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Cost Analysis of the Legal Declaratory Relief Requirement for Withdrawing Clinically Assisted Nutrition and Hydration (CANH) from Patients in the Permanent Vegetative State (PVS) in England and Wales

Adam Formby, Richard Cookson, Simon Halliday

CHE Research Paper 108

Cost analysis of the legal declaratory relief requirement for withdrawing Clinically Assisted Nutrition and Hydration (CANH) from patients in the Permanent Vegetative State (PVS) in England and Wales

[1]Adam Formby
[2]Richard Cookson
[3]Simon Halliday

[1]School of Sociology and Social Policy, University of Leeds, UK
[2]Centre for Health Economics, University of York, UK
[3]York Law School, University of York, UK

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Centre for Health Economics
Alcuin College
University of York
York, UK
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Declarations

Institutional provenance

This study was conducted by researchers from the University of York, under the auspices of the Cardiff-York Centre for Chronic Disorders of Consciousness (CDoC). CDoC is a multi-disciplinary group of researchers exploring the cultural, ethical, legal, social and historical dimensions of Chronic Disorders of Consciousness: coma, the vegetative and the minimally conscious state (http://cdoc.org.uk).

Authorship

Adam Formby conducted the data collection and the preliminary analysis and report writing; Richard Cookson supervised the analysis and undertook the final analysis and report writing; Simon Halliday supervised the analysis and re-drafted the legal sections. All three authors contributed to study design, interpretation and writing up.

Funding

Adam Formby worked on this study during his time as a 'discipline hopping' post-doctoral fellow in CDoC, based at the York Law School and the Centre for Health Economics. His fellowship was funded by the University of York Centre for Chronic Diseases and Disorders (C2D2), an institute-wide 'virtual centre' for funding and supporting research at the University of York, with support from a Wellcome Trust Institutional Strategic Support Fund award [ref: 097829/Z/11/A]. Richard Cookson and Simon Halliday are full time academics employed by the University of York. No other sources of funding were received for the study.

Earlier versions of the material in this report were presented at a day conference in York on 9th May 2014 ("Withholding and Withdrawing Treatment from Patients in a Vegetative or Minimally Conscious State") and at the Annual Meeting of the Law and Society Association Minneapolis, USA, 30th May 2014.

Summary

Aim

To estimate the NHS cost per case of the legal declaratory relief process in relation to withdrawal of clinically assisted nutrition and hydration (CANH) from patients diagnosed as being in a permanent vegetative state (PVS), in relatively 'straightforward' cases where family and clinicians agree this is in the best interests of the patient.

Methods

The method employed is an incremental cost analysis of declaratory relief compared with no declaratory relief, from an NHS cost perspective, including litigation costs borne by the NHS as well as ongoing care costs. The comparator is the currently recommended medical decision making process prior to application for declaratory relief, including PVS diagnosis by the treating clinician following a structured assessment process, confirmation of PVS diagnosis by a medical second opinion, and best interest decision making in consultation with the patient's family. We estimate care costs based on a previously validated NHS costing tool for specialised nursing care for patients with long-term neurological conditions – the 'Needs and Provision Complexity Scale' – supplemented with our own partial 'micro-costing' of additional resource use items excluded from this tool, in particular costs of medication and feeding, tracheotomy, and hospital 'blue light' events. As a check, we also perform our own full 'micro-costing' of the care costs. We estimate legal costs through 'micro-costing' of the relevant legal costs borne by the NHS, excluding court infrastructure costs falling on the Ministry of Justice rather than the NHS. Our estimates of resource use are based on expert opinion; our unit costs are based on published estimates where possible and expert opinion where necessary.

Results

The PVS declaratory relief process lasts, on average, nine months and costs the NHS about £122,000 per case. This comprises about £53,000 in legal costs and about £69,000 in on-going care costs which we estimate cost just over £7,500 per month. We have not included court infrastructure costs in these estimates, which fall on the Ministry of Justice rather than the NHS. We estimate that the fastest a case can be heard, in the absence of delays, is three months. We estimate that a declaratory relief process lasting three months would cost £76,000.

Discussion

The £122,000 cost to the NHS of each 'straightforward' declaratory relief application can be expected to displace alternative NHS services and thereby cause a loss of more than 9 quality-adjusted life years (QALYs) from other NHS patients. This is based on the current best estimate from analysis of data on local NHS expenditure and health outcomes, that a reduction of £13,000 in NHS expenditure causes a loss of one QALY (Claxton et al. 2013).

