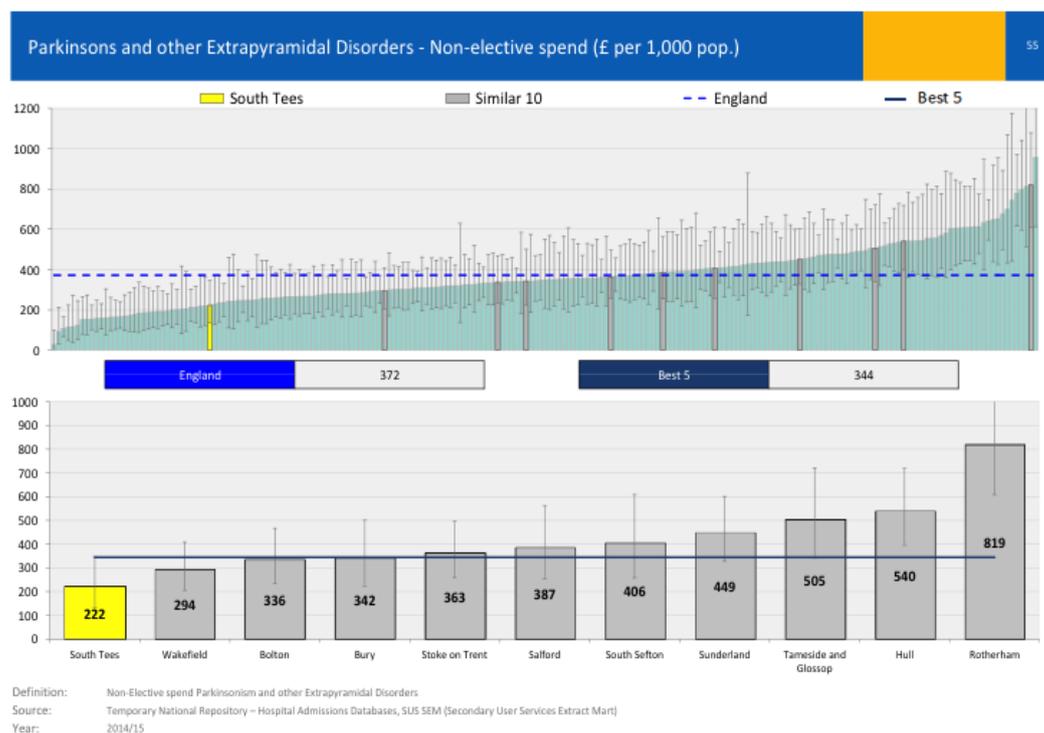
- Reduction in admissions: £60,000 (6 months data)
- Reduction in length of stay: £43,000 value of bed days saved
- Nursing home admissions: No verifiable benefit to date
- Clozapine initiation: £26,392 (compared to planned inpatient)
- Apomorphine initiation: £12,480

PASU - the broader financial picture

“Commissioning for Value” is a partnership between NHS England and Public Health England, designed to provide high-level data on neurological services across England. Data from April 2016 is presented below.

In our case, South Tees CCG is compared to the 10 most demographically similar CCGs (traditional communities with deprived areas and poorer health). The data are used to identify realistic opportunities to improve health and healthcare for your population.

Parkinson’s services in South Tees CCG are performing well, particularly in terms of non-elective spend. We have the lowest spend on emergency admission for Parkinson’s out of the 9 other comparator CCGs.



Whilst we do not have similar benchmarking data from before the PASU intervention, we feel that this highlights the benefits of having a well-resourced, responsive, multi-disciplinary Parkinson’s service.

Part 4: Learning from your project

Did we achieve our aims?

We set up the PASU with one aim - to improve care for Parkinson's patients with complex needs.

In some respects, it is no surprise that, if you set up a new service, full of staff with passion and expertise, then the quality of care improves. However, in the face of a progressive, neurodegenerative disorder, it was much less clear if we would be able to show improvement, particularly using simple, free-to-use health metrics.

In this sense, our team views the service as a great success. The data show our interventions delivered improvements in quality of life and, in many cases, reduced caregiver strain. Whilst we did not win every battle, the feedback from patients shows that the clinic offers an invaluable resource.

How did we staff the unit?

