A simulation-based decision support tool for informing the management of patients with Parkinson's disease

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Abstract

We describe a decision support toolkit that was developed with the aim of assisting those responsible with the management and treatment of Parkinson's disease (PD) in the UK. Having created a baseline model and established its face validity, the toolkit captures the complexity of PD services at a sufficient level and operates within a user friendly environment, that is, an interface was built to allow users to specify their own local PD service and input their own estimates or data of service demands and capacities. The main strength of this decision support tool is the adoption of a team approach to studying the system, involving six PD specialist nurses across the country, ensuring that variety of views and suggestions are taken as well as systems modelling and simulations. The tool enables key decision makers to estimate the likely impact of changes, such as increased use of community services on activity, cost, staffing levels, skill-mix, and utilisation of resources.
Such previously unobtainable quantitative information can be used to support business cases for changes in the increased use of community services and its impact on clinical outcomes (disease progression), nurse visits and costing.

Keywords: Discrete even simulation, decision support toolkit, Parkinson's disease, patient flow modelling.

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1. Introduction

Parkinson's disease (PD) is the second most common chronic neurodegenerative condition in older people especially beyond the age of sixty (De Rijk, et al. 1997). The diagnosis has profound implications for the individual and their family, as well as major cost implications for health and social services. Recent estimates show that there are 127,000 people in the United Kingdom (UK) living with the disabling effects of Parkinson's, a number expected to increase to 165,000 by 2020 (Parkinson's UK 2011).

The symptoms of Parkinson's disease can be split into motor and non-motor. Motor symptoms, which are more obvious and tend to be the first to be noticed, include stiffness and tremor leading to lack of mobility. Non motor symptoms such as depression, psychotic symptoms, dementia, sleep disturbance, fall, and autonomic disturbances, are also problematic. These symptoms tend to occur first, but often go unnoticed due to the difficulty in making a definitive diagnosis of PD (Parkinson's UK 2012).

There are four known stages of PD (Parkinson's UK 2012): 1) *diagnosis* phase is when first recognition of symptoms and signs are observed, however diagnosis is not yet established, 2) *maintenance* phase is when diagnosis has been established and where team of experts notice absence of postural instability, 3) *complex* phase is when a patient has unstable co-morbidities, and 4) *palliative* phase is when a patient has advanced comorbidity. In the UK, maintenance and complex stage patient's accounts approximately for a half and a third of the PD population, respectively (Parkinson's UK 2012) (around 14% is at the diagnosis stage and 3% palliative although figures may vary geographically, e.g. rural vs. urban areas).

The treatment of PD is complex and resource intensive, requiring a multi-disciplinary team including neurological physicians, general practitioners (family doctors), specialist nurses, physiotherapists, speech therapists, occupational therapists and palliative care specialists. Coupled with an increasing PD population, it is no surprise that health care systems around the world find the management of such patients more and more challenging. In England in particular, the National Health Service (NHS) is faced with additional pressures stemming from ever increasing resource and capacity constraints (e.g. reduction in budgets, fewer doctors and nurses, reduced number of hospital beds, etc.). In general the NHS faces an unprecedented resource challenge: net savings of £20 billion must be achieved over the

coming 4-5 years, representing a productivity improvement challenge of around 4% a year (Chris 2010). Therefore, hospitals and commissioners (payers) of health services need to find effective and efficient ways of delivering services to achieve the best outcomes for PD patients who need care and support at all times. The key question is where and how to make changes to ensure that care and support are delivered in an efficient and effective manner. Not surprisingly, the answer is not that simple.

Each individual patient's requirement depends on the severity and stage of their condition. Some could be seen by neurologist on a monthly basis, while others quarterly; Parkinson's specialist nurses may see some patients once a month, whereas others twice a year; in addition, PD patients are generally referred to a combination of community services (CS) depending on the stage of their disease, such as physiotherapy, psychiatry, speech and language therapy, occupational therapy, dietician and palliative care. Physiotherapy can improve balance and flexibility; improve functional independence, including mobility and activities of daily living. Occupational therapy improves personal self-care activities, such as eating, drinking, washing and dressing; maintain work and family roles, employment, home care and leisure activities. Speech and language therapy optimises speech intelligibility, ensuring an effective means of communication throughout the course of the disease. Therefore, effective deployment of community services is considered to be key in improving quality of life and increase patients understanding of their own disease journey, while empowering patients to better self-manage their own condition.

The evidence to support the use of community services in PD is limited and yet patients feel that it is effective (NICE 2006). At the same time, it is thought that increased use of community services could potentially reduce unnecessary hospital admissions, reduce the need for consultations with specialists and facilitate the earlier discharge of patients from hospital with support in the community (NICE 2006). In many cases, commissioners would prefer more use of primary care in the community as opposed to secondary care provided in hospitals, simply because primary care is generally much cheaper than secondary care. For instance, the average unit cost of a PD patient admitted to inpatient care as an emergency admission is £2,133 (based on an average length of stay of 6.3 days) and the average unit cost of neurologist visits is around £145. In contrast, units costs associated with community services are in the region of £38-£98 (e.g. physiotherapy £38, occupational therapy £56 and speech and language therapy £98) (Department of Health 2012).

Such a complex care system of possible interactions between PD patients and a variety of services and care givers makes it challenging for planners and decision makers to come up with better ways of providing the appropriate treatment at the right time and in an efficient manner. Thus the need for a decision support tool that captures the complexity in the system at a sufficient level and is user friendly such that it can be easily understood and manipulated by end users. The tool should respond to the concerns of these end users and enable them to achieve a better understanding of the system structure and operations and how these influence key performance metrics, such as activity results (e.g. the number of patients treated per year), resource utilisation levels (e.g. neurologist, nurses, and beds) and clinical and cost outcomes (e.g. disease progression). In this context, the tool should accommodate the playing-out of a range of policies and scenarios relevant to decision makers and allow testing of the possible impact of these scenarios on the care system performance indicators.

The current study has two objectives. First, to explore the impact of a range of changes to the Parkinson's disease pathway using discrete event simulation (DES) and to explore the utility of this approach in this setting. Secondly, to develop a user friendly decision support toolkit (a further development on the DES model) with relevant simulation controls. The objective here is to get users to interact with the model by enabling them to make necessary changes to the input parameters, so that the model is service specific with a customized set of results, focusing on activity, costing, resource utilization and disease progression (a proxy measure of clinical outcome). These indicators are thought to be valuable for key decision makers in the process of commissioning and re-designing services.