1. Introduction

1.1 The declaratory relief (DR) process

Since the development of the diagnostic category of the 'permanent vegetative state' ('PVS') in the early 1970s (Jennet and Plum, 1972), legal systems across the world have had to grapple with the question of whether the treatments that sustain the lives of patients in the PVS should be continued or terminated. Patients in the vegetative state (VS) have a sleep-wake cycle, and respond to stimulation including reflex and spontaneous behaviours, such as grasping and grimacing. However, they have no environmental awareness or purposeful movement (Fritz and Bunn, forthcoming). A vegetative state lasting more than 4 weeks after a brain injury may be diagnosed as 'prolonged'. However, patients are not usually diagnosed as *permanently* in a vegetative state (PVS) until at least 12 months after a traumatic brain injury and 6 months after a non-traumatic brain injury (Royal College of Physicians, 2013).

In some jurisdictions, legal developments have been prompted or informed by high profile and tragic cases, England and Wales amongst them. The situation of Anthony Bland, the young football fan catastrophically injured in the Hillsborough disaster, was the subject of the House of Lords' first consideration of an application to withdraw the treatment that was sustaining the life a patient in the PVS. In this 1993 case (*Airedale NHS Trust* v *Bland* [1993] AC 789), the court established a lasting precedent that it is lawful in England and Wales to discontinue the clinically assisted nutrition and hydration ('CANH') of a patient in the PVS. According to the legal precedent set in Bland, as soon as a patient in an ongoing vegetative state is diagnosed by their treating clinician as being in a *permanent* vegetative state (PVS), it is no longer legally in the patient's best interests to continue receiving CANH.

In the 20 or so years since the decision in Bland, the legal expectation has been that the court will be involved by way of declaratory proceedings in every decision to withdraw CANH from PVS patients, even where families and the healthcare team agree that it is an appropriate course of action. The House of Lords originally framed this requirement of legal declaratory relief as a matter of good practice:

> The decision whether or not the continued treatment and care of a P.V.S. patient confers any benefit on him is essentially one for the practitioners in charge of his case. The question is whether any decision that it does not and that the treatment and care should therefore be discontinued should *as a matter of routine* be brought before the Family Division *for endorsement* or the reverse. The view taken by the President of the Family Division and the Court of Appeal was that it should, *at least for the time being and until a body of experience and practice has been built up which might obviate the need for application in every case*. As Sir Thomas Bingham M.R. said, this would be in the interests of the protection of patients, the protection of doctors, the reassurance of the patients' families and the reassurance of the public. I respectfully agree that these considerations render *desirable* the *practice of application*. (*Airedale NHS Trust* v *Bland* [1993] AC 789, at p. 859; emphases added)

However, following the passage of the Mental Capacity Act 2005, the requirement has now become a matter of legal obligation, as set out in the Court of Protection Rules (S.I. 2007/1744) and the 2005 Act's Code of Practice (para 6.18).

1.2 Concerns about the declaratory relief process

The direct legal supervision of CANH withdrawal decisions in relations to *all* patients in the PVS, even where health care teams and families agree on CANH withdrawal, is unusual in international terms (Halliday et al, *forthcoming*). Existing evidence suggests that most foreign jurisdictions permit

withdrawal of CANH from such patients without recourse to the courts. It is also unusual when set against the context of wider English medical law. As the British Medical Association has pointed out:

> As expertise and professional guidelines develop on PVS, the BMA can see no reason to differentiate between decisions for patients in PVS and those for patients with other very serious conditions where ANH is not considered to be a benefit, which are currently governed by established practice without the need for legal review... The BMA hopes that in future the courts will decide that PVS cases no longer inevitably require court review, where consensus exists, as long as such withdrawal is in accordance with agreed guidelines. (BMA, 2007: 61)

Equally, the requirement of declaratory relief in these cases also brings economic costs to the NHS, in terms both of the necessary litigation costs and the on-going care costs while declaratory relief is obtained. These economic costs to the NHS are the subject of this paper.