Staffing the unit could have been a real challenge – and this part of project was not all plain sailing. We struggled to appoint a physiotherapist due to initial staff shortages. Turnover of staff also created some challenges, although we are blessed with excellent therapists in our Trust, and the replacements proved more than equal to the task.

Support from the leads for Physiotherapy and Occupational Therapy has been unwavering. I consider us very lucky in this regard, and am not sure other regions would necessarily have the same experience. We also developed a close working relationship with the local mental health trust (Tees, Esk, and Wear Valleys NHS Trust) and, without this, would not have been able to deliver some of the most important mental health interventions.

I'm not sure how we achieved this level of support, if I am being totally honest. There is a history of collaborative working within our region and so, in this regard, we were clearly fortunate. Early on in the planning, I made a point of organising face-to-face meetings with key individuals and, where this was not possible, phone calls were the preferred method of communication. Email was a last resort! This personal approach allowed for far quicker decision making and avoided potential misunderstandings.

Did we fulfill the training remit?

One of our hopes, going into the PASU project, was that it would have an educational role, both for the team itself, and for other clinicians and therapists in the region. In this respect, again, PASU has been a huge success. Numerous health care professionals, as well as medical, nursing and therapy students, have attended PASU for training.

We now have a highly trained, passionate and motivated team, who feed off each other's enthusiasm, and an environment that promotes innovative approaches to managing such a complex, progressive neurological disorder. For example, our therapy assistant, Jan, has been instrumental in setting up a choir for patients and carers, a "Parkinson's Bootcamp" and educational sessions for patients and carers on dementia. More of Jan's interventions can be seen in the appendix. We also have a Community Psychiatric Nurse, Nina, who, by her own admission, knew very little about Parkinson's at the start of the project. Nina is now looking at ways to further develop her role within the team and, without her support, the clozapine service would never have been a success. We have also been able to find additional funds to allow our Occupational Therapist, Debra, to join the Parkinson's team full-time, making her one of very few specialist Parkinson's OTs in the UK.

Did we make our case for "PASU - year two"?

As you will see in the next section, we were able to collect data that were meaningful to the hospitals providing staff to the unit, and to the local CCGs. Without this, we would not have been able to make a case for future funding for the unit.

What advice would I offer to others thinking of setting up a similar service?

If we were setting out to do this all again, I'm sure there are things we would do slightly differently. If there are any "top tips" to be had, then these are they:

- Make sure you can identify staff as passionate about improving care as you are – they are around, but might not have had an opportunity to show it yet.
- Develop relationships with service leads. There is no way to get the staff you need without their support.
- Make phone calls and meet face-to-face. E-mails will not cut it, if you need to convince someone to change his or her mind.
- Think about what matters most to stakeholders in the service. Everyone wants high-quality services, but that alone is not always enough.
 - For the hospital it might be shorter waiting times and improved patient flow that swing it.
 - For the CCGs, it might be reduction in unplanned admissions and more cost-effective community treatments.

Part 5: Sustainability and spread

As previously mentioned, we always felt that, if we had a responsive, multi-disciplinary service, resourced to meet the complex needs of our patients, we would be able to improve outcomes.

What was much less certain, throughout the course of the project, was if we could make the financial argument for the service to be commissioned, once the Health Foundation funding came to an end. We knew that, if PASU was to have a future, we would have to be able to show its value, not just to patients, but also to the organisations funding it – the hospital trusts and departments providing the staff, and the CCGs who would, ultimately, be required to pay for their patients to attend.

We were careful to select metrics that we felt would matter to the hospitals and the CCGs. It was important that we were able to meet with the CCG in advance of commencing the pilot, so that we had agreement over what data would help make the strongest case for PASU being commissioned.

Being able to show that, since PASU opened its doors, emergency admissions to hospital had fallen dramatically was crucial. Response time for the service remains excellent and waiting times have fallen considerably. Perhaps most importantly, the fact that we could deliver treatments in a community setting, at a fraction of the cost of “business as usual”, also provided a compelling argument for further funding.

Our neuroscience manager, and business manager, were hugely important both in defining the data set we would later collect, but also in collating the data on admissions and length of stay, and the costs incurred. They were also instrumental when it came to meetings with the CCGs and the writing of the formal business case.

