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A Discrete Event Simulation model to evaluate the use of community services in the treatment of patients with Parkinson's disease in the United Kingdom.

--Manuscript Draft--

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Abstract:	<p>Background: The number of people affected by Parkinson's disease (PD) is increasing in the United Kingdom driven by population ageing. The treatment of the disease is complex, resource intensive and currently there is no known cure to PD. The National Health Service (NHS), the public organisation delivering healthcare in the UK, is under financial pressures. There is a need to find innovative ways to improve the operational and financial performance of treating PD patients. The use of community services is a new and promising way of providing treatment and care to PD patients a reduced cost than hospital care. The aim of this study is to evaluate the potential operational and financial benefits, which could be achieved through increased integration of community services in the delivery of treatment and care to PD patients in the UK without compromising care quality.</p> <p>Methods: A Discrete Event Simulation model was developed to represent the PD care structure including patients' pathways, treatment modes, and the mix of resources required to treat PD patients. The model was parametrised with data from a large NHS Trust in the UK and validated using information from the same trust. Four possible scenarios involving increased use of community services were simulated on the model.</p> <p>Results: Shifting more patients with PD from hospital treatment to community services will reduce the number of visits of PD patients to hospitals by about 25% and the number of PD doctors and nurses required to treat these patients by around 32%. Hospital based treatment costs and overall should decrease by 26% leading to overall savings of 10% in the total cost of treating PD patients.</p> <p>Conclusions: The simulation model was useful in predicting the effects of increased use of community services on the performance of PD care delivery. Treatment policies should be revised and updated to formalise the use of community services and integrate these better in PD care. Awareness of PD patients on the advantages of community services should be increased so that more patients could use and benefit from these services.</p>
Corresponding Author:	Raheelah Ahmad, PhD Imperial College London London, UNITED KINGDOM
Corresponding Author Secondary Information:	
Corresponding Author's Institution:	Imperial College London
Corresponding Author's Secondary Institution:	
First Author:	Reda Lebcir, PhD
First Author Secondary Information:	
Order of Authors:	Reda Lebcir, PhD Eren Demir, PhD Raheelah Ahmad, PhD

	Christos Vasilakis, PhD
	David Southern, MSc
Order of Authors Secondary Information:	
Response to Reviewers:	<p>BHSR-D-16-00518R4</p> <p>Thank you for the opportunity to make the following revisions:</p> <p>1. We have noticed that Figure 1 has been re-adapted or reused from a previous publication - http://www.tandfonline.com/doi/full/10.1080/00207543.2015.1029647</p> <p>Please cite your reference to this paper within the figure caption for Figure 1. Here, please also state that the figure has been reused/adapted from this source.</p> <p>Response: The reference is already included (number 7) in the reference list. The following caption has been added to Figure 1: Adapted from: Demir et al, 2015 [7]</p> <p>2. Please add the section "Supplementary file list". Here, please list the following about your supplementary file:</p> <p>Response: added on page 42 Supplementary File list: Supplementary file 1: BMC HSR Data for simulation model Title of data: Table 7. Data used for the simulation model Description of data: Table providing details of parameters used in the simulation model including the source, distribution type and the value entered in the model. A reference to this on also added on page 13: (see Table 7 in the supplementary file).</p> <p>3. Please change the heading 'Abbreviations' to 'List of abbreviations'.</p> <p>Response: changed</p> <p>Kind Regards Dr Raheelah Ahmad on behalf of the co-authors</p>

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Title: A Discrete Event Simulation model to evaluate the use of community services
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¹Reda Lebcir. University of Hertfordshire. Hatfield AL10 9AB, UK.

M.R.Lebcir@Herts.ac.uk

²Eren Demir. University of Hertfordshire. Hatfield AL10 9AB, UK.

E.Demir@Herts.ac.uk

³Raheelah Ahmad. Imperial College London.

raheelah.ahmad@imperial.ac.uk

⁴Christos Vasilakis. University of Bath. Bath BA2 7AY, UK.

C.Vasilakis@Bath.ac.uk

⁵David Southern. Pathways Communications. Kennett CB8 8RW, UK

David@Pathwaycommunications.co.uk

Corresponding Author: Dr Raheelah Ahmad. Imperial College London. Faculty of
Medicine, Hammersmith Campus, du Cane Road, London, United Kingdom W12
0NN.

Tel.: + 44 (0)203 313 2732.

E-mail address: raheelah.ahmad@imperial.ac.uk

Abstract

Background: The number of people affected by Parkinson's disease (PD) is increasing in the United Kingdom driven by population ageing. The treatment of the disease is complex, resource intensive and currently there is no known cure to PD. The National Health Service (NHS), the public organisation delivering healthcare in the UK, is under financial pressures. There is a need to find innovative ways to improve the operational and financial performance of treating PD patients. The use of community services is a new and promising way of providing treatment and care to PD patients a reduced cost than hospital care. The aim of this study is to evaluate the potential operational and financial benefits, which could be achieved through increased integration of community services in the delivery of treatment and care to PD patients in the UK without compromising care quality.

Methods: A Discrete Event Simulation model was developed to represent the PD care structure including patients' pathways, treatment modes, and the mix of resources required to treat PD patients. The model was parametrised with data from a large NHS Trust in the UK and validated using information from the same trust. Four possible scenarios involving increased use of community services were simulated on the model.

Results: Shifting more patients with PD from hospital treatment to community services will reduce the number of visits of PD patients to hospitals by about 25% and the number of PD doctors and nurses required to treat these patients by around 32%. Hospital based treatment costs and overall should decrease by 26% leading to overall savings of 10% in the total cost of treating PD patients.

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Conclusions: The simulation model was useful in predicting the effects of increased use of community services on the performance of PD care delivery. Treatment policies need to reflect upon and formalise the use of community services and integrate these better in PD care. The advantages of community services need to be effectively shared with PD patients and carers to help inform management choices and care plans.

Keywords: Parkinson's disease; Community Services; Discrete Event Simulation; National Health Service; United Kingdom.

Background

1
2
3 Neurodegenerative conditions and motor neurone affecting cognitive and physical
4 ability have life changing impact on individuals, families and carers. Medical
5 interventions are of limited benefit for these progressive illnesses if social care and
6 support for managing daily activities is lacking. Fundamental to the management of
7 such conditions is the coordination of care across different health and social care
8 sectors. From a health systems perspective, models of integrated and efficient
9 service delivery and care are required particularly in the context of aging populations;
10 a challenge particularly in high income countries. Impact extends across the
11 healthcare economy (primary, community, secondary and tertiary care) as well as to
12 other public services including transport, employment and housing needs [1]. For
13 long-term progressive conditions, key questions arising are *which treatment*
14 *pathway?* and *where?* to achieve the best outcome for patients and healthcare
15 providers and carers. To answer these questions we focus on one particular
16 condition, Parkinson's disease (PD) in a country where the population age profile is
17 changing, the United Kingdom (UK).

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19 PD is the second common chronic neurodegenerative condition in older people
20 especially beyond the age of sixty [2,3]. The most common early symptoms of the
21 disease are problems with movement and this includes tremor, stiffness, slowness,
22 and paucity of movement [4]. As the disease progresses, additional non-motor
23 symptoms such as depression, psychotic symptoms, dementia, sleep disturbance,
24 falls, and autonomic disturbances become more common adding to the burden of the
25 disease and its effects on patients and those involved in their treatment and care.
26 The late phases of the disease are generally characterised by increased motor
27 complications, disability, and mortality [5].

1 PD is a challenging disease from a clinical perspective as it affects older adults who
2 may also be suffering from other conditions. There is difficulty in diagnosis
3 especially in early stages, the condition is associated with a wide range of
4 symptoms, is progressive and there is currently no cure for the disease. As a result,
5 the treatment and management of PD is complex and resource intensive due to the
6 involvement of a multidisciplinary team and several services in its management. The
7 complexity is increased by the fact that the disease does not just affect the patient,
8 but the effects extend to families, employers, and a wide range of public services
9 [1,5].

10 The disease progresses over four phases and these impact directly on the treatment
11 provided to patients [6]. The Diagnosis phase reflects the initial stage when a patient
12 is suffering from PD like symptoms and signs, but there is no formal confirmation that
13 the patient has PD. Once the diagnosis tests are conducted and PD is confirmed, the
14 patient moves to the Maintenance phase. Depending on the patient status, either no
15 treatment is provided at this phase or a treatment involving small doses of one or two
16 drugs is given. As there is no cure for PD, the aim of the treatment is to slow the
17 progression of the disease so that the patient quality of life is not affected. As the
18 symptoms worsen and more functions of the body are affected, the patient enters the
19 Complex phase in which the number of drugs and their doses are increased and, in
20 some cases, neurosurgery is performed. The final phase, known as Palliative, is
21 characterised by high risks of physical and mental disabilities and significant threats
22 to life.