1.3 Aims of this study

This study is the first attempt to estimate the costs to the NHS of the declaratory relief process in England and Wales for withdrawal of CANH from patients in the PVS. It aims to compare the incremental costs per case of the current decision-making model where declaratory relief is a requirement, with an alternative model where it is not. It is not viable to estimate the total savings to the NHS that abolition of the declaratory relief requirement would bring, as no data exist about the prevalence of PVS in England and Wales and it would be difficult to predict the overall effect of law reform on the number of cases of CANH withdrawal. There are currently no reliable data on the incidence or prevalence of prolonged disorders of consciousness in general, of which vegetative state is just one particular case. Prevalence data are likely to be particularly unreliable in relation to PVS, since diagnosing a vegetative state as permanent is a highly complex and specialised task that carries a grave legal implication – i.e. that it is legally not in the best interests of the patient to receive CANH. Qualitative data suggest that some families are intimidated or offended by the prospect of legal process, and so might become more willing to support withdrawal of CANH in the absence of that legal process. Yet, at the same time, other families may become less willing to support withdrawal of CANH, insofar as they take reassurance from the court with respect to responsibility for the death of their relatives (Halliday et al, *forthcoming*). Moreover, it is hard to estimate the 'transaction costs' of legal reform, such as the costs of Parliamentary time and the costs of drawing up new legal and NHS guidance.

The primary costing perspective is that of the NHS, including both medical and litigation costs borne by the NHS. We do not analyse wider public sector costs borne by the Ministry of Justice in providing court infrastructure services, such as general courtroom functioning and judge time. This NHS cost perspective is adopted in order to address concern about health opportunity costs in terms of NHS resources that could otherwise be used to deliver health services and health benefits to other patients.

1.4 Decision-making alternatives compared in the incremental cost analysis

According to the relevant legal and medical guidelines, the current initial medical stage ought to include a thorough medical assessment of the PVS diagnosis, including all relevant assessment processes (such as the Wessex Head Injury Matrix [WHIM] and the Sensory Modality and Assessment and Rehabilitation Technique [SMART]), and also meetings between family, carers and clinicians in order to reach a judgement on the best interests of the patient. In formal terms at least, the current decision making process in England and Wales for withdrawal of CANH from an individual in the PVS can be divided into two distinct stages.

First, there should be a medical process in which the treating consultant diagnoses the patient as PVS. Accurate diagnosis is a complex process requiring assessment at multiple time points by a multi-disciplinary team of experts. Due to the fact that the patient's responses are often delayed, inconsistent and/or confounded by accompanying disabilities, their condition may change, and there is always a degree of subjectivity in assessing disorders of consciousness. The diagnostic process involves the interpretation of data from a range of sources – including medical notes, patient observations by family members and care staff at multiple time points, the outcomes of structured assessments of the awareness and abilities of vegetative patients – such as WHIM and SMART – and input from multiple disciplines including physiotherapy, occupational therapy, speech and language therapy, neuropsychology, nursing and rehabilitation medicine (Royal College of Physicians, 2013: 14). This diagnosis should then be confirmed by a second senior consultant. The diagnosis implies that, from a legal perspective, it is not in the patient's 'best interests' to continue CANH. It is a legal (Mental Capacity Act 2005, s. 4) and good practice requirement (Royal College of Physicians, 2013) that decisions about 'best interests' are made in consultation with the patient's family.

Second, there must be a legal process whereby the best interests decision must be declared lawful by the Court of Protection – the process of obtaining 'declaratory relief'. As part of this process, the Official Solicitor commissions a third expert opinion to confirm again the diagnosis. This third opinion involves a review of all the relevant data (medical notes, the outcomes of the structured assessment tools), in addition to discussions with the health care team and family members, and a visit to the patient.

Thus, our analysis will compare the incremental cost per case of two different decision making models:

a) *No Declaratory Relief (NDR)* – the medical decision making process comprising the PVS diagnosis by the treating clinician, the confirmation of the diagnosis by a second opinion, and the best interest decision to withdraw CANH made in consultation with the patient's family.

b) *Declaratory Relief (DR)* – the current two-stage process, comprising the above medical decision making process, followed by a second legal process of obtaining declaratory relief which involves a third expert opinion and court hearings.

In practice, however, the relevant guidelines are not always followed, and all the appropriate medical assessment processes and meetings between family, carers and clinicians are not always undertaken prior to the initiation of the declaratory relief proceedings. It is not clear, however, that accounting for these empirical realities would substantially change the results. On the one hand, it would increase the cost per case of NDR due to undertaking additional tests and meetings that were supposed to occur under DR but which in reality do not always occur. On the other hand, we would need to allow for the increased legal delays and costs of DR due to medical and legal paperwork not being properly prepared in advance of initiating legal proceedings. In the absence of evidence on either of these issues, it is not clear which way these two counteracting influences would shift the balance of costs. On balance, therefore, we consider our simplified analysis to be approximately accurate.