2. Choosing the modelling approach

The patient flow model within the decision support tool can be developed in a number of ways, including using 1) a statistical framework, 2) system dynamics modelling, and 3) discrete event simulation (either with the process-centric or agent-based approach). The statistical approach would capture the flow of individual patients through the process of care, where patient frailties are modelled as random effects. System Dynamics (SD) modelling focuses on aggregate flows of patients and the feedback effect that may be present in the system and the effects of time delays and non-linear relationships between these flows. Discrete event simulation (DES) has the ability to model individual patients and their unique trajectories as they flow through the care system and to incorporate a large number of different patient attributes such as age, gender and disease stage. It allows for the running of

the model over extended time horizons. Patients move through the model and they can experience events at any discrete point in time. Moreover, DES provides the flexibility to incorporate capacity and resource constraints explicitly and to capture the "competition" between competing modelled entities for access to limited resources.

Although capturing physical patient pathways can be immensely useful to better understand the major drivers of a system (i.e. reduce inefficiencies, improve patient experience, reduce cost), there are three shortcomings towards the implementation of the statistical framework, including data related to tracking individual patient pathways and outcomes longitudinally over the full care cycle may not be available or when there is a very large number of observations and pathways/outcomes to consider.

Similarly, SD is appropriate when the focus is on the high level aggregated elements of a system where the interest is on the general patterns of a system's behaviour over an extended period of time. In this particular context, the level of detail at which the PD care system needs to be represented will be extremely difficult to represent through an SD model. Discrete event simulation also has drawbacks such as the need for more and finer grained values for input parameters, longer model implementation times and increased computational costs associated with running experiments. However the need to track individual patient journeys (or trajectories) through the care system, the ability to capture the complex web of interactions of patients going through the diagnosis stage to various forms of treatment that is informed by the disease progression of each simulated patient, and the need to model notions of limited availability of resources (such as care givers' time) have motivated us to select DES.

2.1 Discrete-event simulation in healthcare

DES has been commonly used in health management especially since the 1990 due to the increased complexity of health care systems, the shift to more evidence based decision making in the health sector, and the significant improvements in DES software capabilities and ease of use. These applications have been first reviewed by England and Roberts (1978), who surveyed 92 models covering areas such as laboratory studies and emergency services. This was followed by Klein et al (1993), who presented a review of the use of DES and System Dynamics (SD) in health care management with a focus on medical and operational decision making and health planning. Similarly, Jun et al (1999) analysed the use of DES in health care in single and multi-facility clinics such as outpatient clinics, emergency

departments, and surgical centres and areas such as patients scheduling and admission, scheduling and availability of resources, bed and staff sizing and planning. More recently, Gunal and Pidd (2010) conducted a review on health care performance using DES and describe models related to Accident & Emergency (A&E) services, inpatient services, outpatient clinics, specialised hospital units, and hospital admission services.

Many of the studies reported in these reviews relate to patients flows modelling. In this context, Swisher et al. (2001) developed a DES model to study the performance of a physician clinic in one of the towns in the United States. The model represented the layout and the stages patients go through in the clinic, the categories of resources required for the treatment of patients, and the types of medical conditions treated. Several scenarios were tested regarding staffing levels and facility size and how they affect the financial performance of the clinic, and patients and staff satisfaction. In another study by Brailsford and Schmidt (2003), the behavioural aspects of patients were integrated into a DES model representing the screening of diabetic retinopathy in the United Kingdom (UK). The disease affects the human sight and may lead to blindness, hence the importance of the screening process. The model included the physical and behavioural factors affecting screening attendance compliance of patients and was used to test 10 different behavioural scenarios with the aim to determine the number of total years of sight saved over a 25 years period.

The evaluation of policies to prevent mother to child HIV transmission in developing countries was studied by Rauner et al (2005). In this context, a DES model incorporating the time related evolution of female populations including birth, aging, pregnancy, and giving of birth was linked with the progression of HIV and its treatment. The model was calibrated with data from Tanzania and used to evaluate policies to prevent transmission of HIV from mother to child. The model was run for a 12 years period in order to determine the number of HIV/AIDS deaths, which could be prevented. Pligrim et al (2009) built a DES model to evaluate the cost effectiveness of care options for patients with bowel cancer in the UK. The model portrayed the patients' flows through a comprehensive care pathways structure including patient presentation, referral and diagnosis, treatment, follow up, possibility of recurrence, treatment, and end of life. The model was used to evaluate 13 care options recommended by the English Bowel Cancer Advisory Committee as possible areas of service improvement and their impact on incremental life years gained, quality adjusted life years, and the cost per life year gained.

3 Material and methods

3.1 Information sources for the model

In this study, we involved health care professionals and potential end-users from the outset. The modelling requirements were developed following semi-structured interviews and group meetings with 6 PD specialist nurses. We used simulation software known as SIMUL8 (http://www.simul8.com/), which enabled us to design and implement a user friendly graphical interface with simulation controls for end users. Therefore, in this work we developed a DES model for better management of PD pathway with simulation controls and a graphical user interface. Users could easily specify their demand levels, make assumptions related to all aspects of patient pathways; specify the scenarios to compare against; state the allocation of resources (e.g. nurses, neurologist); and specify disease progression from one disease category to another (e.g. complex to palliative care). The results are then illustrated in two formats, a reduced custom report with key performance metrics and a detailed breakdown of model outputs exported to Microsoft Excel spread sheet, where two sets of scenarios can be compared against each other.

3.2 High level description of the decision support tool

This PD simulation was developed to be used nationwide by a major pharmaceutical company to facilitate service change in the UK with the aim of benefiting patients, the healthcare provider and the company who also supply some of the drugs used in the pathway. As the envisaged end users were not meant to be simulation experts we designed and implemented from the outset a graphical user interface to facilitate the running of the simulations by non-experts and without the need for retorting to the research team for future experimentation. Figure 1 shows a high level representation of the resultant simulation-based decision support tool for informing the management of patients with Parkinson's disease. The tool is made up of six sets of key inputs (identified at the conceptualisation phase) and four sets of key outputs which are considered to be the key performance indicators of the system's operation. The tool comes pre-populated with values for all the input parameters as these were estimated through the structured interviews we had with the six PD specialist nurses and the analyses of the national English hospital episodes statistics dataset. The end users however are able to change the values of the input parameters (see Table 1 for details) according to the configurations of their local services. Two sets of input parameters can be entered namely scenario 1 (baseline model) and scenario 2 the experiment (or intervention).