As a result, we have agreed a modified service model for PASU that has the support of all the key stakeholders. A tariff has been agreed for year two, and we expect to be “open for business” (again!) at the start of October 2016.

It is hard to say if there will be spread beyond our region. We have had a large number of visiting clinicians and therapists over the course of the project. Some have come from outside the area and were keen to see the service model in action. We have also discussed components of PASU, particularly the mental health aspects, with other services – most recently in Sunderland and Newcastle-upon-Tyne. There is considerable interest in the clozapine model and, given the positive impact for patients, and the highly cost-effective nature of the intervention, it seems likely that more clozapine services will become available, at least in part, as a result of the PASU data.

A key milestone for us is the publication of the 12-month PASU outcomes. We will look to present these at national meetings (British Geriatric Society; Association of British Neurologists), either in platform sessions or as posters. We also aim to

publish the outcomes in health service literature and via the Parkinson's Excellence Network.

We are in the process of making a short movie, to highlight the service more effectively. This will include interviews with patients, carers, staff and commissioners. This should be ready by October '16.

We were delighted to win the "National Patient Safety Award for Long-Term Conditions" in July '16. This award recognises services that provide proactive, holistic, preventive and patient-centred care, that also focuses on safety. The award helped to raise the profile of the PASU service and provided an additional incentive to commissioners to support us going forward.



<https://www.patientsafetycongress.co.uk/2016-patient-safety-awards-winners>

Appendix 1: Resources and appendices

Project Timelines

Follow the link to a more detailed timeline of the project.

<http://www.tiki-toki.com/timeline/entry/591775/PASU-timeline/>

Resources

Word cloud

We have generated a word cloud from the clinic letters of patients seen in the first 6 months of the project. It gives an insight into the kinds of problems faced by our patients.

Interestingly, the theme that emerges most often is “time”. We believe that time spent with our patients is an important determinant of quality of care. Time is something that was lacking in the “business as usual” model, and has become a central tenant of the PASU service.



Videos

Follow the links for watch some videos of patients we have seen in PASU. Without the service, the lives of our patients would be much, much harder. But don't just take our word for it, listen to the people that actually know what it is like.

Why clozapine matters in Parkinson's disease

This is George, with his daughter Tracey. George has Parkinson's disease, and has been troubled with severe, treatment-resistant hallucinations for months. He and Tracey were struggling at home - both were exhausted and George was very distressed.

<https://vimeo.com/153295013>

Peter's story - why mental health matters in Parkinson's disease

This is Peter. He has Parkinson's disease. Recently, he has been struggling with hallucinations. As you can see, these are having a huge impact on his quality of life and are becoming increasingly difficult to deal with. Peter, and his family, have kindly agreed to share their story with you, so we can raise the profile of this complication and help you understand why mental health matters in Parkinson's.

(PS the subtitles are as much because of Peter's Parkinson's, as they are his excellent Belfast accent - which I share!)

<https://vimeo.com/153700844>

When clozapine works - Michael and James

Michael has Parkinson's. James is his son and carer. Together, they have been having a terrible time coping with horrible hallucinations. Here, they chat about what has been happening, and tell us about their experiences of a drug called clozapine.

<https://vimeo.com/174264103>

Intestinal levodopa gel infusion - Peter's story

Peter is young. He has had Parkinson's for many years and his life had become ruled by the unpredictability of his medications. He was a virtual prisoner in his own home. Following assessment in PASU, we commence him on an intestinal infusion of levodopa gel. Here, Peter tells us what his life was like before the treatment, and what difference it has made. The video starts with some footage of him before the new treatment commenced.

<https://vimeo.com/159267124>

The Tremorloes

A little out of season now, but thanks to the hard work and enthusiasm of our therapy assistant - Jan - we now have a choir up and running. We think there are good scientific reasons why singing is good for people with Parkinson's. Better yet, the choir has a terrific social aspect to it - and a brilliant name to boot.

<https://vimeo.com/153702519>

Website

Information for patients can be found on the South Tees NHS Trust website.

<http://southtees.nhs.uk/services/neurology/parkinsons-disease-service/parkinsons-advanced-symptom-unit-pasu/>

Service user quotes

I haven't seen Dad walk for months - until today

It's been a revelation .. for someone to consider me, the carer. Nobody has ever asked me how I feel before

Parkinson's is an extremely distressing condition making it difficult for patients to remain positive but having the specialist clinic in our backyard makes things so much better.