1.5 Related issues not addressed in our analysis

The focus of our incremental cost analysis is restricted to relatively 'straightforward' PVS cases in which both families and the health care team agree that withdrawal of CANH is in the best interests of the patient. We do not focus on contested situations where there is disagreement within families, or between families and health care teams about the appropriateness of CANH withdrawal, or

disagreement amongst clinicians about the PVS diagnosis. Our cost analysis includes declaratory relief for the small proportion of patients in the PVS who have made an 'Advanced Decision to Refuse Treatment' (ADRT) under the Mental Capacity Act 2005 to refuse medical treatment in the eventuality of being in the PVS. These cases still require declaratory relief to establish that the patient is indeed in a permanent vegetative state from which recovery is highly improbable and to establish the validity and applicability of the advance directive. However, our analysis does not include patients who have conferred a lasting power of attorney (LPOA) under the Mental Capacity Act 2005 to make such treatment decisions and where this surrogate decision-maker refuses consent to continued CANH. These cases also still require an application to the Court of Protection, but the legal process is shorter and so the costs would be substantially lower.

Finally, our analysis does not focus on decision making about patients in a 'minimally conscious state' ('MCS'), who have intermittent and various levels of awareness of self and environment. In contrast to patients in the PVS, the law currently offers little substantive guidance relating to the best interests of MCS patients. Whereas the Bland case set a precedent that it is not in the best interests of a PVS patient to be maintained in life by CANH, no such precedent exists in relation to MCS patients and so each case must be considered on its own merits. In *W* v *M* [2011] EWHC 2443, for example, it was held that it was in the best interests of that particular patient for her life to be maintained through CANH. Yet in *United Lincolnshire Hospitals NHS Trust* v *N* [2014] EWCOP 16, the Court of Protection declared that it was lawful and in the particular patient's best interests for her clinicians (a) not to make any further attempt to secure a means of providing artificial nutrition; and (b) to withdraw the provision of intravenous fluids.

2. Ethical Considerations

A cost analysis of this nature must be sensitive to the view that there may be areas of medical practice where economic analysis should not be undertaken. It may seem unethical to consider the financial costs of caring for profoundly vulnerable people, such as PVS patients, since this may seem to carry the ethically controversial implication that withdrawal of treatment from vulnerable patients can be justified on purely financial grounds. We do not believe our cost analysis carries any such implication, for three reasons. First, our analysis focuses on cases in which the family and treating clinicians are all in agreement that withdrawal of CANH is in the best interests of the PVS patient. Second, our analysis does not aim to inform the patient level decision about whether or not to withdraw CANH from a particular PVS patient. Rather, it aims to inform the social level decision about the appropriate legal and regulatory framework for making patient level decisions. In principle, therefore, this analysis is compatible with the principle that patient level decisions about particular PVS patients should be made in the best interests of those patients, and should not consider financial costs. Finally, costs falling on cash-limited NHS budgets are not 'purely' financial, in the sense that they also have a health opportunity cost in terms of NHS services and health benefits that could otherwise be delivered to other patients. Ultimately, therefore, financial costs to the NHS do translate into human costs – albeit human costs borne by unidentified other patients because we do not know precisely what other NHS services are foregone or who would have used them.

3. Study design

The method employed is that of an incremental 'cost analysis' rather than 'cost-benefit', 'cost effectiveness' or 'cost-utility' analysis. We focus exclusively on costs to the NHS, and do not seek to quantify the non-financial benefits and harms to PVS patients and their families. We estimate care costs based on standard NHS costings for patients with long-term neurological conditions, supplemented with our own partial 'micro-costing' of additional resource use including costs of CANH and hospital 'blue light' events. As a check, we also performed our own full 'micro-costing' of the care costs – that is, we itemised each type of resource use and multiply the volume of resource use times an appropriate unit price. We estimate legal costs by micro-costing the relevant legal costs borne by the NHS, excluding court infrastructure costs falling on the Ministry of Justice. The list of resources and estimates on the quantities of resource use in a 'typical' case forms the bedrock of our cost analysis.

3.1 Data sources

For estimating care costs, we drew heavily on previous NHS cost analyses for patients with severe and complex neurological disabilities based on the Needs and Provision Complexity Scale (NPCS) (Siegert et al. 2012, Turner-Stokes, Bill and Dredge, 2012; Turner-Stokes et al. 2013). The NPCS is a tool for measuring the needs of patients with long-term neurological conditions and estimating the cost of meeting those needs (http://www.kcl.ac.uk/lsm/research/divisions/cicelysaunders/resources/tools/npcs.aspx).