The scenarios are then compared with respect to key performance indicators (i.e. activity, costs and staff utilization).

Internally, the model captures various patient categories flowing through PD services including individual progression from diagnosis, treatment and disease states, to community services.

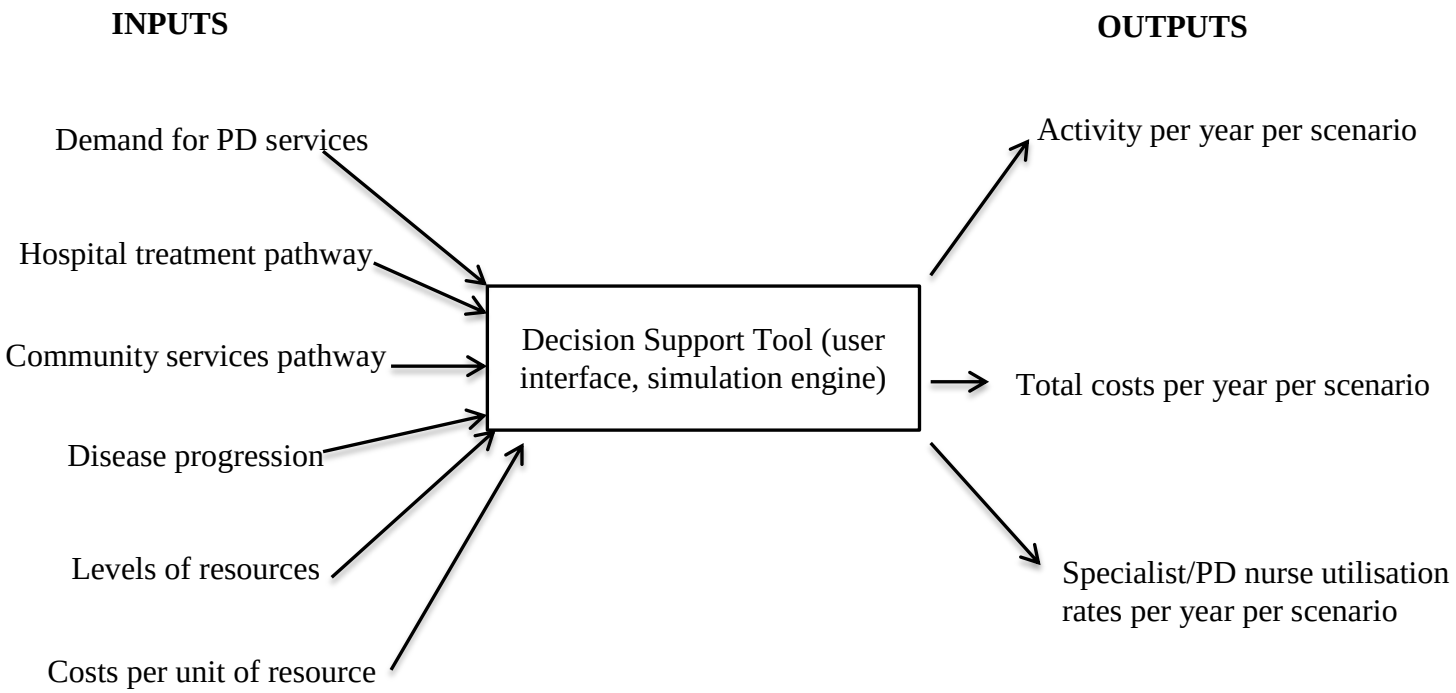

Figure 1: A high-level representation of the simulation-based decision support tool for informing the management of patients with Parkinson's disease.

3.3 Additional setting description

The first stage of the pathway mapping was a round table meeting held with the national committee of the Parkinson's Disease Nurse Specialist Association (PDNSA) in November 2012 (PDNSA n.d.). The PDNSA is based in the UK and was established in 1999 to act as an international resource and network for specialist nurses and allied healthcare professionals working in the field of Parkinson's disease management. The PDNSA is autonomous but collaborates closely with other organisations to promote the role of the Parkinson's Nurse Specialist, and to provide developmental opportunities, education and support. The round table meeting consisted of structured conversation coordinated by the authors. The objective

was to explore the PD pathway in order to establish what in the experts' opinion were important areas for development.

The second phase of the pathway mapping consisted of structured interviews with members of the PDSNA national committee and other influential PD nurses between January and March 2013. The interviews were conducted 'on line' using WebEx technology to allow the interviewer to share a working diagrammatic representation of the pathway. The interviewer discussed each stage of the pathway with the interviewee taking account of the interviewee's opinion and adjusting the pathway in 'real time' as comments were made. The involvement of the model user in model construction ensured that a high degree of realism is built into the model through reasonable assumptions regarding system structure. Once the interviewee was satisfied with the structure of the pathway the interview was closed. The interviews were recorded so that the interviewer could review comments after the event to ensure that all salient points had been captured. In total six experts were interviewed iteratively (see Figure 2 for the finalised pathway mapping of PD).

PD comprises a complex set of services offered in and out of hospital (i.e. in the community). According to the interviews conducted, the typical care system in England involves diagnostic, treatment and monitoring activities. Typically patients first present (or arrive) to a PD outpatient clinic via referral from their GP, accident and emergency (A&E), other hospital department (e.g. care of the elderly), or from other services. At this stage (i.e. diagnosis - top half of Figure 2), if PD is suspected by a consultant, further diagnostic tests are carried out by a secondary care specialist (i.e. neurologist) in the form of medication (known as PD medication) and/or the imaging of the brain (advanced diagnostic imaging) by a radiographer. A PD medication can be administered at the stage of diagnosis to see if there are improvements in symptoms of PD, which could enable the specialist to rule signs of PD. If PD is diagnosed, patients are categorised depending on the stage of their disease (diagnosis, maintenance, complex or palliative) and treatment commences, typically within 1-4 weeks of being diagnosed.

