How many patients in a prolonged disorder of consciousness might need a best interests meeting about starting or continuing gastrostomy feeding?

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Abstract.

Objective: To estimate the number of people in a prolonged disorder of consciousness (PDOC) who may need a formal best interests decision-making process to consider starting and/or continuing life-sustaining treatment each year in the population of a developed country.

Method: Identification of studies on people with a prolonged disorder of consciousness giving information about incidence, and/or prevalence, and/or cause ,and/or location of long-term care. Sources included systematic reviews, a new search of Medline (April 2018), and a personal collection of papers. Validating information was sought from existing data on services.

Results: There are few epidemiologically sound studies, most having bias and/or missing information. The best estimate of incidence of PDOC due to acute-onset disease is 2.6/100,000/year; the best estimate of prevalence is between 2.0 and 5.0/100,000. There is evidence that prevalence in the Netherlands is about 10% of that in other countries. The commonest documented causes are cerebral hypoxia, stroke, traumatic brain injury, and tumours. There is some evidence suggesting that dementia is a common cause, but PDOC due to progressive disorders has not been studied systematically. Most people receive long-term in nursing homes, but a significant proportion (10%-15%) may be cared for at home.

Conclusion: Each year about 5/100,000 people will enter a prolonged state of unconsciousness from acute onset and progressive brain damage; and at any one time there may be 5/100,000 people in that state. However, the evidence is very limited in quality and quantity. The numbers may be greater.

Introduction.

"*If we develop a policy for making best interests decisions about starting or continuing gastrostomy feeding in people with a prolonged disorder of consciousness, how many patients should we expect to see within this policy each year?*" This simple question has arisen in the context of developing such a policy in England and Wales. This article sets out the available evidence to give an approximate, 'good enough' estimate, which should help ensure that proposal proposed are feasible.

Decisions about starting, continuing and stopping life-sustaining treatments, especially gastrostomy feeding, in people with a prolonged disorder of consciousness are controversial [1][2][3][4] and strong views are held. [5][6] While many people say that personally they would not want treatment continued, they are nevertheless less likely to support stopping treatment for others. [7][8]

A person's attitude to limiting life-sustaining treatment is influenced by religious beliefs and other cultural factors. [8][9] Different intensive care units within one US state and system have different approaches, [10] and different countries have different approaches. [3][8][11][12] To ensure a more consistent approach, many countries are now developing policies in accordance with evidence and, often, within an ethical and/or legal framework. This includes policies for people with a prolonged disorder of consciousness. [13]

In England and Wales, legal [14][15] and clinical guidance [16] has led to an expectation that a court needs to review all decisions about life-sustaining treatments in people with a prolonged

disorder of consciousness, especially withdrawal of clinically assisted nutrition and hydration (gastrostomy feeding). Recent guidance may reduce the use of the court. [17]

Policies on people with a prolonged disorder of consciousness need to balance practical considerations, including resources used, against ensuring that the process both is and is seen to be sound and fair, and open to review. The main determinant of the feasibility and cost of a policy is the number of people likely to fall within the remit of a policy. This article estimates the number of patients likely to be affected by a policy in England and Wales. The figures are likely to be similar in most developed countries.

Context in England and Wales.

The first UK clinical guidance was published in 1993, [18] and the case of Tony Bland generated the first legal guidance [14]. By 1996 the difficulty in determining complete unawareness (i.e. the so-called vegetative state) was recognised [19], in 2002 the minimally conscious state was defined, [20] and in 2003 further clinical guidance emerged. [21] Practice Direction 9E [15] updated English legal guidance in 2014, but was withdrawn in December 2017. These two clinical syndromes - vegetative state and minimally conscious state - are now referred to collectively as a prolonged disorder of consciousness (PDOC) [16].

In England and Wales, there is an urgent need to review both the legal and clinical guidance in relation to people in a state of a prolonged disorder of consciousness. This need arises from:

- the lack of any clear boundary between the vegetative state and the minimally conscious state; [19][22] the original legal position [14] was predicated on the unique features of being definitively unaware, but this distinction is invalid.
- the difficulty in giving a definitive, 100% certain prognosis [22][23]

- the enactment of the Mental Capacity Act 2005,[24] which changed the legal emphasis from deciding whether a treatment was futile [14] to considering whether treatment was in a person's best interests
- the acceptance, in English law, that best interests are not synonymous with survival or with length of life [24]
- the realisation that people with progressive disorders may also enter a prolonged disorder of consciousness, well known in 1994 [25][26] but overlooked
- an increasing clinical wariness about making decisions in this situation, leading to prolonged delays [27].