23 The treatment modes for PD include inpatient, outpatient, and community care and
24 require a range of clinical specialists [7]. Inpatient care involves drug treatment and
25 surgery in hospitals. Outpatient care provides drug treatment and, in some

1 instances, specialised therapies such as Physiotherapy, Psychiatry, Occupational
2 Therapy, and Speech and Language Therapy. This care takes place mostly in
3
4 General Practitioners (GPs) clinics and sometimes in hospitals. Community care,
5
6 which focuses on specialised therapies, is provided in local care units, known as
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8 Community Services, with the support of local pharmacies and social services.
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12 The UK population is aging and, therefore, it is expected that the number of people
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14 who will be diagnosed with PD will increase in the future. In 2012, the number of
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16 people aged 65 years and over was 10.84 million from which 1.44 million were aged
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18 85 years and over. The number of people aged 65 years and over is expected to
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20 raise to 17.79 million from which 3.64 million will be aged 85 years and over in 2037
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22 [8]. The latest available data suggest that the number of individuals living with PD in
23
24 the UK is 127,000, corresponding to a prevalence rate of 27.4/10,000 [9]. This
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26 number is expected to rise in line with the population ageing trend and to reach
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28 165,000 in 2020 [9].
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36 Healthcare in the UK is delivered free of charge, by a public organisation known as
37
38 the “National Health Service (NHS)”. Current evidence suggests that the NHS is
39
40 struggling to cope with the demand for PD treatment and care. A National Audit
41
42 Office report found that although access for patients with neurological conditions
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44 including PD to health services improved since 2007, spending increased by 38
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46 percent in real terms and the quality of care declined during the same period [1]. Just
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48 over half (66%) of GP referrals meet the National Institute for Clinical Excellence
49
50 (NICE) guidelines of a specialist appointment within 6 weeks and 14% of patients are
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52 readmitted within 28 days of discharge. Recent work has shown that less than a
53
54 quarter of PD patients (22%) have a personal care plan [10].
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1 This situation is alarming especially as the NHS is faced with additional pressures
2 stemming from ever increasing resource and capacity constraints and the need to
3 improve operational and cost efficiency. The NHS has a target of making a net
4 saving of £20 Billion over the coming 4-5 years [11]. However, given its sheer size
5 and complexity (the NHS employs more than 1.6 million people and deal with more
6 than 1 million patients every 36 hours [12]), the challenges are significant.

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15 In this new reality of “doing more with less”, it is necessary to identify areas where
16 efficiency gains can be made. This is challenging in the case of PD given the wide
17 range of treatment modes and therapies required by patients, the different settings
18 where the treatment is provided, and the need to customize the treatment at an
19 individual patient level depending on their disease stage, severity of the symptoms
20 and support structures available. For example, some patients may be seen by a PD
21 doctor or by a PD nurse monthly, quarterly or every 6 months, for single or multiple
22 therapies. A better understanding of the different possible configurations to deliver
23 treatment and care to PD patients and the evaluation of the operational and cost
24 performance of these configurations is required so that the most efficient ones are
25 identified.

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45 Treatment configurations involving increased use of community services could yield
46 significant efficiency gains. Treating more patients in community services may
47 reduce unnecessary hospital admissions, the need for consultations with PD doctors
48 and nurses, and facilitate the earlier discharge if admitted [5]. Treating patients in
49 community services has a significant cost advantage over treatment in hospitals. The
50 average cost to treat a PD patient admitted to inpatient care as an emergency
51 admission is £2,133 (based on an average length of stay of 6.3 days) and the
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1 average cost of a PD doctor visit is around £145. In contrast, the costs associated
2 with community services are in the region of £38 to £98 (e.g. physiotherapy £38,
3 occupational therapy £56 and speech and language therapy £98) [13]. The
4 additional benefit is that community services improve patients' understanding of their
5 own disease journey and empower them to better self-manage their condition. This
6 is why they have been welcomed by patients [5].
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18 The lack of research to evaluate operational and cost performance of possible
19 configurations is surprising given the potential efficiency gains which could be
20 achieved through increased deployment of community services. The vast majority of
21 research, with regard to PD performance evaluation, has focused on quality of life of
22 patients and the effects of PD symptoms and social factors on the physical and
23 psychological wellbeing of patients [14-17]. The literature covering the evaluation of
24 PD care configurations includes only a 2011 report by the UK National Audit Office,
25 which recommends the use of community services and recently published research
26 providing some evidence that the use of community services reduces PD doctors
27 and nurses' activity levels [7]. This is a clear research gap, which warrants further
28 investigation.
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45 The aims of this study are therefore: First, to develop a Discrete Event Simulation
46 (DES) model, which captures the PD treatment pathways and service configurations
47 including community services; Second, to determine possible and realistic policies,
48 which could be implemented with regard to an increased use of community services
49 and how these would affect hospital based treatment; Third, to evaluate the impact
50 of the implementation of these policies on a number of operational and cost
51 performance indicators relevant to the delivery of PD treatment and care. This
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1 should provide an indication of the feasibility and scale of efficiency improvement,
2 which could be achieved by shifting more PD patients to community services and
3
4 allow health managers to make informed decisions with regard to the best ways to
5
6 reconfigure the PD care delivery system in the UK.
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10 11 12 **Methods**

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16 We developed a Discrete Event Simulation (DES) model [18-20] to portray the
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18 structure and configuration of the PD treatment and care system including patients'
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20 pathways, disease phases, treatment modes, and the resources required to provide
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22 treatment and care. DES is appropriate in the context of this research as it enables
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24 the modelling of patients at the individual level including disease evolution over time
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26 and how a patient moves through the different parts of the care system. DES makes
27
28 it possible to represent different patient general attributes such as age and gender
29
30 and clinical specific attributes such as disease phase and treatment mode. As time
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32 progresses, patients' attributes are altered to reflect changes in their status. This
33
34 allows the tracking of patients as they evolve in the care system including the events
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36 they experience at different points of time. DES provides the flexibility to incorporate
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38 capacity and resource constraints explicitly, and to capture the resource allocation
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40 policies and priority rules where entities compete for limited resources. This feature
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42 is extremely important in health contexts, as clinical activities such as diagnosis,
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44 treatment, and consultations require a mix of specialised resources (doctors, nurses,
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46 beds, operating theatres, and so on) and these resources are, in most cases, not
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48 sufficient to meet the required level of demand.
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DES has been applied to health management since the 1990s driven by the increased complexity of health care systems, the considerable advancements in DES software capabilities, ease of use, and the shift to more evidence based decision making in the health sector [21-24]. The increased popularity of DES in health management is reflected in the literature reviews, which show an upward trend in terms of the number of DES applications and the areas covered by these applications [23,25]. Examples of these applications include modelling of patient flows in hospitals and accident and emergency departments in particular [26,27], reconfiguration of care delivery services and capacity planning and management in the health sector [28-31], cost effectiveness of treatment procedures [32-35], patients' compliance with screening procedures [36], and policies to prevent transmission of diseases [37].

33 *Simulation Model Development*

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The model was developed in collaboration with health care professionals and potential end-users and its building process started with a meeting with the National Committee of the Parkinson's Disease Nurse Specialist Association (PDNSA) in late 2012. Six PD specialist nurses were involved and provided detailed information regarding patients' pathways and treatment procedures, the services and resources required in the diagnosis and treatment of PD, and the rules and policies associated with the management of the patients. Semi structured interviews were conducted with the nurses and led to an initial mapping of the PD patients' pathway structure. This map was further developed and refined through structured interviews with members of the PDSNA national committee, who checked that the initial map