Having being diagnosed of PD, patients move into the treatment part of the pathway (bottom half of Figure 2). Initial treatment is usually carried out by a secondary care specialist, where the patient can be referred to surgery (on a very small number of cases), pharmacological management or community services (e.g. physiotherapy, occupational therapy, speech and

language therapy, palliative care and dietician). Parkinson's specialist nurses play a crucial role at this stage in managing and determining the needs of PD patients. Therefore, both the specialist and PD specialist nurses are involved in the treatment process. The details of the organisation of care into and around these two activities and further into community services depends on the service provider. For example, in certain localities some providers may make more of use community services than elsewhere.

Pharmacological management is carried out by the specialist and a PD specialist nurse. Patients in the diagnosis, maintenance, complex and palliative care stage of disease are reviewed 2, 4, 5 and 6 times in a year, respectively. At the review consultation the possibility of disease progression is evaluated and decisions about escalating the treatment regimen (e.g. from maintenance to complex) are made. Primary care (or community services) is more complex and decided upon the needs of patients, hence the percentage of patients routed out to a particular community service varies considerably between PD services.

Note that, each individual patient's trajectory through the four known stages of Parkinson's disease influences to a large extent the type, location and intensity of care services in each individual's care package. Thus, a decision support tool designed to help planners and managers set-up and run such a complex care system should take into account the organisation, availability and cost of care services but also the number of patients and the stage in the disease progression each patient within the care system is.

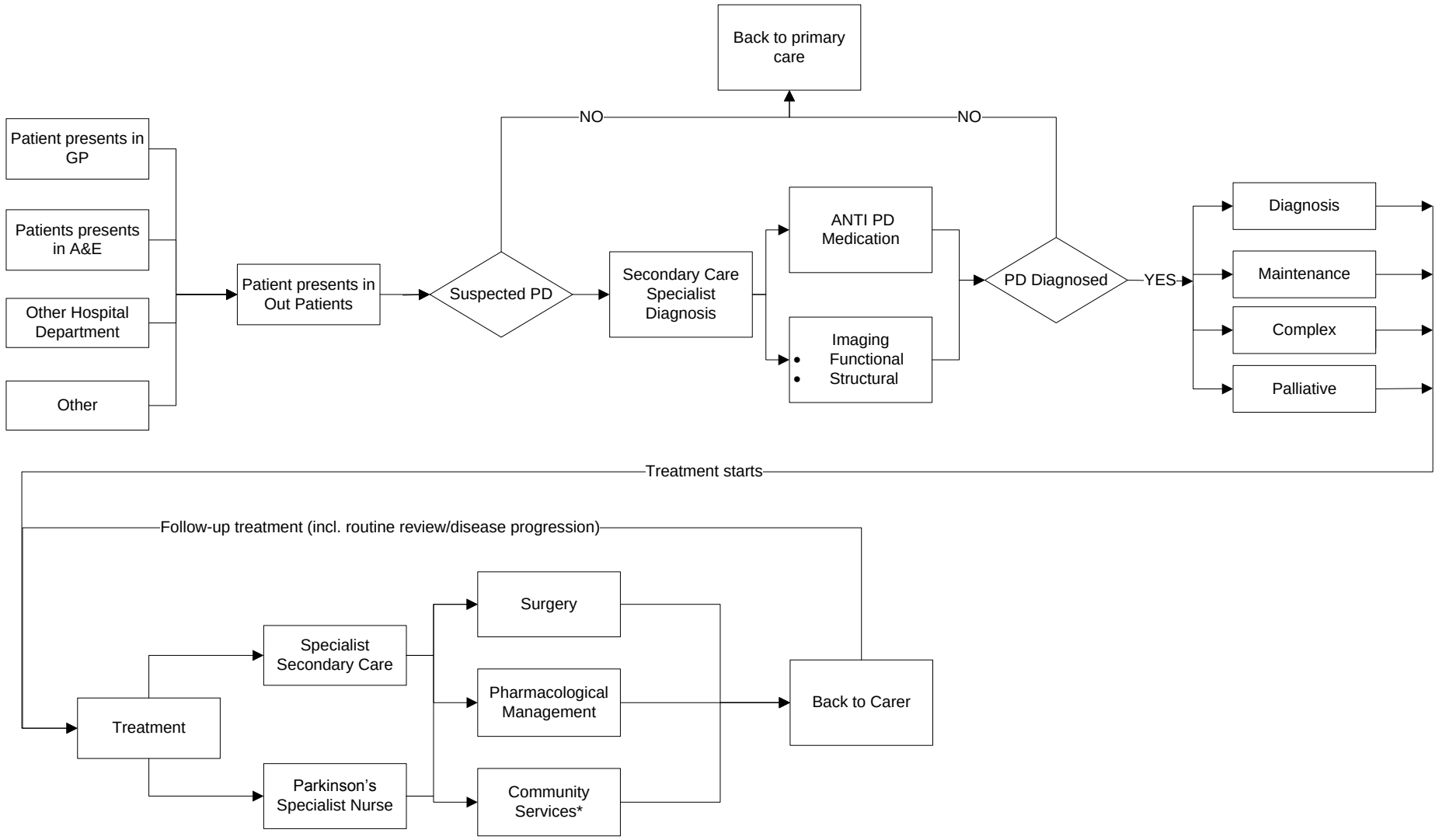

Figure 2. Conceptualised pathway for Parkinson's disease patients. * Community services include Physiotherapy, Psychiatry, Occupational Therapy, Speech and Language Therapy, Palliative Care and Dietician. Pharmacological management refers to medication. GP: General Practitioner; A&E: Accident & Emergency; PD: Parkinson's Disease.

3.4 Model building including assumptions

As it is the case in modelling studies, some aspects of the real life service were not included in the model (if they were not relevant to the objectives of the study) and others were modified for simplification purposes. These were discussed and agreed upon by the nurses and specialists who were consulted during the model building process. The capacity relevant to the study was mostly related to the telephone interviews we had with six Parkinson's disease specialist nurses. Other staff specialties (e.g. administrative clerks, other specialists that were not included) and infrastructure elements (e.g. consultation rooms, mode of transportation used for community visits) that could be seen as capacity constraints were not included in the model as these were not seen as critical by the stakeholders. There are no cancellations (either patient or service initiated) of outpatient consultations or community based visits. Death in the model only occurs from the palliative stage and is related to PD (Robinson 2004). The presence of co-morbidities and other factors, such as socio-economic status or living arrangements, that may complicate the provision of care for a particular patient were not included in the model.