For our own 'micro-costing' study we also obtained data on the unit costs of resource use from Unit Costs of Health and Social Care 2012 (Curtis 2012). We also reviewed the judgments of all PVS cases that have gone before the Court of Protection, to help estimate the typical duration of such cases and gather information on the nature of the process. Where no evidence is available, we have also made assumptions about particular cost parameters based on information from the recently published Royal College of Physicians best practice guidance for patients with prolonged disorders of consciousness (Royal College of Physicians 2013) and consultation with medical specialists with experience of the declaratory relief process. These specialists include two neurologists with experience as expert witnesses in PVS cases held at the Court of Protection.

Published information on resource use and unit costs of legal representation and medical expert witnesses were not available, so we made assumptions following consultation with consultants, barristers and solicitors who have been involved in several PVS cases of declaratory relief. We also took Court of Protection fees from the HM Courts and Tribunals Service website at http://hmctsformfinder.justice.gov.uk/courtfinder/forms/cop044-eng.pdf

3.2 Key assumptions

Several key assumptions underpin our economic analysis. The first is that the NHS funds the application for declaratory relief. A review of relevant case law reveals that this is usually (though not always) the case. The second key assumption relates to the delay between a 'best interests' decision to withdraw CANH from a PVS patient and the declaration of that decision's lawfulness. Clearly, the actual time taken varies between cases. Only a few of the published judgments detail the timelines involved. Our costs analysis assumes that, on average, the delay is 9 months. This assumption derives from discussions with clinicians and lawyers who have considerable experience of the declaratory relief process. A recent study found that the average delay may be longer than this in other kinds of cases heard by the Court of Protection (http://sites.cardiff.ac.uk/wccop/files/2015/01/Local-Authorities-Use-of-the-CoP.pdf). However, we believe our estimate of 9 months is a more appropriate and conservative estimate for PVS cases of this highly specific kind.

The third key assumption is that, although patients in the early stages of their disorders of consciousness are likely to spend time in specialist hospital rehabilitation units, the vast majority (95%) of patients in a *permanent* vegetative state are cared for in nursing homes, with only a small proportion being cared for in family homes (5%). This assumption derives from discussions with experienced clinicians.

The fourth assumption is that legal costs are all 'fixed costs' that do not vary with the duration of the DR process.

Lastly, we assume that only two court hearings take place: one preliminary directions hearing and a final hearing.

4. Results

Figure 1 presents our estimates of the average legal and ongoing care cost to the NHS of the declaratory relief (DR) process. Medical care costs increase with time duration, whereas legal costs are fixed. Using our assumption of 9 months for the time taken between a best interests decision to withdraw CANH and the declaration of lawfulness, we estimate the average additional costs of the DR process to be about £122,000, comprising about £53,000 in fixed legal costs and about £69,000 in ongoing care costs. We have rounded these figures to the nearest thousand, to avoid giving an impression of spurious accuracy.