1 reflected the patients' pathways and suggested corrections where gaps were
2 identified.
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5 The interviews indicated that the first point of contact of a patient with the PD care
6 system is a visit to a PD outpatient clinic following referral from a General
7 Practitioner (GP), Accident and Emergency (A&E) units, outpatient department, or a
8 hospital department. Diagnostic tests are carried out on the patient, and, if PD is
9 confirmed, patients are categorised into one of the disease phases (Diagnosis,
10 Maintenance, Complex or Palliative) and treatment commences. The treatment is
11 supervised by a PD doctor and takes the form of a referral to surgery (in a small
12 number of cases), treatment via drugs, special therapies (eg Physiotherapy,
13 Language and Speech Therapy, Occupational Therapy) in community services, or a
14 combination of these treatment modes (for example treatment via drugs and special
15 therapies) (See Figure 1) The PD specialist overseeing the treatment of each
16 individual patient is supported by a PD specialist nurse, who plays a critical role in
17 the management of the PD patient and determination of their treatment needs.
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40 As there is no known cure for PD, the treatment is a continuous process over time
41 and the patient remains in treatment indefinitely. Patients meet their allocated PD
42 doctor and PD nurse on a regular basis and the frequency of these meetings
43 depends on the disease phase of the patient. The treatment guidelines indicate that
44 patients in the Diagnosis, Maintenance, Complex and Palliative phases meet with
45 the PD doctor and PD nurse 2, 4, 5 and 6 times a year respectively. In these
46 meetings, disease progression is evaluated and decisions about changes to the mix
47 of drugs to be given to the patient are made. Requirements regarding the use of
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2 primary care or community services for special therapies are also determined in
3 these meetings depending on the medical state of the patient.
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7 One important aspect of the meetings between the PD doctor and the patient is the
8 assessment of the medical status of the patient and the decision keep or change the
9 disease phase of the patient. As described earlier, once a patient is formally
10 diagnosed with PD, that patient is allocated to one of the four phases of the disease
11 (Diagnosis, Diagnosis, Maintenance, Complex, Palliative) as this determines the
12 treatment process and the frequency of the patient's meetings with the PD doctor
13 and PD nurse. The decision to keep or alter the patient's phase will, consequently,
14 have important implications for the treatment and management of patients as it
15 affects the level of resources required for the treatment and the needs in terms of the
16 special therapies prescribed for the patient.
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33 The information generated in the interviews regarding the PD patients' pathways
34 (shown in Figure 1) and how the patients are treated and managed were entered in a
35 simulation model built using the software SIMUL8 (www.simul8.com). The model
36 represented the four different sources (GPs, A&E units, outpatient department,
37 hospital department), which bring patients to the PD care system, progression
38 through different disease phases (Diagnosis, Maintenance, Complex, and Palliative),
39 treatment modes, the mix of resources required for the treatment, and the special
40 therapies provided in community services (see Figure 2 for a snapshot of the
41 SIMUL8 model).
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1 As the model is aimed for decision makers, a friendly and easy to use interface was
2 added to the SIMUL8 model. The interface is animated and allows users to test
3 policies regarding changes to demand levels, patient pathways, allocation of
4 resources, and disease progression (See Figure 3). These policies are represented
5 in the form of scenarios, which the decision makers could input on the interface and
6 then run the model. Once a scenario run is completed, the model generates a results
7 summary on the key performance indicators of interest to decision makers, which are
8 also shown on the model interface. In addition, the model generates a complete set
9 of results can be exported to an Excel spreadsheet to enable more detailed analysis.
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24 *Model parameters and validation*

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29 Several sources of information were used to estimate the values of the parameters
30 entered in the model (see Table 7 in the supplementary file). The NHS English
31 Hospital Episodes Statistics (HES) data set (the biggest and most comprehensive
32 official health statistics database in the UK) and interviews with PD doctors and
33 nurses were the sources for parameters regarding origin of referrals, PD progression
34 and treatment, and provision of community services.
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46 Given that PD treatment in the UK is decentralised and entities, known as NHS
47 Trusts, are responsible for providing care at a regional level, the parameters related
48 to the number of patients and treatment modes were estimated from one big NHS
49 Trust, which provides a full set of treatment modes including special therapies in
50 community services. In this Trust, the breakdown of new PD patients by source of
51 referral is 75%, 15%, 5%, and 5% for GP, A&E, outpatients, and other hospital
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1 department respectively. The distribution of patients by disease stage category is
2 mostly constant at 10% Diagnosis, 60% Maintenance, 25% Complex and 5%
3 Palliative. Visits to PD doctors occur once a year in the Diagnosis phase, 2 to 3
4 times a year in the Maintenance phase, and 3 to 4 times a year in the Complex and
5 Palliative phases. Patients are seen 2 to 4 times a year by a PD nurse except in the
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9 Palliative phases. Patients are seen 2 to 4 times a year by a PD nurse except in the
10 Palliative stage where a customised care plan is designed and patients are seen by
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13 a PD nurse once a month.
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19 Information regarding the use of community services is scarce and mostly
20 unrecorded, so the research team relied on the extensive experience of PD nurses
21 to estimate the parameters related to these services. Following interviews, we
22 determined the percentage of patients referred to community services including
23 those using a single specialised therapy (eg physiotherapy) or a combination of
24 therapies (eg speech and language therapy and occupational therapy). The number
25 of visits per year to community services including visits to single or combination of
26 specialised therapies and the community services therapy specialists required in
27 these visits were also determined from the interviews. The breakdown of patients
28 using the different types of therapies in the Trust from which the data was collected
29 was confirmed by senior PD doctors and nurses to be, on average, equal to 45% for
30 physiotherapy, 42.5% for speech and language therapy, 35% for occupational
31 therapy, 22.5% for psychiatry services, 7.5% for dietician, and 7.5% for palliative
32 care.
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56 The unit costs associated with the different modes of treatment (hospital, outpatient,
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59 community services) were determined using the Healthcare Resource Group (HRG)
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1 code, which provide standardised and reference costs for the treatment of different
2 diseases and clinical conditions in the UK. The HRG codes and their associated
3 costs are publicly available on the UK Department of Health website [13]. These
4 codes enabled us to estimate the treatment costs for the different treatment modes
5 including those related to the provision of specialised therapies in community
6 services. Extra costs were included to reflect instances of unexpectedly long stay in
7 hospitals or additional treatments and tests. The number of staff available and their
8 salaries were determined from interviews. The list of data entered in the model is
9 presented is included in an additional file with this paper.
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24 The model was put to validation tests to ensure that it can be confidently used to
25 simulate alternative scenarios regarding the treatment procedures of PD patients
26 and determine the most appropriate policies out of the simulation results. The
27 validation tests covered two aspects: (i) the model's ability to replicate historical
28 observations and (ii) the extent to which the model was a correct representation of
29 the PD care system (face validity). Data representing the current situation in the
30 selected Trust was entered into the model and then run for a period of 3 years and
31 the results generated by the model were compared to those taken from the Trust
32 data. The model results were very close to those observed in the real world on a
33 number of variables for which real world data were available. A summary of the
34 simulation and real world results for this validation test are presented in Table 1.
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53 Face validity was performed by showing the PD care system map and the simulation
54 model to each nurse individually and then to all nurses in a group workshop. The
55 model structure was confirmed to be highly representative of the real world PD care
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1 system by all nurses. The engagement of the nurses and their continuous
2 involvement and feedback was instrumental in achieving face validity for the model.
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4 **Insert Table 1 Here**
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8 **Simulation Scenarios and results** 9

10 In addition to building the DES model, this research has two additional aims, which
11 are (i) to determine the possible and realistic policies, which could be implemented
12 with regard to an increased use of community services in the treatment of PD
13 patients and (ii) to evaluate the impact of the implementation of these policies on a
14 number of operational and cost performance indicators relevant to the delivery of PD
15 treatment and care. Following extensive discussions with decision makers and
16 experienced PD doctors and nurses, four possible scenarios were determined and
17 selected for simulation on the model. These scenarios are as follows:
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- 31 • Scenario 1: *Low increase in community services*. Under this scenario, 10%
32 more patients will be shifted to treatment in community services.
33
- 34 • Scenario 2: *Medium increase in community services*. Under this scenario,
35 20% more patients will be shifted to treatment in community services.
36
- 37 • Scenario 3: *High increase in community services*. Under this scenario, 40%
38 more patients will be shifted to treatment in community services.
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- 40 • Scenario 4: *Very high increase in community services*. Under this scenario,
41 50% more patients will be shifted to treatment in community services.
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51 Following the selection of scenarios, further discussions were carried out with the
52 decision makers to determine the most appropriate indicators, which could be used
53 to evaluate the operational and cost performance of the different PD treatment
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1 configurations reflected by the scenarios. These indicators were divided into three
2 categories: (i) Level of Activity (ii) Resources Requirements and (iii) Cost of Care.
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4 The full list of performance indicators is presented in Table 2.
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7 **Insert Table 2 Here**
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11 To achieve robustness of the results, each scenario was run 100 times (using
12 different random numbers each time) for a period of three years with a “warm up”
13 period of 1 year. Results were collected on the performance indicators for the four
14 scenarios. An analysis of these results suggests the following
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- 21 • Level of Activity: The results indicate that the policy to shift more treatment
22 activities to community services will ease significantly the workload of hospital
23 based staff (See Table 3). The expected number of visits to hospitals
24 decreases steadily from 18582 visits under the baseline scenario to 13889
25 visits under scenario 4. This trend becomes steeper as the fraction of patients
26 treated in community services goes up (See Figure 4). Starting from the
27 baseline scenario, the percentage decline in the expected number of visits to
28 hospitals is 7%, 10%, and 17% under scenarios 1, 2, and 3 respectively and
29 reaches a maximum value of 25% under scenario 4.
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32 The impact of the policy on the number of visits to community services
33 therapies is much more important. The expected number of these visits
34 should increase slightly under scenario 1 (by approximately 4% from 11910 to
35 12397 visits) and then the rate of increase will become more significant at
36 14% and 33% under scenarios 2 and 3 respectively. However, for scenario 4,
37 the increase in the expected number of visits becomes extremely sharp with a
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total of 22211 visits, which is equivalent to an 86% increase compared to the baseline scenario (See Figure 5).

Insert Table 3 Here

- Resource Requirements: The level of hospital resources, expressed in terms of the total number of Full Time Equivalent (FTEs) for hospital doctors and nurses, required to treat PD patients should go down as more patients are treated in community services rather than in hospitals (See Table 4). The decrease in the number of required FTEs becomes more important as higher fractions of patients are directed to community services. Specifically, the percentage reduction in FTEs will be 7% and 9% under scenarios 1 and 2 respectively before increasing to 16% under scenario 3 and then doubling to 32% under scenario 4.