3.5 Input parameters

Model inputs included staffing levels, staff salary, staff availability, treatment pathways (hospital and the community), percentage of patients falling into each category, year on year percentage increase in arrivals, costing of each service, existing and new patient arrivals and disease progression parameters (see Table 1 for details). The vast majority of input parameters are user specified and in a number of occasions the parameter values are estimated using data from the national Hospital Episodes Statistics (HES). Where data is available appropriate estimates are provided for guidance but the user may change as and if required. The HES dataset contains personal, medical and administrative details of all patients admitted to, and treated in, NHS hospitals in England.

The justification for allowing the values of input parameters to be user defined is because of the wide variation between and within services across the country. For example, the number of patients within a service varies dramatically, with some services having less than a 1000 patients, whereas others having more than 2000. In this case, the tool calculates the average number of arrivals per day (based on 5 days a week Monday – Friday, 9:00am – 17:00pm) which then becomes the parameter for the Poisson distribution. Again, using the HES dataset we provide the number of existing PD patients within the service provider (NHS Trust) or Clinical Commissioning Group (CCG) and if the figure is not appropriate for the analysis

users may change accordingly. CCGs are groups of General Practitioners and from April 2013 they will be responsible for commissioning and designing local health services in England.

A typical percentage of patients falling into each category (i.e. patient type) are as follows: 10% diagnosis, 60% maintenance, 25% complex and 5% palliative care. The average percentage of patients presenting to the service via GP, A&E, outpatients and other hospital department are 75%, 15%, 5%, and 5%, respectively. The number of times patients seen by neurologist and PD nurses each year by service providers do not change significantly. Typically, a new diagnosed patient would normally be seen by a neurologist once a year and few times by PD nurses in between, whereas maintenance category patients would be seen every 3-6 months, complex patients every 4-6 months, and a care plan would be prepared for palliative patients, possibly seen by the nurse once a month.

Unfortunately, there is very little data or knowledge about the use of community services and based on the interviews we had with PD specialist nurses, there is large variation in their responses about the utilisation of such services. Therefore the tool first asks users to specify the percentage of patients within their population that are referred to community services by type of service. Secondly, from those patients that are referred to a combination of community services, we then ask users to specify the number of times (i.e. follow-ups) each patient type are seen by a physiotherapist, psychiatrist, speech and language therapist, occupational therapist, palliative care nurse, and a dietician (per year).

In addition, questions surrounding resource requirements are also asked. A specialist or PD nurse may also refer a patient to a community service and a resource is attached for each referral, e.g. physiotherapist, psychiatrist, occupational therapist, speech and language therapist and dietician. To address this complexity we ensured that the numbers of resources, percentage of patients routed out to a particular community service, follow-ups, etc. are all user defined. Note that there are limited numbers of specialists, PD nurses and community workers within the PD services, hence this is a limited capacity simulation.

The next set of input parameters relates to disease progression. A limitation associated with this parameter is the lack of data availability to capture the relevant distribution and parameter estimates for each transition (e.g. diagnosis to maintenance). When data is not

available the triangular distribution is typically used in many simulation studies (Robinson 2004) as the parameters are fairly straightforward to elicit: in this case, the minimum, average and maximum number of years (or months) it takes for a patient to move from one disease category to another. Again users would need to specify these parameters according to the disease progression within their PD population, that is, patients moving from one stage to another, e.g. maintenance to complex.

We established the unit costs of PD patients who have attended A&E and discharged for inpatient care using the Healthcare Resource Group (HRG) code. This included the unit cost of the HRG and any payments due because of an unexpectedly long stay in hospital, or for any specialist care or additional treatments and tests (so-called unbundled payments). We also calculated outpatient and community service costs using their corresponding HRG codes. The HRG codes and their associated costs are publicly available at Department of Health website under Reference Costs for 2012-13 (see (Department of Health 2012) for details).

The final sets of parameters are staff salary and the number of available staff. Staff salaries are selected from a drop down list. The numbers of available staff are defined by the user.

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4 Illustrative results

4.1 Simulation parameters

For illustration purposes of the model and the tool, we chose to evaluate the likely effect size of some changes that seek to increase the use of community services, in line with current policy guidance for PD patients. The number of patients requiring treatment, which determines the level of demand on care services is not constant over time, but has an upward trend. The model captures this aspect through the year to year percentage increase in number of patients in the service. The data collected from the services studied in this project that these percentages are 5% at the end year 1, 3.5% at the end of year 2, and 6.5% at the end of year 3 leading to a total cohort size of 1211 patients by the end of year 3. Among these patients, 10% belong to the Diagnosis category, 60% to the Maintenance category, 20% to the Complex category, and 10% to the Palliative category. With regard to the number of

nurse visits there are 2, 3, 4, and 6 visits on average per year for the Diagnosis, Maintenance, Complex, and Palliative groups, respectively. The model was populated with a cohort size of 1000 patients at the beginning of year 1.

The level of utilisation of the different types of community services, represented by the fraction of PD patients directed to these services, was confirmed by experienced nurses and consultants. This analysis suggested that on average 42.5% of patients are directed to speech and language therapy, 35% to occupational therapy, 22.5% to psychiatry services, 7.5% for dietician, 7.5% to palliative care, and 45% to physiotherapy. The model was run for 3 years with a warm up period of 1 year (determined using the Welch method) to make sure that results are not collected until all patients in the cohort have gone through the PD care system and had an initial contact with a nurse, secondary care worker, or a community service. The weekly simulation period is Monday to Friday from 9am to 5pm reflecting the current operating arrangements in the PD care services.

4.2 Model validation

The model validation process was carried out by comparing the expected number of nurses and consultants visits over a 3-year period using the known data in the actual care system with the simulation results. As described in the previous section, the cohort size is expected to reach 1211 by the end of year 3. The total number of visits over a 3-year period was calculated taking into account the total cohort size, the fraction of the PD category, the number of visits per year for each category, and the simulation duration of 3 years. As an example, the total number of nurse visits for the Diagnosis group is equal to 1150 x 0.1 x 2 x 3 that is 690 visits over three years (0.1 is the proportion of Diagnosis group patients, 2 is the number of nurse visits in a year, and 3 is the simulation period in years). Similarly, for the Maintenance group we have 1150 x 0.6 x 3 x 3 = 6210 visits over three years. The cumulative number of nurse visits for all PD patients' categories (including complex and palliative) was calculated as 11,730 visits. This compares to an average total number of 11,106 visits (the 95% lower and upper bounds of the confidence interval are 10940 and 11210 visits, respectively) generated by the simulation model results, which is different by 6% from the real world results.