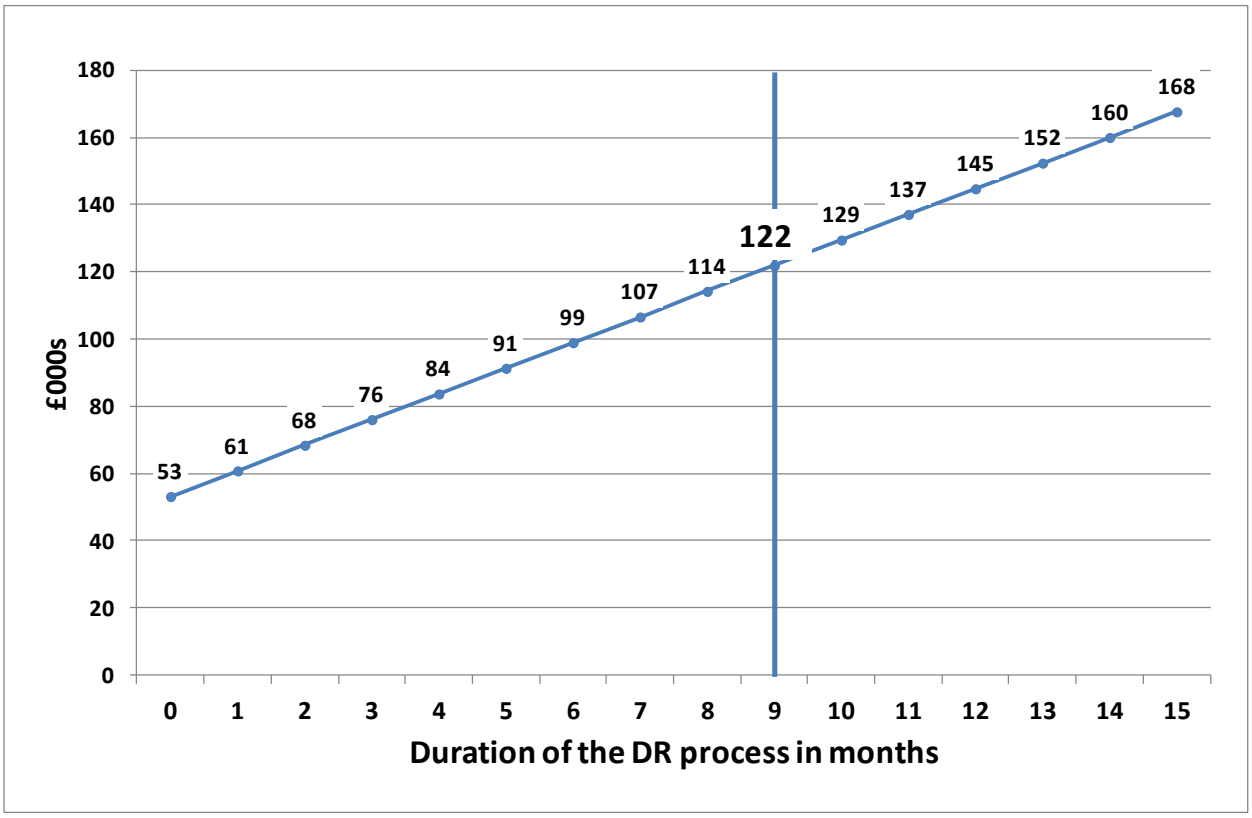

Figure 1: Total NHS costs of the DR process (£000s), including both legal costs and ongoing care costs

Note to Figure 1

1. We assume the DR process on average takes 9 months.

4.1 Ongoing care costs

Most PVS patients are cared for in specialised nursing homes, but a few are cared for in private family homes. These different care settings have slightly different costs, so to estimate an average cost for a 'typical' PVS patient we need to estimate the proportion of PVS patients treated in these different settings. As noted above, we have estimated that:

- 95% of PVS patients are in specialised nursing homes
- 5% of PVS patients are cared for at home

We assume that no PVS patients are cared for in hospital rehabilitation units. Patients are often treated in such units at early stages of their disorder of consciousness, but not at the later stages that we are considering here. Nonetheless, for completeness, we also provide estimates of the cost of care in hospital rehabilitation units below, to put the other cost estimates into context. The costs below are averages; as with any other form of health care there are of course substantial variations

in cost between individual patients due to variation in individual needs and in local provider unit prices and patterns of care.

Specialised Nursing Home: The basic average annual cost of a PVS patient in a specialised nursing home has been ascertained through NPCS costing computations as £71,656 (Siegert et al. 2013; costing algorithm page 8). However, we need to add to this a further annual cost of percutaneous endoscopic gastrostomy (PEG) feed and medication costs of £8,213 per year, plus tracheotomy costs of £5,200, bringing the total annual cost to £85,069. This is based on an expert assumption that the costs of medication and PEG amounts to £20-£25 per day; from which we have taken an average of £23 per day, and that 50% of patients require tracheotomy which costs about £200 a week.

At home: To ascertain the costs of care of a typical PVS patient at home, we examined patient level data on need level and cost based on the NPCS costing tool. We examined data on 8 PVS patients obtained from a specialised NHS trust in London, and found that the median PVS patient had an average annual cost of £116,012 over a year based on a Northwick Park Dependency Scale (NPDS) need level of 46. As a check on these estimates, we also examined data on 33 MCS patients and found they had similar need levels and costs, as would be expected. The family will bear additional out-of-pocket costs themselves, but in this study we are focusing on costs to the NHS only.

Hospital Rehabilitation Unit: A regional level hospital rehabilitation unit is the most intensive form of care available to a PVS patient. Turner Stokes and colleagues place an annual cost of a PVS patient in this context at £193,450 based on a cost per day of £530, or £146,730 in a local district level unit based on a cost per day of £402 (Turner-Stokes, Bill and Dredge, 2012).

To these costs we have also added costs to the NHS of 'blue light events' that result in a visit to hospital, such as pneumonia and urinary tract infections. These costs were based on expert opinion of one event per year (12 months) and that 1 episode would last 10 days, with a hospital treatment cost of £500 per day based on NHS Reference Costs (Department of Health, 2013). This then becomes an additional one off cost of £5,000.