Routine health service data in the UK do not give dependable information on the number of people with prolonged disorders of consciousness. This follows on from:

- the wide distribution of patients in a prolonged state of unconsciousness
    - in many different settings, especially nursing homes
    - under the care of many different clinical teams initially, with general practitioners (family doctors) likely to be the lead doctor in over 80% of cases in the long-term
- the lack of any person, team, or organisation with specific responsibility for
    - clinical care and decisions beyond the first few weeks or months
    - financing care and, especially, for any legal process or clinical process associated with making best interests decisions
- a general failure of health information systems to identify and record any consequences of illness, excepting death.

This paper has focused on identifying evidence that:

- relates to people who have a disorder of consciousness that exceeds seven days [23][28]
- allows an estimate of the:
    - incidence, number of new cases each year and/or
    - prevalence, the number of cases in a defined population and/or
    - underlying causes of the clinical state and/or
    - different care-setting people may be in.

Method.

Studies relating to people in a prolonged disorder of consciousness (vegetative state, minimally conscious state) were identified in several ways:

1. Although it was not a formal systematic review, the seminal early paper on all aspects of the Vegetative State [25] reviewed papers up to 1993-94 and references within the section on epidemiology were looked at.
2. Reviews and systematic reviews were found by a search on Medline, and the individual studies within these were then looked at.
3. An independent search of Medline was also undertaken (Appendix 1).
4. Last, I have collected papers on people with a prolonged disorder of conscious over many years, and other papers were found in this collection.

The studies selected were read to extract data relevant to estimating:

- prevalence (the number present in a given population at a specific time);
- incidence (the number of new cases arising within a defined population over a set time);
- diseases causing the disorder;
- location of long-term care.

Where possible, information on whether the state was secondary to an acute onset episode of brain damage or a progressive disease was extracted.

Appendix one shows the search strategies, and also lists all the papers used to show their origin within these processes. In addition, appendix one includes some unpublished information arising from a Freedom of Information request to the 213 clinical commissioning groups covering England in 2016, asking them to report how many people with a prolonged disorder of consciousness were being funded by the continuing healthcare fund; this is a fund that pays all care costs for eligible patients and people with an acute-onset prolonged disorder of consciousness should always receive this funding. [16], The data were used as a rough check on the validity of the estimated figures.

Appendix one

Results.

Table one shows the five review papers found: the first published in 1994, [25] two published in 2014 [29][30], a systematic review restricted to head injury [31] and a narrative review [32]. These reviews reveal how few primary studies there are, especially of incidence, and how low the quality of most studies is. Studies from the Netherlands all emphasise the low prevalence there (0.2/100,000), attributed to their particular clinical practice [11][12].

Table one

Table two shows 16 individual studies which had a primary focus on disturbed consciousness (rather than on a specific cause of brain damage). It includes four recent studies not included in the other reviews. Table three shows information about studies that focused on specific diseases causing a prolonged disorder of consciousness.

Table two

Table three

Incidence.

No studies examining the incidence arising from congenital or progressive causes were identified. Only three studies allow any estimate of incidence arising from all causes [33][41][47], and one is methodologically too weak to be dependable [41]. The strongest study [47] suggests an incidence of new patients with an acute onset prolonged disorder of consciousness at four weeks after onset of 2.6/100,000/year.

Studies on populations of people with traumatic brain injury suggest an incidence of 0.29 – 0.7/100,000/year at four weeks from this cause, and that between 3% and 7% of all incident cases of severe brain injury are in a prolonged disorder of consciousness at six months. [31][48]

Prevalence.

Excluding studies from the Netherlands, the estimates of prevalence vary between 1.7 – 86.9/100,000. The one very high estimate [46] came from a study that found that 63% of people in the vegetative state were aged over 80 years and 65% had cerebrovascular disease. The remaining estimates are under 5.0/100,000. The reports give insufficient information about cause to determine how inclusive the samples were, but few studies record any people with progressive disease. Appendix one shows the data from the Clinical Commissioning Groups in England, relating as far as is known to people with acute onset conditions. The data are poor, but one interpretation is that the prevalence of people with a prolonged disorder of consciousness being funded by the National Health Service is around 3.0/100,000.