A similar process was used with regard to the total number of consultants' visits. The results generated by the calculations based on real world information were 10, 350 visits for the real world, and 9,558 visits generated by the model, that is a difference of 7% (the 95% lower and upper bounds of the confidence interval are 9,377 and 9,739 visits, respectively). On this basis, the model results were deemed robust to allow experimentation with alternative scenarios to take place.

To achieve face validity (whether the model appears reasonable on the face of it), the model was shown to each nurse individually and then in a workshop including all six nurses. The model structure was confirmed to be highly representative of the real world PD care system by all five nurses in the individual meetings and during the workshop where the whole group was present. In general, the continuous engagement of the PD nurses throughout the study increased significantly the confidence in the validity of the model.

4.3 Experimentation

The aim of the experiment is to assess the possible impact of shifting more PD patients from hospital care to community care services. Although there is a belief based on anecdotal evidence that this should have a positive impact on the operational and financial performance of the PD care system, it is important to support this by stronger evidence including quantification of any benefit of such policy. In this context, the simulation model developed in this research was used to evaluate the impact of several scenarios, which reflect the policy of patients shifting to community services.

The parameter values of the experiment were determined through a workshop with experienced senior nurses and consultants from different PD care units in the UK. The participants were asked to come up with estimates of the reduction in average annual nurse and consultant visits if the use of community services were to increase by 10% (this value was suggested by the participants as the most likely feasible increase in the next three years). In order to make the simulation results more realistic, each participant was asked to give three estimates of the decreases in the number of visits. Three scenarios were identified from the care service providers and these are: pessimistic, realistic, and optimistic. The average decrease was 5%, 10%, and 20% for the pessimistic, realistic, and optimistic situations,

respectively (Table 2). The practical meaning of the figures in Table 2 is that the inter-visits interval duration is increased from its current level.

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Each simulation was run 100 times (with different random seeds) and each run for 3 years to capture the individual trajectories in the cohort over this period and to estimate the likely impact of changes on performance indicators related to activity, costs, and utilisation of resources (e.g. nurses). Results were collected regarding the activity, cost, and utilisation of resources under the three scenarios mentioned above. Specifically, the performance indicators used to evaluate the scenarios are "specialist nurse activity (SNA)", "specialist nurse cost (SNC)", total specialist nurse service hours (TSNH)", and "total FTE needed for specialist nurse (TFTE)". For each indicator we calculated the mean and 95% confidence interval. A summary of the results is presented in Table 3.

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The results indicate that increasing use of community services will have a positive impact on the specialist nurses level of activity and its associated costs. The level of activity decreased markedly for a gain of around 21% (11,106 to 8,708). This is quite significant taking into account the fact that nurses in the PD treatment services are highly utilised and under huge workload pressure. There is a noticeable small variation in the CIs and the reason for this is that we assumed the number of times a patient sees a PD specialist nurse in a year is fixed (according to the interviews we had with the nurses), hence no distributional assumption were made on these visits. This small variation is caused by the number of "new" arrivals each year during simulation run. When the model was tested to examine the impact on community service visits, there is a wide variation between runs, simply because a distributional assumption was made (i.e. Poisson). What is important to a tool user is the overall impact of these reductions. For example, reducing the visits of "Diagnosis, Maintenance, Complex and Palliative" categories from 2, 3, 4 and 6 visits per year to 1.8, 2.7, 3.6 and 5.4, respectively, has a dramatic impact on the overall PD nurse visits (11,106 to 8,758). Note that the model enables users to run current visits (scenario 1) vs. any number of visits (scenario 2).

The other positive impact of the increased community services policy and its resulting decrease in the activity levels of nurses is the reduction of nurses' costs. In this context, the costs saving under the pessimistic, realistic, and optimistic scenarios are £109,800, £157,400, and £234,800 respectively. These reductions which vary between 10% under the pessimistic scenario and 21% under the optimistic scenario are significant in the PD care services and the general health care services, where squeezed budgets and funding cuts are expected to become a common feature of the health care landscape in the future.

The reduction in nurses' activity has also an impact on the number of total hours of specialist nurse service. As seen on Figure 3 the number of hours goes down as we move from the current to the optimistic scenario. It is interesting to see that the most significant decrease occurs when we move from the current to the pessimistic scenario where the number of hours drops by around 40% from 8330 hours to 5004 hours and then to 4766 and 4379 hours under the realistic and optimistic scenarios. This non-linear reduction is quite interesting as the reductions of 5% (current to pessimistic), 5% (pessimistic to realistic) and 10% (realistic to optimistic) lead to 40%, 5%, and 8% respectively. These results are very significant, from a management perspective, as even the smallest possible reduction in nurses' visits due to increased utilisation of community services appears to lead to substantial reduction in the specialist nurses workload (as reflected in the total number of FTEs). The same trend can be observed here as the total FTEs decreases by 40% from current to pessimistic, 5% from pessimistic to realistic, and by 8% from realistic to optimistic.

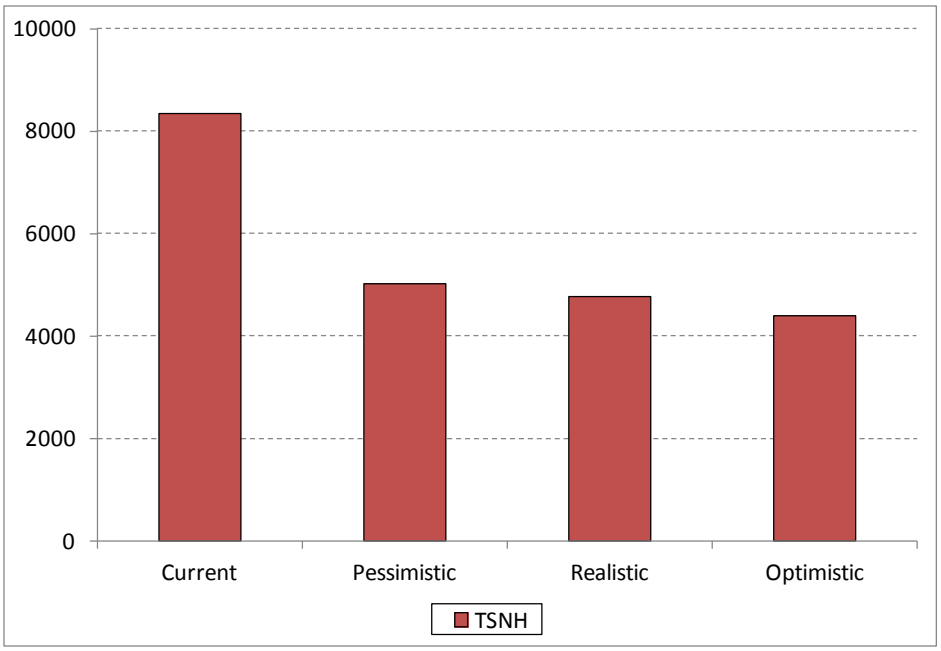

Figure 3: Simulation results of the required total specialist nurse service hours (TSNH) for each scenario (mean values - 95% CIs are too narrow and were omitted from the Figure).