Insert Table 4 Here

- Treatment Costs: The results regarding the expected hospital costs, community services costs, and total PD treatment costs are presented in Tables 5 and 6, and Figure 6. These results show that hospital treatment costs should decline as policies regarding a higher use of community services are implemented. The rate of the decline becomes more important as higher fractions of patients are treated in community services. The hospital costs under the baseline scenario are £3,363,050 and these are expected to go down to £3,126,780 and £3,007,710 that is a percentage decrease of 7% and 11% for scenarios 1 and 2 respectively. With regard to scenarios 3 and 4, the

1 decrease in the hospital costs is more important at £2,762,790 and 2,494,460,
2 which is equivalent to a percentage decrease of 18% and 26%.
3

4 The trend of the community services costs is similar to that of the number of
5 visits to community services. As more patients are directed towards these
6 services, their associated treatment costs go up by 4% to £755,434 under
7 scenario 1, 14% to £824,044 under scenario 2, and 33% to £961,398 under
8 scenarios 3 from £725,954 under the baseline scenario. This upward trend
9 becomes substantially higher for scenario 4 as they reach £1,356,124, which
10 is equivalent to an 86% increase compared to the baseline scenario.
11

12 With regard to the total PD treatment costs, which includes both the hospital
13 costs and the community services costs, adoption of policies to shift a higher
14 number of patients to treatment in community services should lead to
15 reduction in the total PD treatment costs. These saving are made possible as
16 the decrease in hospital costs offset the increase in that of the community
17 services leading to net gains with regard to total PD treatment costs. It is,
18 however, interesting to notice that total PD treatment costs are on a steady
19 decreasing pattern reaching their minimum under scenario 3. The pattern is
20 then reversed when considering scenario 4. Compared to the baseline
21 scenario, the percentage decrease in total PD treatment costs is 5%, 6.3%,
22 and 9% under scenarios 1, 2, and 3 respectively. This percentage gain in total
23 PD treatment costs is then reduced to only 5.8% under scenario 4 as these
24 costs raise again to reach a level higher than that of scenarios 2 and 3 and
25 close to that of scenario 1.
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55 **Insert Table 5 Here**

56 **Insert Table 6 Here**

Discussion

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5 The study indicates that adoption of Community Services could lead to positive
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7 outcomes in terms of lower total PD treatment costs, decrease in the workload and
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9 activity levels of clinical staff in hospitals, and reduced requirements in terms of
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11 hospital resources and clinical headcount. This is helpful to policy makers who are
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13 required to provide treatment and high quality care for an increased number of PD
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15 patients in the context of reduced public funding for health. As more resources are
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17 freed in hospitals, this opens up the possibility to absorb the increasing demand for
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19 PD treatment and, consequently, reduce the time PD patients need to wait before
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21 commencement of treatment.
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29 This positive impact within hospitals, however, must be viewed in conjunction the
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31 increased costs and workload that shifting patients to community services brings.
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33 Successful implementation of any such policy involving shifting across sectors must
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35 be supported by a careful processes of capacity management in community
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37 services, work-force planning and training programs. Revised procedures of
38
39 commissioning and purchasing of services for PD patients, must be in parallel with
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41 effective integration between health and social services. It is critical for policy makers
42
43 to adopt a holistic approach to the management and treatment of PD patients.
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45 Focusing on the benefits of the policy on one element delivering the treatment
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47 (hospitals) and ignoring the spill over effects on the other element (community
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49 services) may lead to the opposite of what the policy is intended to achieve.
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2 From a scale perspective, the overall performance gains, which could be achieved at
3 the UK level could be important. The results reported in this study are for a single
4 Trust only, but given that there are more than 350 NHS Trusts in the UK [8], the
5 potential magnitude of total savings in PD treatment costs is significant. As the NHS
6 is in financial deficit (£471 Million in the financial year 2014/15), the important
7 potential cost reductions resulting from a wider use of Community Services can
8 contribute toward much needed sustainable solutions.
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12 The results also suggest that there is an “optimal” fraction of PD patients, which
13 could be shifted to Community Services. The overall PD treatment costs have a
14 decreasing pattern up the scenario where the shift is at a level of 40%; but total costs
15 increase beyond this percentage. This finding has important implications with regard
16 to scaling of Community Services and the best allocation of patients between the
17 hospital and Community Services settings.
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21 In addition to the benefits from the care delivery perspective, there is strong
22 evidence that patients find community services a friendlier environment and where
23 staff are more able to delivery tailored care accounting for personal needs and
24 circumstances of patients [6]. This “human” aspect has been highlighted by the
25 advocates of a wider use of these services as positive psychological impact of
26 treatment in community services is as important as the medical treatment itself. This
27 is especially important for those patients facing social exclusion, which can
28 exacerbate some PD symptoms (such as depression and dementia). As such,
29 community services can play an important role in reversing PD patients’ low
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1 satisfaction with quality of care and their complaints about the lack of attention
2 towards their psychological welfare.
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7 The importance of community services in the treatment and management of patients
8 with PD was highlighted in policy documents and treatment delivery framework about
9 a decade ago [5,38]. However, the acknowledgment of their important role gained
10 momentum in recent years due to increased demand and the pressures to deliver
11 efficient and high quality care to PD patients [39,40]. The results of this research are
12 in line with this renewed policy direction and add to the evidence that Community
13 Services can be an important element of an innovative PD care delivery model.
14 Making such a model successful, however, requires an alignment between the
15 capacity in resources such as PD nurses and therapists and the level of demand for
16 care in community services. In this context, the processes of workforce planning and
17 training programs need to be designed with current and future shifts toward
18 community services [40,41].
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39 Adequate resource availability is important to the ensure quality of the care provided
40 in community services to maximise impact on quality of life (5,42,43). The integration
41 between health services and social services is another key driver of quality of care in
42 Community Services [39,42]. As care in community services is organised in
43 Multidisciplinary Teams (MDT) including PD nurses, therapists, and social services
44 workers, it is critical that the mix of resources to constitute the MDT are available and
45 that the MDT functions in a coherent way to meet the multiple needs of PD patients.
46 This requires high levels of coordination between health and social services in terms
47 of the management of care plans for patients, provision of services in a timely
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1 manner, and the planning of workforce development and training activities. PD
2 nurses fulfil a pivotal role as part of the MDT team and in promoting up take of
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4 community services at periodical meetings with patients where treatment needs and
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6 care plans are discussed [39,43].
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12 To ensure equity of access, health service commissioners would need to review
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14 disparities in community provision between urban and rural areas across the UK.
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19 The findings of the research are based on results obtained from the application of
20
21 the DES model to a single (albeit large) Trust in the UK. It is expected that the
22
23 general findings regarding the positive impact of increased use of community
24
25 services may be generalised to other Trusts of various sizes in the UK. The model
26
27 developed reflects the patients' pathways recommended by policy documents in the
28
29 UK such as NICE guidelines [5] and which were confirmed to be relevant and
30
31 practicable by PDNSA nurses in the Trust. Cost data were from the Department of
32
33 Health and not expected to vary widely in different Trusts. However, it is possible
34
35 that the "optimal" fraction of patients to be shifted to community services (40% in the
36
37 Trust studied in the current research) is different in other Trusts due to varying
38
39 patient numbers and distribution of patients between the four stages of the disease.
40
41 The methodology and model is easily transferable to other contexts, as variables are
42
43 explicit and variation can be accounted for, generating new optimal service
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45 configuration. Where Trusts operate a significantly different patient pathway and/or
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47 community services are unable to provide the full range of services, the current
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49 model would require significant revision.
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1 The model was developed with the active engagement of policy makers and staff
2 involved in the provision of PD treatment and care. This collaborative effort led to a
3 feeling of problem ownership by the stakeholders and was a critical factor in the
4 adoption of the model and its results. This positive outcome was also facilitated by
5 the increasingly friendly and easy to use Simulation software, which is lowering the
6 technical barriers faced by health managers and enabling them to play a more
7 assertive role in building and using simulation models. The current study reflects well
8 this evolutionary process and the move from the times when model building was the
9 sole responsibility of technical experts to the current contexts where this
10 responsibility is shared by the problem owners and the modellers [44].
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27 The current study highlights also the growing role Simulation modelling is playing in
28 the context of the shift towards more “evidence based” decision making in the health
29 sector. It has been observed that in several instances, health managers had a clear
30 idea about the decisions to be made to improve performance, but lacked the
31 evidence to make a case to decision makers. By providing that evidence, simulation
32 modelling fills this gap and allow policies to be selected and implemented with
33 confidence and with a clear vision about what is expected in the future.
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46 The study, of course, has some limitations. The model represented a single Trust
47 and this has implications for generalizability of the results as discussed earlier. The
48 model did not take account of the psychological attributes of the patients and how
49 these could influence the progression of the disease and the effectiveness of the
50 treatment. Furthermore, as it is virtually impossible to wholly represent real world
51 complexity of health systems [23], the results of this study should be interpreted with
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1 care. The model includes a number of assumptions and simplifications, and
2 increased complexity would be introduced by: the different age categories of
3 patients; co-existence of other medical conditions in addition to PD for some
4 patients; different socio-economic status of patients; effects of syndromes such as
5 lack of mobility, depression, and dementia on attendance of planned appointments in
6 hospitals and community services. Opportunity costs to patients and indeed carers
7 are important but outside the scope of this current study. Future research and model
8 development which integrates both the provider and patients' perspectives are
9 needed.