Data relating to specific conditions.

The multi-society task force clearly listed the great variety of causes of a prolonged disorder of consciousness, [25] classifying them into three groups: acute brain injuries, degenerative and metabolic disorders, and developmental malformations.

The studies in table two illustrate the range of conditions associated with a prolonged disorder of consciousness. Among the acute conditions, the common conditions include cerebral hypoxia [26][37][45][47] and stroke [36][38][40]; traumatic brain damage accounts for a minority of cases in most studies. [54] Other conditions of uncertain frequency include brain tumours [33][34] and subarachnoid haemorrhage [51].

The importance of progressive and chronic conditions was known in 1991 [26], and has been confirmed in those studies likely to identify progressive disorders [40]. Specific conditions identified occasionally include developmental disorders [34], Parkinson's Disease [40] and dementia [40], with several studies reporting a range of other 'miscellaneous' diagnoses. Cases before the courts in England have also involved people with multiple sclerosis [55] and Huntington's disease [56]. Prolonged disorders of consciousness are most common in the elderly [38][46] and in one study the mean age was 78 years [40].

Care setting.

Almost all studies have concentrated upon hospitals and nursing homes, but the evidence shows that patients may be at home in the community [36]; in one study from Italy, 58/345 (17%) people were at home in the long-term [44]. About 10% of cases in England funded by continuing healthcare were at home (Appendix one).

Discussion.

This review has demonstrated how little dependable and clinically useful published data there are about patients with prolonged disorders of consciousness, either in relation to epidemiologically-sound, descriptive matters or in relation to more practical matters such as service development and delivery.

Several factors limit the accuracy of the information presented here. Identifying relevant studies is difficult because there are no agreed specific terms for the clinical condition. In addition to the terms commonly used in England - vegetative state, minimally conscious state and prolonged disorder of consciousness - papers may use many other specific terms, such as apallic syndrome, low awareness state, and unresponsive wakefulness syndrome. Reassuringly, although a review using a much greater range of search terms in 2013 did find more studies [30], most were of low quality and the estimates were similar to those presented here. The simple search used in this review found several new studies, most published after the two more detailed systematic reviews. [29][30] It is unlikely that an existing but unidentified study will significantly alter the estimates given here.

Many of the reviewed studies suffer from weak methodology and/or poor description. The methods of case ascertainment are rarely well described and are usually weak. The basis for making a diagnosis is rarely well described. Operational definitions for the vegetative state and the minimally conscious state, or for prolonged, persistent or permanent disorders are rarely specified and may differ between studies. Trying to distinguish differences between different categories of people within the spectrum of prolonged disorder of consciousness would not be possible on the basis of any published studies.

The population at risk is often not specified or easily identified. Most studies are restricted in their scope, considering only patients selected by diagnosis, severity or other factors and/or only recruiting from selected settings. Furthermore, terms such as incidence and prevalence are used loosely and often incorrectly; they may also not be used when it would be appropriate to use them.

Bias may arise not only from the methodological weaknesses given above, but also from pre-existing, often unstated or unrecognised assumptions. For example some people assume that the term, vegetative state, only applies to people who have an acute onset brain damage. Indeed, much of the research has focused on traumatic brain injury, and many clinicians only think of head injury when discussing the problem.

The almost complete absence of any published research concerning people with, for example, multiple sclerosis, Huntington's disease, Alzheimer's disease and other disorders probably reflects this bias. It is common experience that patients in the later stages of diseases such as Huntington's disease, multiple sclerosis and Parkinson's disease may enter a state of prolonged disorder of consciousness, sometimes remaining alive in that state for many years.

The one outlier study suggesting a prevalence of 87/100,000 [46] is notable for the large proportion of people aged over 80 years and the large proportion of people with stroke. While this could be secondary to a fault in the study, it is more likely that the research recruited from a population not normally considered. A high proportion of people with a prolonged disorder of consciousness was also found in the other study that specifically investigated older people. [40] Most studies have shown stroke to be common cause, [25][35][37][39] and stroke incidence increases with age. There is some evidence in support of this observed high rate. About 20% of

all nursing home residents have had a stroke. [58] Further, about 5% of nursing home residents receive gastrostomy feeding, [59] and it seems likely that a significant proportion of these have a prolonged disorder of consciousness secondary to stroke and/or dementia.