5 Discussion and Conclusion

The current research addresses a top-of-the-agenda issue in health and social care management as it focuses on the policies related to service re-design and how they have an impact on the performance of health and social care systems. The importance of the research can be appreciated in the current context of increasing demand on health service provision at the time when we are moving to the new reality of tighter public finances.

This might mean providers and purchasers of services (i.e. NHS Trusts and Clinical Commissioning Groups, respectively) may need to re-design services with increased use of community services as opposed to treating patients within a hospital setting, simply because this is the way care has been organised over a number of years. Could these changes ensure that patients receive the right care at the right time and in the right place? How do we explore the impact on different metrics of a range of system changes? Our solution was to construct a decision support tool using discrete event simulation with a user friendly interface and simulation controls of Parkinson's disease pathway, calibrated with existing data and expert opinions from five nurses ranging from south of England to North with a combined experience of 85 years.

The tool allows decision makers to better understand the operation of the system in relation to key performance metrics associated with activity, cost implications, resource utilisation (neurologist and nurses) and disease progression (a clinical outcome). The ease of use of the tool with relevant set of exported results means that senior decision makers could be more proactive with evidence based approach in re-designing their care pathway to assist nurses, clinicians and commissioners in finding the most efficient and effective delivery of care to the elderly with Parkinson's disease. In this context, the illustrative scenarios tested on the tool are a sample of a wider range of policies, which can be evaluated through this DSS. This can only be welcomed given the importance of and efficient and high quality healthcare delivery for the wellbeing of individuals and society.

The simulation results suggest that an increase use of community services will have a positive impact on the workload and utilisation of PD specialised nurses. Therefore, the policy rationale that making more use of community services to treat and monitor the evolution of the PD patients health state and, therefore, alleviate the workload pressures on nurses is strongly supported by the simulation results. As such, the simulation based DSS developed here is a very good example of the "evidence based decision making" tools, which have gained in popularity in the last few years especially within the healthcare management sector. It is also a good example of how a DSS can be developed and used in the context of integrating health (i.e. in the hospital) and social care (i.e. in the community) systems.

The research has some methodological and contextual limitations. First, the unavailability of relevant data about community services meant that we relied on expert opinions and judgment, which can be affected by subjective biases. Second, given the lack of data, we assumed that disease progression, that is the distribution of patients moving from one disease category to another, has a triangular distribution. In addition, we did not take account of co-morbidities and interactions with other diseases which may impact on the speed of disease progression and the associated level of care. The model was built using information from a single context, which can "corrupt" the results and reduce confidence in the validity of the results and the ensuing policy decisions.

The decision support tool used in this research offers decision makers a powerful tool to appreciate the complexity of the PD pathway, understand its inner working, and the parameters driving their behaviour and performance. In fact the tool, in addition of providing

the means for numerical experimentations can also be classified as a 'tool for thinking' (Pidd 2003), enabling key decision makers to challenge their assumptions and see the systems in which they operate in a new light. Furthermore, they offer nurses, clinicians and managers the opportunity to evaluate the implications of possible policies and actions on the performance of their systems before the actions are implemented in the real world, hence avoiding the trap of 'doing things and hoping for the best'. To the best of our knowledge no decision support tool at this scale within a simulation environment has been published or disseminated for PD pathway modelling.

As described earlier in the paper the tool was designed with the aims of supporting front-line staff and managers in testing out the likely impact of suggested changes in the PD patient pathway on a number of key performance indicators. The authors have first-hand experience of the frustrations that can sometime accompany planning and approving new services in healthcare systems. Often changes are introduced without proper consideration of the impact on the service. It is also often the case that those people working in the healthcare system know how they would like to improve the service they deliver but lack the expertise to frame those improvements in a manner that will allow a strong case to be made to board-level executives and holders of budgets. This tool therefore has been designed to allow 'non-simulation experts' to test change on the pathway in a validated simulation that will present the impact of changes in a way that can be easily understood by both the executive and pathway specialists. It is the intention that this will facilitate service planning and decision making and speed up the pace of change in the PD pathway. Furthermore, the use of simulation as a decision making tool is still in its infancy within the healthcare sector in the UK. We would therefore recommend that a longer term study on the impact of the PD simulation would be helpful. We would suggest following the progress of service development projects that use simulation in comparison with those that do not. Such simulation tools would also benefit enormously by richer and better quality primary care data which would add considerable to the robustness of the assumptions that are used to support the simulation.

The decision support tool is currently being used by a major pharmaceutical company to facilitate service change in the UK. The simulation is being used nationwide by the pharmaceutical company's healthcare development team with the objective of developing PD

services for the benefit of patients, the healthcare provider and the company who also supply some of drugs used in the pathway.

In conclusion, the study provided previously unobtainable quantitative information which could be used to support business cases for changes in the increased use of community services and its impact on clinical outcomes (disease progression), nurse visits and costing. The main strength of this decision support tool is the adoption of a team approach to studying the system, involving five PD specialist nurses across the country, ensuring that variety of views and suggestions are taken as well as systems modelling and simulation. This led to a model with high face validity and credibility among its users.

Future work could explore additional ways in which the current model could incorporate individual patient characteristics which may alter patient pathways (e.g. disease severity, age group, gender, etc.) and explore the impact on activity results and costing. Furthermore, the evaluation of performance would be more realistic if it included performance indicators related to quality of care and its impact on the quality of life of patients, and investigated how these aspects may affect readmission, mortality and the movement of patients between the different care services within the pathway.