24 Conclusions

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29 The number of patients affected by PD is increasing and this trend is expected to
30 continue and magnify in line with the UK population structure and ageing. This
31 creates significant pressures on PD and wider services in the absence of a cure.
32 Current evidence suggests that treatment of degenerative neurological diseases
33 such as PD is expensive, inefficient, inaccessible to a considerable number of
34 patients, and of sub-optimal quality. Financial austerity and cuts to public funds
35 allocated to the health sector demand innovative solutions for care delivery leading
36 to efficiencies across a healthcare economy. The current study is particularly timely
37 against this background and explores the possibility and scale of efficiency gains,
38 which could be achieved if Community Services are more widely adopted and
39 become an integrated part of the PD treatment process.
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In terms of policy, current PD treatment and patient management guidelines and procedures are a decade old, and may no longer be appropriate in the current NHS environment. The formal evaluation of innovative treatment procedures such as the use of community services could offer policy makers insights about more effective ways of caring for PD patients whilst enhancing quality. The advantages of community services need to be effectively shared with PD patients and carers to help inform management choices and care plans.

The successful application of Simulation Modelling in this research and the enthusiasm and engagement of key participants strengthens the argument for co-developing policy improvement. As the complexity of health these systems increases in an environment of constrained resources, so too does the need for evidence based decision making. Simulation modelling is well positioned to provide that evidence and allow policy makers to face upcoming challenges with greater confidence.

List of Abbreviations: CI Confidence Interval; DES Discrete Event Simulation; GPs General Practitioners; NICE National Institute for Clinical Excellence; NHS National Health Service; PD Parkinson’s Disease; SLT Speech and Language Therapy UK United Kingdom; NHS National Health Service

1 **Authors' contributions:** ED and DS conceptualise and developed the DES model.
2
3 RL analysed the results and wrote the paper with the contribution of RA and CV. All
4
5 authors agreed on the final version of the paper.
6

7
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9
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11
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13
14 Leake.
15
16

17 18 **Declarations**

19 **Ethical approval and consent to participate:**

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22 The data collection for this study did not require ethics approval as: derived from
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25 secondary sources which are clearly set out in the paper b. did not include any
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28 patient level identifiable data c. did not include any patient/public participants d. is
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31 categorized as a service evaluation using a consultation approach with the 6
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<http://www.hra.nhs.uk/documents/2013/09/does-my-project-require-rec-review.pdf>

The nurses involved in the research opted to participate. The interviews were not mandatory. Verbal consent was sought from the nurses. The nurses who participated in the study had given full consent.

Consent to publish: Not applicable

Availability of Data and Materials: The data entered in the model is included in the additional file "BMC Health Services Research paper additional file data for the

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model", which has been submitted with the paper.

The HRG data used to estimate some of the parameters in the model is publicly available on the UK Department of Health website. The link to the website and the date when it was accessed are available on the list of references of the paper (Reference number 13 on the references list)

The HES dataset, which was used to estimate some parameters for the model, is held in the computer of one of the authors. The HES dataset has been purchased by the University of Hertfordshire from the National Health Service and it is restricted to academic research use only. It cannot be made publicly available as this is one of the conditions of acquiring the dataset. In addition, the data is not readable and needs database programming to be extracted, hence it cannot be made accessible.

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Table 1: Simulation and real world results for model validation

Performance Indicator	Simulation Results Mean 95% (LCI, UCI)	Real World Results	Difference (in Percentage)
PD doctors' visits	8225 (7732, 8801)	8061	2% (-4%, 8%)
PD nurses visits	10357 (10046, 10771)	10875	-5% (-8%, -1%)
PD doctors service hours	8225 (7978, 8554)	8061	2% (-1%, 5%)
PD nurses service hours	10357 (10150, 10978)	10875	-5% (-7%, 1%)
PD doctors total FTEs	1.07 (0.995, 1.123)	1.04	3% (-4%, 7%)
PD nurses total FTEs	3.4 (3.230, 3.502)	3.57	-5% (-10%, -2%)

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Table 2 Definition of the performance indicators

Performance Indicator	Definition
Level of Activity	
PD doctors' visits	Number of consultations of PD patients with doctors in hospitals
PD nurses visits	Number of consultations of PD patients with nurses in hospitals
Physiotherapy visits	Number of consultations to provide Physiotherapy to PD patients
SLT therapy visits	Number of consultations to provide SLT therapy to PD patients
Psychiatry visits	Number of consultations to provide Psychiatry therapy to PD patients
Occupational therapy visits	Number of consultations to provide Occupational therapy to PD patients
Palliative care visits	Number of consultations to provide Palliative care therapy to PD patients
Dietician visits	Number of consultations to provide Dietician therapy to PD patients
Resource Requirements	
PD Doctors service hours	Number of PD doctors working hours required to provide treatment to patients
PD nurses service hours	Number of PD nurses working hours required to provide treatment to patients
PD Doctors Total FTEs	Number of Full Time Equivalent (FTEs) of PD doctors required to provide treatment to patients
PD Nurses Total FTEs	Number of Full Time Equivalent (FTEs) of PD nurses required to provide treatment to patients
Treatment Costs	

1	PD Doctors cost	Total PD doctors costs required to treat patients in hospitals
2	PD Nurses cost	Total PD nurses costs required to treat patients in hospitals
3		
4	Physiotherapy costs	Total costs required to provide Physiotherapy to PD patients
5		
6	SLT costs	Total costs required to provide SLT to PD patients
7		
8	Psychiatry costs	Total costs required to provide Psychiatry therapy to PD patients
9		
10	Occupational therapy costs	Total costs required to provide Occupational therapy to PD patients
11		
12	Palliative care costs	Total costs required to provide Palliative care therapy to PD patients
13		
14	Dietician costs	Total costs required to provide Dietician therapy to PD patients
15		
16		

18 Table 3: Average, 95% lower and upper CI results for the Number of visits to PD
19 doctors and nurses
20

21 Performance	Baseline	Scenario 1: Low use of CS	Scenario 2: Medium Use of CS	Scenario 3: High Use of CS	Scenario 4: Very High Use of CS
22 Indicator					
23 PD doctors' visits	8225 (7732, 8801)	7494 (7194, 7944)	7158 (6872, 7516)	6537 (6145, 6798)	5873 (5638, 6108)
24 PD nurses visits	10357 (10046,10771)	9854 (9263,10248)	9553 (8980, 10126)	8831 (8301, 9449)	8016 (7695, 8417)
25 Total Hospital Visits	18582 (17778, 19572)	17348 (16457, 18192)	16711 (15852, 17642)	15368 (14446, 16247)	13889 (13333, 14525)
26 Physiotherapy visits	3554 (3341, 3767)	3700 (3552, 3922)	4036 (3915, 4319)	4708 (4567, 5038)	6755 (6552, 7228)
27 SLT visits	3357 (3256, 3592)	3494 (3389, 3704)	3811 (3620, 4002)	4447 (4314, 4714)	6379 (6124, 6762)
28 Psychiatry visits	1776 (1723, 1847)	1850 (1739, 1943)	2019 (1938, 2120)	2355 (2214, 2449)	3378 (3175, 3581)
29 Occupational therapy visits	2335 (2265, 2428)	2420 (2323, 2589)	2640 (2561, 2746)	3079 (2987, 3264)	4150 (3901, 4441)
30 Palliative care visits	454 (440, 481)	477 (453, 496)	519 (498, 555)	606 (570, 648)	731 (702, 760)

Dietician visits	434	456	496	579	818
	(421, 451)	(442, 488)	(481, 531)	(562, 614)	(777, 859)

Performance Indicator	Baseline	Scenario 1: Low use of CS	Scenario 2: Medium Use of CS	Scenario 3: High Use of CS	Scenario 4: Very High Use of CS
PD doctors service	8225	7494	7158	6537	5873

Total Community Services Visits	11910	12397	13521	15774	22211
	(11446, 12566)	(11898, 13142)	(13013, 14273)	(15214, 16727)	(21231, 23631)

Table 4: Average, 95% lower and upper CI results for the level of activity of PD doctors and nurses