It therefore seems probable that the estimates of incidence and prevalence derived from the studies will be underestimates, probably quite significant underestimates, for the reasons detailed above:

- failure to include the whole population in most studies, **and**
- failure to consider and identify patients with a prolonged disorder of consciousness from **all causes**, in **all settings**, and of **all ages**.

The implications of the findings for any policy on making best interests decisions about life-sustaining treatment in patients who have a prolonged disorder of consciousness will now be considered; the process itself is discussed elsewhere. [23]

How many people enter a prolonged disorder of consciousness each year, surviving sufficiently long to require formal consideration of their best interests?

The best study available [47] suggests a figure of 2.6/100,000/year, but this will be an underestimate. It did not include people with progressive disorders, and the absence of any people with damage from tumours, infection, and other rare causes suggest that the recruitment may have been incomplete.

One way to check the validity of any epidemiological data is to compare it with data collected routinely in healthcare systems. Unfortunately, there is virtually no relevant routine health service data, which probably reflects a general lack of interest in people with severe disability

requiring long-term support. Despite a recommendation that England and Wales should start registering all people entering a prolonged disorder of consciousness [16], there has been no action over four years. Some available data is considered below, including the data in Appendix one.

The UK Rehabilitation Outcomes Collaborative (UKROC) [57] did record the admission of 250 people with a prolonged disorder of consciousness to specialist rehabilitation centres in 2016; the number is increasing by 15% each year (Lynne Turner-Stokes; personal communication). Using an incidence of 2.5/100,000/year applied to the population of England and Wales (58 million) gives an annual incidence of 1450, and 250 represents 17%. This seems a high proportion of all acute cases, given that significant areas of England and Wales lack centres, and most units have more people referred than can be admitted. Therefore the true incidence may be higher, and is unlikely to be lower.

A second source of information might also help. In the UK, all people who lack mental capacity to make healthcare decisions about accommodation may be made subject to a Deprivation of Liberty Safeguarding order; most people subjected to this order will also lack capacity to make any complex healthcare decisions. In England, in 2014-2015, the rate of accepted applications for Deprivation of Liberty Safeguarding certificates was 122/100,000/year [60]. The rate in 2013-14, when regulations were less all-encompassing, was approximately 7/100,000/year. A significant proportion of these applications will relate to people with progressive disorders and, although obviously not all subjects will have a prolonged disorder of consciousness, a significant proportion will be in a state of reduced awareness.

Assuming that the best evidence on incidence [47] is nonetheless an underestimate of the acute onset incidence, and assuming that the **incidence** of people entering a prolonged disorder of consciousness from a progressive cause is at least 2.5/100,000/year (given the probable high prevalence), it would seem reasonable to plan on the basis of 5/100,000/year entering a prolonged disorder of consciousness; this does not include patients obviously in the end-of-life phase of an illness. It would also seem sensible to assume that over the first 12 months, in patients remaining alive, a further two meetings (at a minimum) should occur.

How many people are there in the population with a prolonged disorder of consciousness?

The best estimate from research data is between 2 – 5/100,000. This is almost certainly an underestimate. As reported in the appendix, a Freedom of Information request was made to the 213 clinical commissioning groups covering England in 2016, asking them to report how many people with a prolonged disorder of consciousness were being funded by the continuing healthcare fund. Only 45 (21%) commissioners replied, and generally the quality of the information provided was very low. The prevalence rate for this selected subset of patients was between 1.7 and 3.85/100,000.

Thus planning on the basis of a prevalence of 5/100,000 is reasonably conservative, taking into account the observed high rates of prolonged unconsciousness in the elderly [40][46]. A yearly review seems reasonable, after the first year.

A policy also need to recognise that, although the great majority of people in a prolonged disorder of consciousness are in nursing homes, an unknown but significant proportion of people live in their own homes; 10% would be a reasonable estimate. In England and Wales, both patients in nursing homes and patients at home are under the care of their general

practitioner (family doctor). Therefore, any policy must recognise that patients will rarely be in a specialist hospital or rehabilitation setting beyond the first few weeks or months , and that general practitioners must play a central role in ensuring high quality management.

Given that general practitioners are already overwhelmed with responsibilities transferred to them from hospital services, and that they will have very little experience of people with a prolonged disorder of consciousness, the commissioners will need to commission a specialist service to assess and manage all patients with a prolonged disorder of consciousness in the community; this would best be provided by a neurological rehabilitation service. The role of the General Practitioner will be to identify any patient with a prolonged disorder of consciousness and to notify them to the responsible specialist rehabilitation service, who should keep a register so that yearly reviews are not forgotten.