It allows staff to work as a team and if any member of the team needs anything they are all together in the same building

I've got my granddad back!

If it hadn't been for the treatment dad got, I would've had to give up work

... it was a great relief to the whole family to get such a balanced, detailed and friendly assessment - a huge boost to us all

PASU staff quotes

"PASU is valuable, enjoyable, timely, educational and really, really rewarding"

Zenita Cowen, PDNS

"MDT working at its best! People are seen by the right person, at the right time. A quality service where the client is the focus of all interventions"

Debra Gallant, OT

"My best day of the week! It's inspiring to see our interventions helping people with Parkinson's, and their relatives"

Viv Horton, Pharmacist

"With PASU, I can visit patients in their own homes and help isolated people get back out into the community. It's incredibly rewarding to help alleviate the symptoms of loneliness"

Jan Duffy, Therapy Assistant

"Working in the PASU team enables me to provide a more holistic, more responsive physiotherapy service. The MDT model means we can provide comprehensive and effective care"

Andy Hall, Physiotherapist

"We had a good service for people with PD before PASU, but it felt disjointed and slow to respond. Now we have a fantastic service, a fantastic team and fantastic outcomes to go with it"

Neil Archibald, Neurologist

"There is an enormous sense of pride and achievement to be told that the PASU team are having such a positive impact on the lives of patients and their families"

Nina Williams, CPN

Details of key questionnaires used

EQ-5D-5L & Your Health Today

Applicable to a wide range of health conditions and treatments, it provides a simple descriptive profile and a single index value for health status that can be used in the clinical and economic evaluation of health care. It is cognitively undemanding, taking only a few minutes to complete.

(time to complete - 5 minutes)

LTC-6

The LTC6 Questionnaire asks patients with a long term condition about their healthcare over the last 12 months. It includes questions about involvement in decision- making, although the focus is on self-management.

(time to complete - 5 minutes)

Caregiver strain index

Data collection tool designed to give some idea of the impact of caring for a person with advanced Parkinson's disease.

(time to complete - 5 minutes)

Other measures

Canadian Occupational Performance Measure (COPM)

The Canadian Occupational Performance Measure (COPM) is an individualized, client-centred measure designed for use by occupational therapists to detect change in a client's self-perception of occupational performance over time.

Goal Attainment Scaling (GAS)

GAS is a method of scoring the extent to which patient's individual goals are achieved in the course of intervention. In effect, each patient has their own outcome measure but this is scored in a standardised way as to allow statistical analysis. Traditional standardised measures include a standard set of tasks (items) each rated on a standard level. In GAS, tasks are individually identified to suit the patient, and the levels are individually set around their current and expected levels of performance.

Short Version of the Warwick and Edinburgh Mental Well Being Scale (sWEMWBS)

Short 7-item version of the Warwick-Edinburgh Mental Well-Being Scale, which was developed to enable the monitoring of mental wellbeing in the general population

and the evaluation of projects, programmes and policies which aim to improve mental wellbeing.

The items are all worded positively and cover both feeling and functioning aspects of mental wellbeing.

Brief Psychiatric Rating Scale (BPRS - expanded)

Detailed, validated tool for the assessment of psychiatric problems in patients with a wide variety of mental health conditions.

Medication reconciliation

Standardised pro forma to ensure an accurate record of patient medications, potential interactions, recent alterations and complications.

Key metrics from the project have already been discussed in detail, but we have attached examples of some of the questionnaires we use for collecting the data in the clinic.