1 hours	(7978, 8554)	(7344, 7719)	(6800, 7444)	(6210, 6995)	(5579, 6108)
2 PD nurses service	10357	9854	9553	8831	8016
3 hours	(10150, 10978)	(9460,10347)	(8884, 10222)	(8301, 9449)	(7776, 8256)
4					
5					
6 PD doctors total FTEs	1.07	0.97	0.93	0.85	0.76
7	(0.995, 1.123)	(0.950,1.028)	(0.892, 0.985)	(0.824,0.884)	(0.722, 0.782)
8					
9					
10					
11 PD nurses total FTEs	3.4	3.2	3.1	2.9	2.6
12	(3.230, 3.502)	(2.976, 3.36)	(2.883, 3.255)	(2.726,3.016)	(2.444, 2.756)
13					
14					
15 Total FTEs	4.47	4.17	4.03	3.75	3.36
16	(4.225, 4.625)	(3.926,4.388)	(3.775, 4.240)	(3.550,3.900)	(3.166, 3.538)
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Table 5: Average, 95% lower and upper CI results for hospital costs

Performance Indicator	Baseline	Scenario 1: Low use of CS	Scenario 2: Medium Use of CS	Scenario 3: High Use of CS	Scenario 4: Very High Use of CS
PD doctors cost	1,809,500	1,648,680	1,574,760	1,438,140	1,292,060

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	(1,755,215; 1,881,880)	(1,549,759; 1,731,114)	(1,511,770; 1,669,246)	(1,366,233; 1,524,428)	(1,214,536; 1,343,742)
PD nurses cost	1,553,550 (1,506,944; 1,662,299)	1,478,100 (1,418,976; 1,566,786)	1,432,950 (1,389,962; 1,490,268)	1,324,650 (1,258,418; 1,377,636)	1,202,400 (1,142,280; 1,274,544)
Total Hospital Costs	3,363,050 (3,262,159, 3,544,179)	3,126,780 (2,968,735, 3,297,900)	3,007,710 (2,901,732, 3,159,514)	2,762,790 (2,624,651, 2,902,064)	2,494,460 (2,356,816, 2,618,286(

Table 6: Average, 95% lower and upper CI results for community services and total PD treatment costs

Performance	Baseline	Scenario 1: Low use of	Scenario 2: Medium Use	Scenario 3: High Use of	Scenario 4: Very High
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Indicator		CS	of CS	CS	Use of CS
Physiotherapy cost	135,052 (126,949; 140,454)	140,600 (133,570; 150,442)	153,368 (145,700; 159,503)	178,904 (171,748; 191,427)	256,690 (243,856; 272,091)
SLT cost	322,272 (306,158; 341,608)	335,424 (322,007; 348,841)	365,856 (354,880; 391,466)	426,912 (405,566; 456,796)	612,384 (581,765; 655,251)
Psychiatry cost	88,800 (85,248; 92,352)	92,500 (86,950; 97,125)	100,950 (96,912; 105,998)	117,750 (110,685; 123,638)	168,900 (158,766; 180,723)
Occupational therapy cost	135,430 (130,013; 144,910)	140,360 (136,149; 147,378)	153,120 (143,933; 162,307)	178,582 (171,439; 185,725)	240,700 (228,665; 250,328)
Palliative care cost	22,700 (21,792; 24,062)	23,850 (22,419; 25,520)	25,950 (24,393; 27,248)	30,300 (29,391; 32,421)	36,550 (35,088; 38,012)
Dietician cost	21,700 (20,832; 23,219)	22,700 (21,338; 23,835)	24,800 (23,808; 25,792)	28,950 (27,792; 30,108)	40,900 (38,855; 43,354)
Total community services Costs	725,954 (690,992, 766,605)	755,434 (722,433, 793,141)	824,044 (789,626, 872,314)	961,398 (916,621, 1,020,115)	1,356,124 (1,286,995, 1,439,759)
Total PD treatment Costs	4,089,004 (3,953,151, 4,310,784)	3,882,214 (3,691,168, 4,091,041)	3,831,754 (3,691,358, 4,031,828)	3,724,188 (3,541,272, 3,922,179)	3,850,584 (3,643,811, 4,058,045)

List of Figures

Figure 1: Structure of the Parkinson's disease patients' pathway

Figure 2: SIMUL8 snapshot of the diagnosis process for Parkinson's disease patients

1 Figure 3: The Parkinson's disease simulation model user interface

2 Figure 4: Expected number of hospital visits

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4
5 Figure 5: Expected number of community services visits

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9 Figure 6: Expected hospital costs, community services costs, and total PD treatment
10 costs

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16 Supplementary File list:

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19 Supplementary file 1: BMC HSR Data for simulation model

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22 Title of data: Table 7. Data used for the simulation model