Table 1 shows the medical cost of care in different settings for different durations (a year, a month and a day). The weighted averages can be interpreted as the average cost of care for a 'typical' PVS patient, with weights reflecting the estimated proportion of patients in each setting. The medical cost of a 'typical' PVS patient in England and Wales is £86,676 per year. We then add the cost of hospital 'blue light' events, on the assumption that on average all patients have one such event per year, bringing the total annual cost to £91,616.

Table 1: Ongoing PVS Care Costs Per Year, Month and Day (2011 figures)

	Cost Per Year	Cost Per Month	Cost Per Day	Weight (Proportion of Patients)
1. Specialist nursing home	85,069	7,089	233	0.95
2. At home	116,012	9,668	318	0.05
3. Weighted average of 1 and 2	86,616	7,218	237	
4. Hospital 'blue light' events	5,000	417	14	
Total cost (3 + 4)	91,616	7,635	251	

Finally, as a robustness check and to help understand the individual components of the cost of care, we also performed our own independent 'micro-costing' of the costs of care for a PVS patient treated at home (details available from the authors on request). By far the largest element of cost is the cost of care assistant staff to provide continuous round-the-clock care, which comprises just over 80% of the cost. The average cost per year from this analysis was £122,683 which is 5% more than the NPCS based estimate of £116,012. However, we use the costs from the NPCS tool, as this official NHS costing tool is based on a more thoroughly validated set of underpinning resource use and unit cost estimates and hence is likely to be more accurate than our own estimate.

4.2 Legal costs

We focus on the out-of-pocket legal fees paid by the applicant, which is usually the NHS. We exclude legal infrastructure costs borne by the Court of Protection and the Ministry of Justice, such as staffing and facilities costs for judges and other court officials. We assume the legal DR process in a relatively 'straightforward' case involves two hearings: a preliminary directions hearing and a final hearing. In some cases things may initially seem straightforward but then later become contested, for example if the consultant acting for the official solicitor raises unexpected concerns about the PVS diagnosis requiring further medical assessment and a third hearing. Since this only happens in a small proportion of cases, however, this would not substantially increase our average cost estimates and so to keep things simple and conservative we do not explicitly cost out this scenario.

Table 2 shows the total legal costs of the declaratory relief process to the NHS. The largest item of legal cost to the NHS, making up more than 80% of the cost, is the legal representation fees. This includes 100% of the fees for the barristers and solicitors acting for the applicant (usually an NHS body) and by convention the NHS also pays 50% of the fees for the barristers and solicitors acting for the Official Solicitor (acting as the 'litigation friend' of the patient). The solicitors' fees include pre-meetings and preparation, instruction of experts and counsel, writing and responding to correspondence, and preparing the application, as well as attending both hearings.

The second largest cost driver is the cost of medical staff time in preparing their medical expert witness reports and, in the case of the third opinion, attending court. We assume that the court requires three written medical witness reports, from (1) the treating consultant, (2) a senior consultant providing a second opinion, and (3) a senior consultant acting for the Official Solicitor to provide a 'third opinion'. Conservatively, we also assume that only one medical witness is required to attend the hearing to give verbal evidence. We estimate that each report requires 9 hours of consultant time, including reading through the bundle of documentation (usually 4 or 5 lever arch files), interviewing staff and family members, and examining the patient, plus further time to write a detailed report. This includes an allowance for travelling, administration and the possibility that report writing takes longer than expected; all of which will depend upon the distances travelled and the complexity of the case, including how far the witness is coming in 'cold' or is already familiar with the case. We estimate that attending court requires 12 hours of senior consultant time, including pre-meetings to prepare for the hearing as well as travel and administration, and a small additional time allowance for the risk that further hearings are required or that more than one medical witness is required to attend. Conservatively, we cost consultant time at NHS service rates of £155 per hour for the treating consultant and £195 for the senior consultants, rather than at higher commercial rates. This is because our focus is on the opportunity cost to the NHS in terms of consultant time taken away from other NHS activities. We do not include the cost of a full *de novo* assessment of the PVS diagnosis, such as a SMART assessment, since we assume this has already been undertaken during the medical best interests decision making process prior to the legal DR process being initiated.

Finally, we have included standard Court of Protection fees of £900, payable by the applicant.