Figure 1: EQ-5D-5L UK English sample version

Under each heading, please tick the ONE box that best describes your health TODAY

MOBILITY

- I have no problems walking about
- I have slight problems walking about
- I have moderate problems walking about
- I have severe problems walking about
- I am unable to walk about

SELF-CARE

- I have no problems washing or dressing myself
- I have slight problems washing or dressing myself
- I have moderate problems washing or dressing myself
- I have severe problems washing or dressing myself
- I am unable to wash or dress myself

USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)

- I have no problems doing my usual activities
- I have slight problems doing my usual activities
- I have moderate problems doing my usual activities
- I have severe problems doing my usual activities
- I am unable to do my usual activities

PAIN / DISCOMFORT

- I have no pain or discomfort
- I have slight pain or discomfort
- I have moderate pain or discomfort
- I have severe pain or discomfort
- I have extreme pain or discomfort

ANXIETY / DEPRESSION

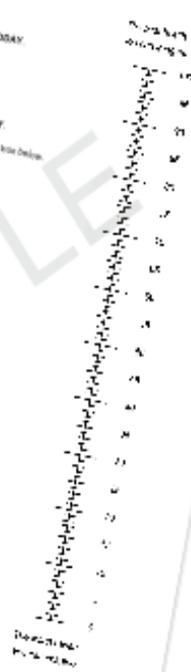
- I am not anxious or depressed
- I am slightly anxious or depressed
- I am moderately anxious or depressed
- I am severely anxious or depressed
- I am extremely anxious or depressed

SAMPLE

- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 00 means the best health you can have.
- 100 means the worst health you can imagine.
- Mark an 'X' on the scale to show how good or bad your health is TODAY.
- Now, please cut!

YOUR HEALTH TODAY =

SAMPLE





Caregiver Screening Tools

1. Modified Caregiver Strain Index^{1,2} (To be completed by the caregiver)
Directions: Here is a list of things that other caregivers have found to be difficult. Please put a checkmark in the columns that apply to you. We have included some examples that are common caregiver experiences to help you think about each item. Your situation may be slightly different, but the items could still apply.

	Yes, On a Regular Basis	Yes, Occasionally	Never
My sleep is disturbed (For example, the person I care for is in and out of bed or wanders around at night)			
Caregiving is inconvenient (For example, helping takes so much time, or it is a long drive over to help)			
Caregiving is a physical strain (For example, being in or out of a chair, effort or concentration is required)			
Caregiving is confusing (For example, helping someone has long or I cannot do things)			
There have been family adjustments (For example, helping has disrupted my routine, there is no privacy)			
There have been changes in personal plans (For example, I had to turn down a job, I could not go on vacation)			
There have been other demands on my time (For example, other family members need me)			
There have been emotional adjustments (For example, seeing arguments about caregiving)			
Someone behaviour is upsetting (For example, incontinence, the person cared for has trouble remembering things, or the person I care for accuses people of taking things)			
It is upsetting to find the person I care for has changed so much from his/her former self (For example, he/she is a different person than he/she used to be)			
There have been work adjustments (For example, I have to take time off for caregiving duties)			
Caregiving is a financial strain (For example, I worry about the person I care for, I have about how I will manage)			

Sum responses for "Yes, on a regular basis" (2 points)
Total Score =

¹ Trunton, M. & Frank, S.S. (2011). Analysis of the revised Zarit Burden Interview and Social Desirability for the Modified Caregiver Strain Index. Issue #14, available online at: www.innovatehealth.org.
² Zarit, J.H. (1988). The Zarit Burden Interview: A new short-scale measure of caregiver burden. *Medical Care*, 26(5), 521-536.



LTC 6 Template



1. How would you describe the amount of information you receive to help you in managing your health?
2. How would you describe the amount of information you receive to help you in managing your health?

1. How would you describe the amount of information you receive to help you in managing your health?

Not at all
Little
Some of my regular needs are met
Most of my regular needs are met
All of my regular needs are met

2. How would you describe the amount of information you receive to help you in managing your health?
3. How would you describe the amount of information you receive to help you in managing your health?

2. How would you describe the amount of information you receive to help you in managing your health?

Not at all
Little
Some of my regular needs are met
Most of my regular needs are met
All of my regular needs are met

3. How would you describe the amount of information you receive to help you in managing your health?
4. How would you describe the amount of information you receive to help you in managing your health?

3. How would you describe the amount of information you receive to help you in managing your health?

Not at all
Little
Some of my regular needs are met
Most of my regular needs are met
All of my regular needs are met

4. How would you describe the amount of information you receive to help you in managing your health?
5. How would you describe the amount of information you receive to help you in managing your health?

4. How would you describe the amount of information you receive to help you in managing your health?

Not at all
Little
Some of my regular needs are met
Most of my regular needs are met
All of my regular needs are met