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25
26 Description of data: Table providing details of parameters used in the simulation
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28 model including the source, distribution type and the value entered in the model.
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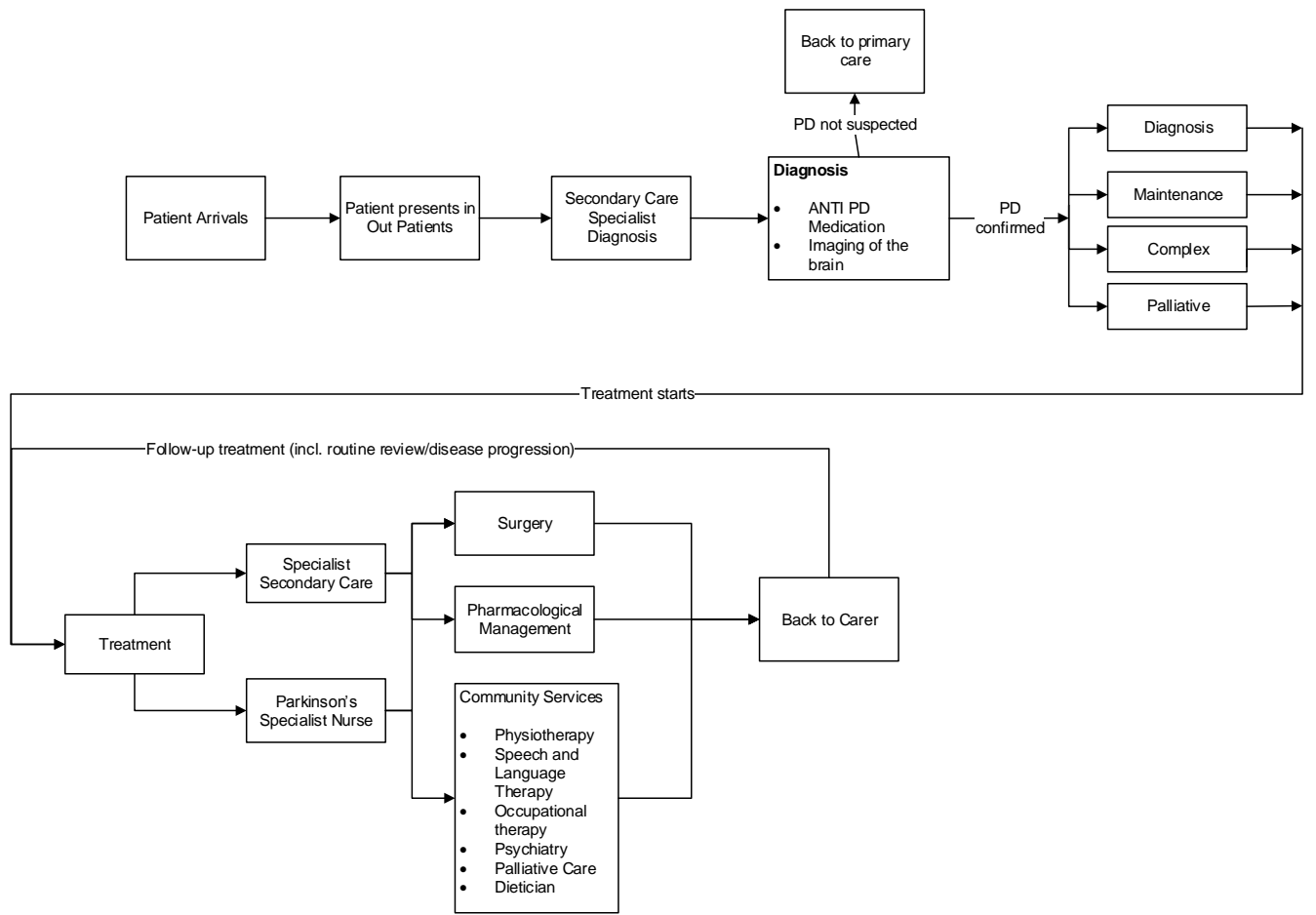
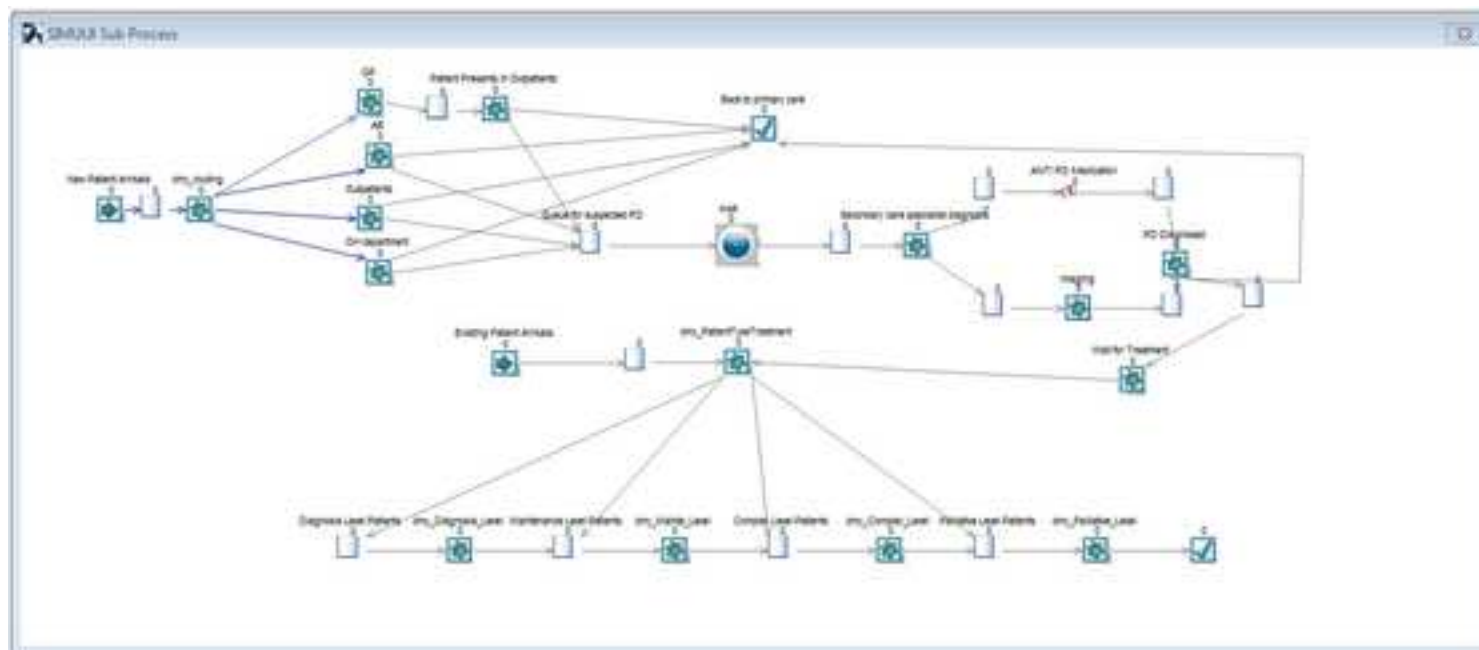
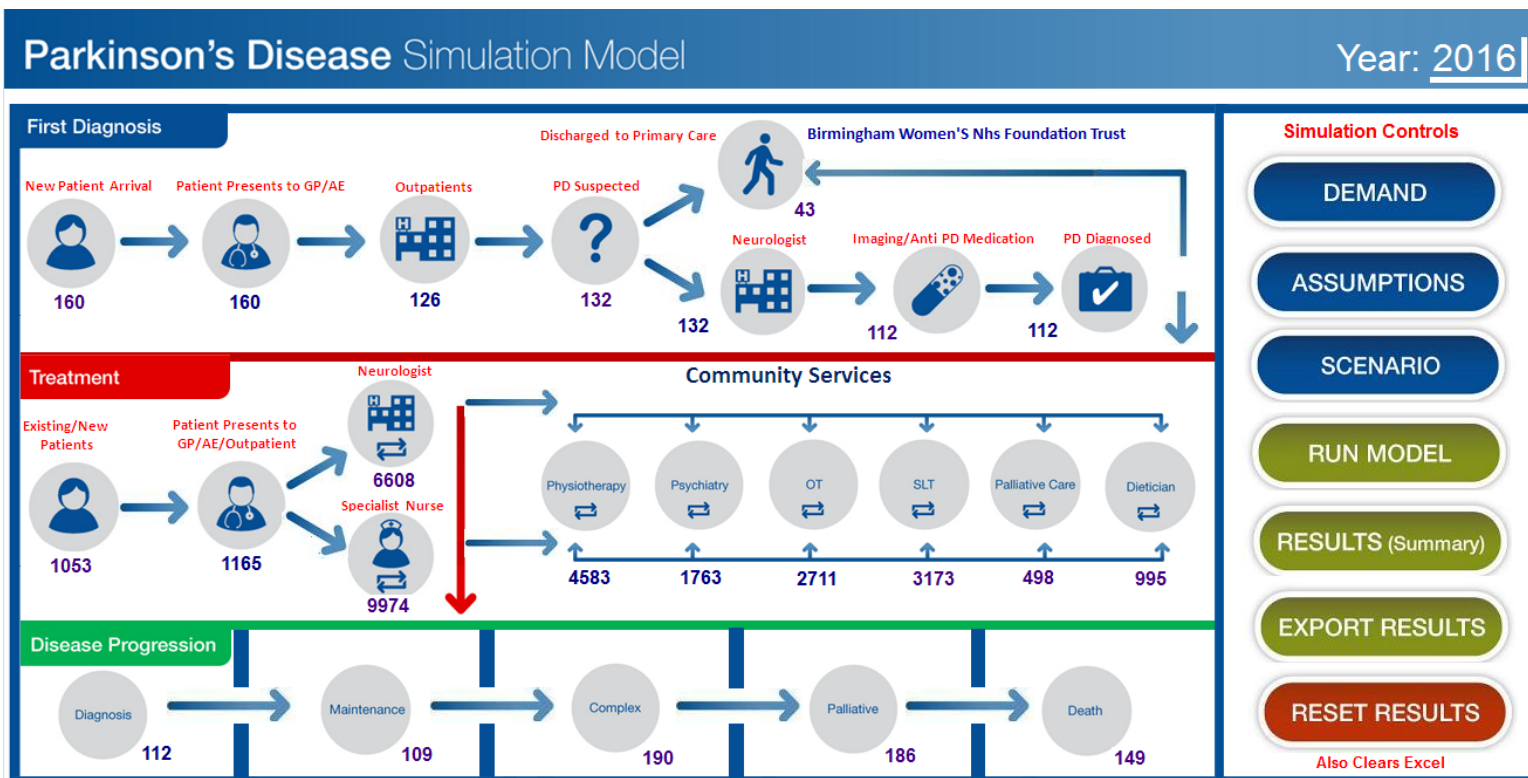
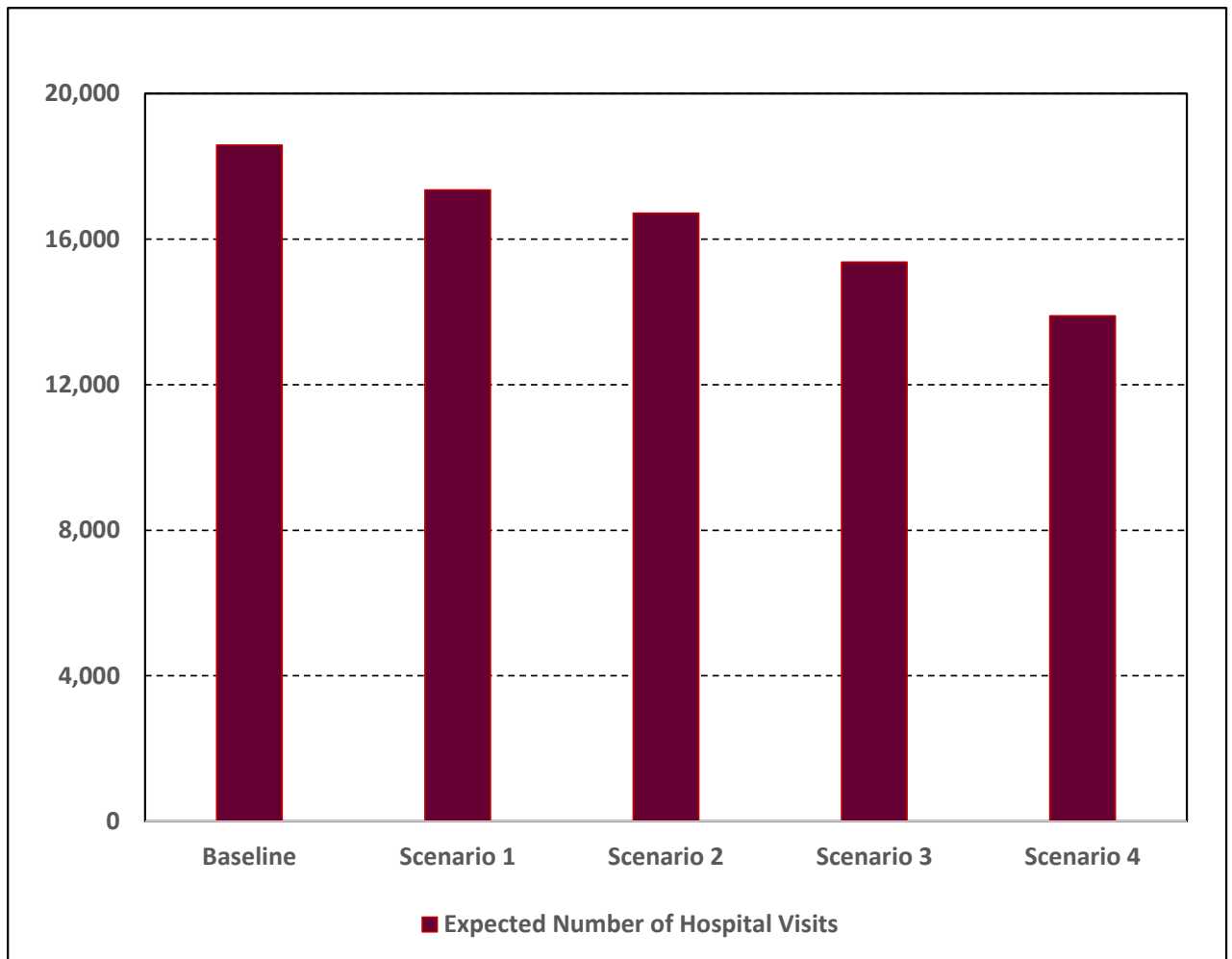
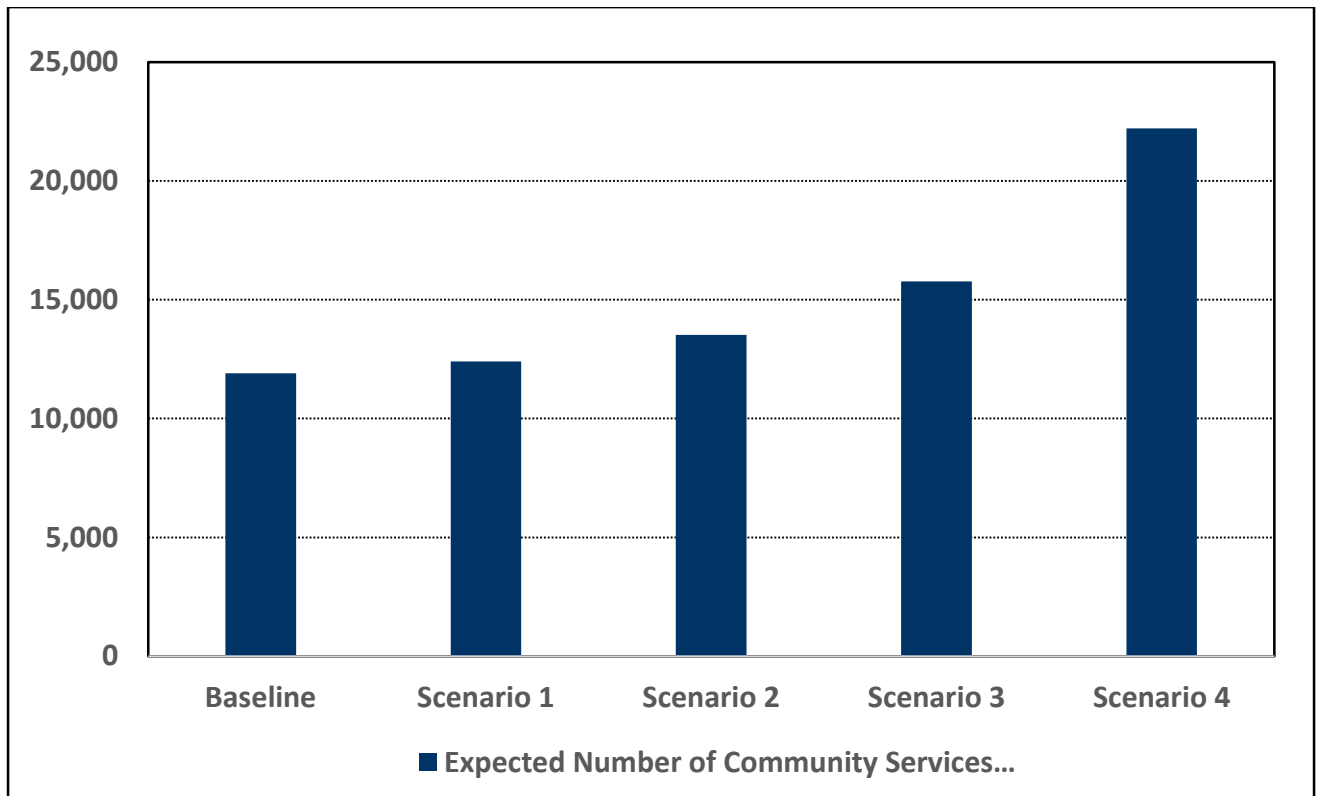