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Table 1 Input parameters.

Parameter	Data Collection	Distribution Type	Input data for experimentation (section 4.3)
Demand			
Existing patient arrival	HES data or user specified	Poisson	Existing patient size = 1000
New patient arrival	HES data or user specified	Poisson	Approximately 50 in year 1, 36 in year 2 and 71 in year 3.
Percentage of patients falling into each category, i.e., diagnosis, maintenance, complex and palliative.	User specified	Multinomial	Diagnosis = 10%, Maintenance = 60%, Complex = 20% and Palliative = 10%
Yearly increase over the three year period	User specified	Multinomial	5%, 3.5% and 6.5%
Percentage of suspected PD patients	User specified	Bernoulli	90%
Percentage of patients presenting through General Practitioner	HES data or user specified	Multinomial	75%
Percentage of patients presenting through A&E	HES data or user specified	Multinomial	15%
Percentage of patients presenting through Outpatients	HES data or user specified	Multinomial	5%
Percentage of patients presenting through other hospital department, e.g. care of the elderly	HES data or user specified	Multinomial	5%
Treatment pathway (in hospital)			
Time between initial outpatient screening to a specialist (i.e. neurologist) for first PD diagnosis	User specified	Uniform	[2, 4] weeks
Time between first diagnosis to the start of treatment	User specified	Uniform	[1,4] weeks
If PD is suspected, what percentage of patients is actually diagnosed for PD?	User specified	Bernoulli	90%
The number of times (in a given year) each patient is seen by a Neurologist (by patient type).	User specified	Fixed	Diagnosis = 1, Maintenance = 2, Complex = 3 and Palliative = 4.
The number of times (in a given year) each patient is seen by a specialist PD nurse (by patient type).	User specified	Fixed	Diagnosis = 2, Maintenance = 3, Complex = 4 and Palliative = 6.
The time it takes for a neurologist to treat patients (in minutes)	User specified	Mean	60 minutes
The time it takes for a specialist PD nurse to treat patients (in minutes)	User specified	Mean	60 minutes
Community services pathway			

Percentage of patients referred to community services, i.e., physiotherapy, psychiatry, speech and language therapy (SLT), occupational therapy (OT), palliative care, dietician.	User specified	Multinomial	Physiotherapy = 45%, psychiatry = 22.5%, SLT = 42.5%, OT = 35%, Palliative = 7.5%, Dietician = 7.5%
The number of times (in a given year) patients are referred to physiotherapy (by patient type).	User specified	Poisson	Diagnosis = 1 Maintenance = 2 Complex = 2 Palliative care = 3
The number of times (in a given year) patients are referred to psychiatry (by patient type).	User specified	Poisson	Diagnosis = 1 Maintenance = 2 Complex = 2 Palliative care = 3
The number of times (in a given year) patients are referred to speech and language therapy (by patient type).	User specified	Poisson	Diagnosis = 1 Maintenance = 2 Complex = 2 Palliative care = 3
The number of times (in a given year) patients are referred to occupational therapy (by patient type).	User specified	Poisson	Diagnosis = 1 Maintenance = 2 Complex = 0 Palliative care = 0
The number of times (in a given year) patients are referred to palliative care (by patient type).	User specified	Poisson	Diagnosis = 0 Maintenance = 0 Complex = 2 Palliative care = 4
The number of times (in a given year) patients are referred to a dietician (by patient type).	User specified	Poisson	Diagnosis = 1 Maintenance = 1 Complex = 2 Palliative care = 3
Disease Progression			
Diagnosis to Maintenance	User specified	Triangular distribution	[min = 1 year, average = 2 years, maximum = 4 years]
Maintenance to Complex	User specified	Triangular distribution	[min = 2 year, average = 3 years, maximum = 4 years]
Complex to Palliative	User specified	Triangular distribution	[min = 3 year, average = 5 years, maximum = 7 years]
Palliative to Death	User specified	Triangular distribution	[min = 3 months, average = 6 months, maximum = 1 year]
Cost			
A&E attendance including hospital admissions	HRG codes (reference costs)	Mean	£2,233
Neurologist	HRG codes (reference costs)	Mean	£220
Imaging	HRG codes	Mean	£100

	(reference costs)		
Anti PD Medication	User specified	Mean	Unknown
Unit cost for PD specialist nurse	User specified	Mean	£150
Physiotherapy	HRG codes (reference costs)	Mean	£38
Psychiatry	HRG codes (reference costs)	Mean	£50
Occupational therapy	HRG codes (reference costs)	Mean	£58
Speech and language therapy	HRG codes (reference costs)	Mean	£96
Palliative care	HRG codes (reference costs)	Mean	£50
Salary			
Specialist PD nurse	User specified	Mean	£36,303
Neurologist	User specified	Mean	£80,810
Number of resources			
Specialist PD nurse	User specified	Fixed	5
Neurologist	User specified	Fixed	2

Table 2: Average nurse visits per year under pessimistic, realistic, and optimistic scenarios

Visits	**Current**	**Pessimistic (5% decrease)**	**Realistic (10% decrease)**	**Optimistic (20% decrease)**
Diagnosis	2	1.9	1.8	1.6
Maintenance	3	2.85	2.7	2.4
Complex	4	3.8	3.6	3.2
Palliative	6	5.7	5.4	4.8

Table 3: The impact of increasing community by 10% on nurse visits and nurse utilisation rates, mean values (95% confidence interval).

Visits	**Current**	**Pessimistic**	**Realistic**	**Optimistic**
Specialist Nurse Activity (SNA)	11,106 (10,940 to 11,210)	10,008 (9,830 to 10,186)	9,532 (9,356 to 9,708)	8,758 (8,574 to 8,942)
Specialist Nurse Cost (SNC)	£1,110,600 (£1,094,152 to £1,127,148)	£1,000,800 (£982,986 to £1,018,614)	£953,200 (£935,566 to £970, 834)	£875,800 (£857,408 to £894,192)
Total Specialist Nurse Service Hours (TSNH)	8,330 (8,206 to 8,454)	5,004 (4,911 to 5,096)	4,766 (4,678 to 4,854)	4,379 (4,287 to 4,471)
Total FTE Needed for Specialist Nurse (TFTE)	1.803 (1.776 to 1.830)	1.083 (0.998 to 1.102)	1.031 (1.012 to 1.050)	0.947 (0.927 to 0.967)