Table 2: Legal costs to the NHS of the DR process

General cost category	Sub-category	Cost	
		£	% Total
A. Legal Representation costs	Total	**45,000**	85
	Plaintiff barrister's fee	15,000	28
	Plaintiff solicitor's fee	15,000	28
	50% of barrister's fee for Official Solicitor	7,500	14
	50% of solicitor's fee for Official Solicitor	7,500	14
B. Medical witness costs	Total	**7,245**	14
	Treating consultant report	1,395	3
	Second opinion report	1,755	3
	Third opinion report (Official Solicitor)	1,755	3
	One witness prepare and attend court	2,340	4
C. Court of Protection costs	Total	**900**	2
	Application fee	400	1
	Hearing fee	500	1
Total		**53,145**	100

5. Discussion

We have estimated that the declaratory relief process lasts, on average, nine months and costs the NHS about £122,000 per case, comprising about £53,000 in fixed legal costs and about £69,000 in ongoing care costs which we estimate on average cost £7,635 per month or £251 per day. We have not included court infrastructure costs in these estimates, such as the cost of courtroom facilities and judge time, which fall on the Ministry of Justice rather than the NHS.

There is a degree of uncertainty around this average cost estimate. One source of uncertainty is variation in the unit cost of care in different institutions and the fees charged by different barristers and solicitors. However, the main source of uncertainty is the duration of the average case. Our estimate of nine months is based on review of the duration of past cases and discussions with barristers and consultants involved in past cases. From these discussions, the main sources of delay appeared to be the scheduling of dates for hearings and the time taken for the medical third opinion to complete their assessment on behalf of the official solicitor, in the context of a national shortage of experienced medical consultants capable of undertaking this specialised and time-consuming task. In the absence of these delays, we estimate that the fastest a case could realistically be processed is three months. If so, that would imply a cost of £76,000 comprising the same £53,000 in fixed legal costs and about £23,000 in ongoing care costs for the three month period.

From a national perspective, the potential total savings from abolishing the declaratory relief requirement in relatively 'straightforward' cases where clinicians and families agree about withdrawal of CANH are very small. Although we do not know exactly how many of such cases have come before the Court of Protection, it has recently been estimated that there has been a little more than 100 cases in the 20 years or so since the Bland case (Kitzinger and Kitzinger, 2015). Some of these cases have involved disputes between families and clinicians, or disagreements about diagnosis. The number of uncontested cases reaching court every year is therefore fairly low, and the total savings to the NHS would be vanishingly small relative to its annual budget, which in 2012/2013 was £105 billion (NHS Confederation 2014).

Nevertheless, each case of legal declaratory relief in the relatively 'straightforward' cases on which we focus clearly imposes a non-negligible opportunity cost on the NHS in terms of other beneficial NHS services that could have been provided using those resources. The NHS exists for the benefit of patients. Costs to the NHS are, ultimately, human costs to individual patients in terms of their health care. It may be appropriate, then, to frame the costs of the declaratory relief process in terms of the standard metric of health benefit that the NHS uses to assess such opportunity costs – the quality-adjusted life year ('QALY'), which represents a year of life in full health. The best available evidence suggests that, on average, every £13,000 (approximately) of reduction in NHS expenditure causes the loss of one QALY (Claxton et al, 2013). This estimate is based on econometric analysis of data on local NHS expenditure and health outcomes. Based on this estimate, we can estimate that each declaratory relief application (in straightforward cases) takes over 9 years of life (quality-adjusted) from other patients. The calculation is simple: the cost of £122,000 is divided by the cost per QALY value of £13,000 to yield 9.4 QALYs foregone.

Alternative ways of translating between financial costs and QALY outcomes, based on different conceptual foundations, generally yield higher cost per QALY values. First, the officially declared National Institute for Health and Care Excellence (NICE) threshold value for considering a technology to be cost-effective is £20,000 per QALY (NICE 2013). Second, analysis of past NICE decisions suggests that the 'revealed' threshold value of a QALY applied by NICE is more like £40,000 per QALY (Dakin et al. 2014). Third, the consumption value of a QALY used by the Department of Health to value health benefits when appraising 'inter-sectoral' public policies with costs falling outside the

NHS budget is £60,000 per QALY (Glover and Henderson 2010, para 5.21). This third approach is not appropriate in our case, since we are only assessing the costs of declaratory relief that do fall on NHS budgets. The cost per QALY values associated with NICE could be considered appropriate if the idea were to apply the same cost-effectiveness test to declaratory relief as is applied by NICE to other forms of NHS activity. Using the 'official' NICE threshold value of £20,000 implies that each declaratory relief decision would need to deliver a health benefit of 6.1 years of life in full health in order to be considered cost-effective by NICE. Alternatively, using the 'revealed' threshold value of £40,000 implies that each declaratory relief decision would need to deliver a health benefit of 3.1 years of life in full health in order to be considered cost-effective. We do not attempt to perform a cost-effectiveness analysis, however, as the appropriate 'quality adjustment' to apply to gains and losses of life in a PVS health state is controversial and data on public views are limited.

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