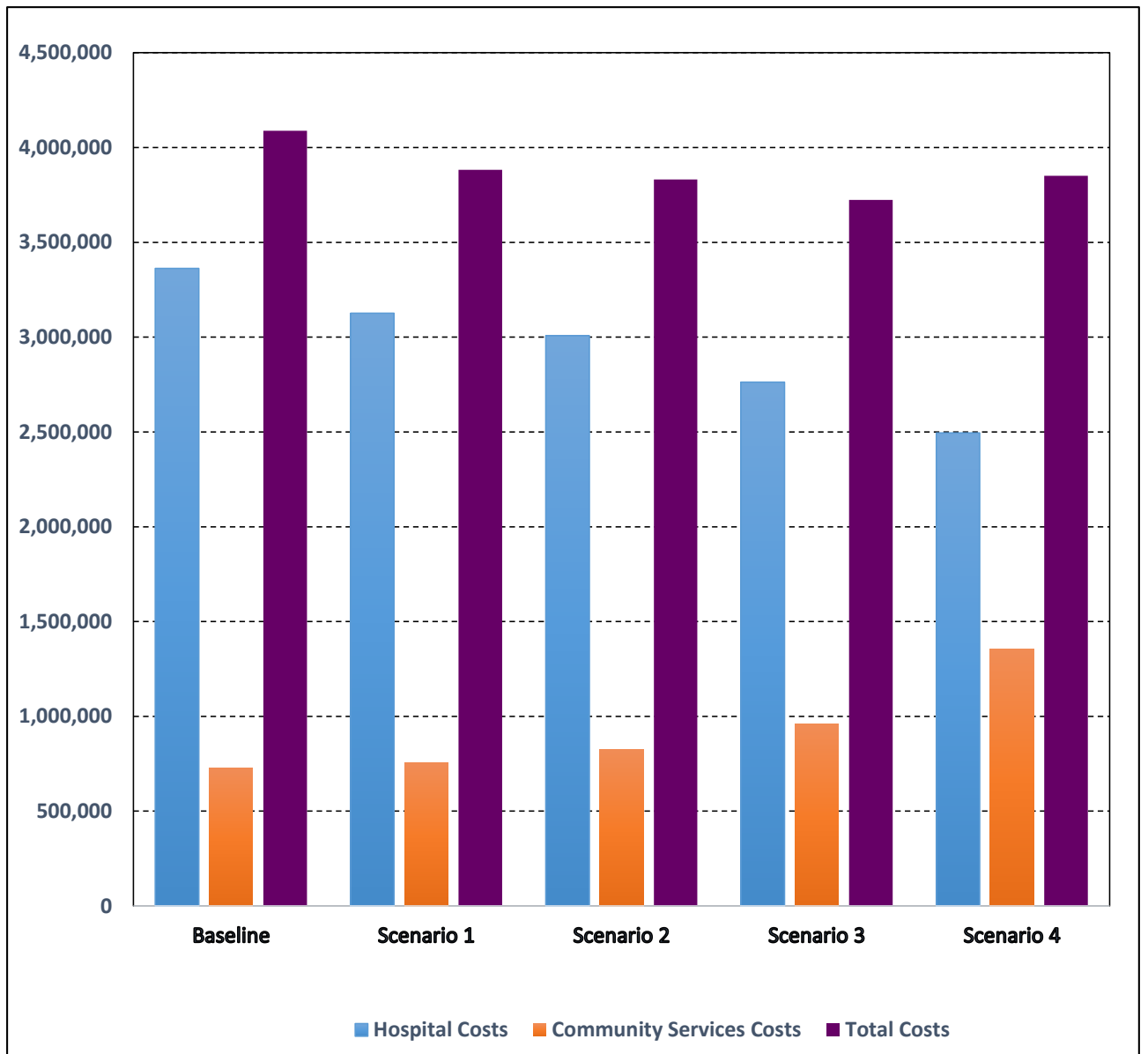
Figure 1 Adapted from: Demir et al. 2015 [7]

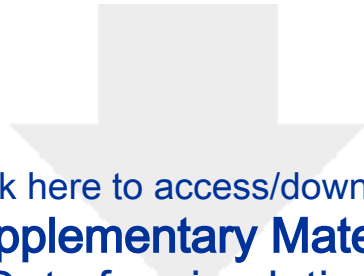












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Supplementary Material

BMC HSR Data for simulation model.docx