Last, the policy must consider that most people with a prolonged disorder of consciousness, if asked, would have said beforehand that they would want treatment stopped; only 14% - 22% of the general public would definitely **not** want treatment stopped in in the vegetative or minimally conscious state [7]. In a population of healthcare professionals, only around 15% - 25% would want to be kept alive if in a vegetative or minimally conscious state [8]. The reasons likely to underlie these attitudes include a prioritisation of autonomy, dignity, fair use of scarce resources, and freedom from distress and pain above remaining alive. [7][61]

Thus, planning should occur on the basis that at least 80% of cases will require a serious consideration of treatment withdrawal. No assumptions about the likely decision should be made prior to holding the decision making meeting; in other words, a uniform policy should apply to every meeting.

Thus, if one assumes

- a population of 58 million in England and Wales,
- a minimum incidence of prolonged disorders of consciousness of 5/100,000/year from all causes
    - with an average of three meetings over the first 12 months after onset
- a minimum prevalence of 5/100,000,
- that everyone should have treatment limitations and withdrawal considered, and
- that every prevalent case should have a yearly review,

then one reaches the following estimates:

- 2,900 new cases a year needing an initial best interests meeting with:
    - about 5,000 further meetings over the next 12 months (allowing for deaths)
    - about 2,300 of the 2,900 cases being considered for treatment limitation
- 2,900 additional long-term cases needing a yearly review, of whom
    - about 2,300 will be considered for treatment limitation when first reviewed

Converting this to a population of 500,000, which is approximately the population considered in relation to hospital services, then the commissioners will need to fund specialist services to provide support to about:

- 50 initial best interest meetings on people entering a prolonged disorder of consciousness, on an ongoing basis each year:
    - 25 will be on people with acute onset brain damage
    - 25 will be on people with a progressive brain damage
- 45 – 70 follow-up best interest meetings a year

They should fund all at a level that allows a full and confident assessment of all aspects of each case [23], so that decisions can be made without need for further delay. They should also fund, through continuing healthcare funding, the long-term care for 25 people at about £100,000 per year. This equates to £2.5M/year/500,000, or £290,000,000 per year for England and Wales.

Clinical Messages:

- There is no dependable research into the clinical epidemiology of people with a prolonged disorder of consciousness;
- The best estimates are an incidence of 5/100,000/year, and a prevalence in most countries (excepting the Netherlands) of 5/100,000;
- The estimates are subject to considerable uncertainty, and are likely to be low.

Competing interests:

I am sometimes asked to undertake clinical assessments on people in a prolonged disorder of consciousness for medico-legal purposes, and sometimes I am paid for this. I am also asked to speak about the topic, though usually unpaid.

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Table one

Reviews of incidence and/or prevalence of prolonged disorders of consciousness.

Authors, publication date, [reference]	**Method**	**Results and/or conclusion**	**Comment**
Multi-society task force on PVS, 1994. [25]	**Stated:** "*including a comprehensive review of all Medline references to the terms 'vegetative state' and 'persistent vegetative state'* and other sources. The reference list is extensive, with many different types of literature.	"*According to estimates, however, in the United States there are 10,000 to 25,000 adults and 4,000 to 10,000 children in the persistent vegetative state"*. Population of US was 263M. which gives an estimated prevalence for adults of 4-10/100,000	19 references given. From the titles, few seem to provide primary data. Nonetheless probably captured all available data at the time.
Beaumont & Kenealy, 2005. [32]	**Narrative** review. No specified search strategy. Reviews other reviews and data. Covered both	Conclude that epidemiological data are of poor quality and likely to be biased. Vegetative state: incidence 0.5 – 2.5/100,000/year, prevalence 4 –	Most sources are book chapters or opinion reviews; little original data referenced.

	vegetative state and minimally conscious state.	17/100,000. Minimally conscious state: were unable to estimate.	
Pisa et al, 2014. [29]	**Systematic** review. Prevalence of both vegetative state and minimally conscious state. Studies 1966-2012. Also considered study methodology.	Only **five** cross-sectional studies on defined population. Eight "*reviews or studies*" excluded as not on a defined population. Vegetative state prevalence 0.2 – 3.4/100,000. Only one study of minimally conscious state; 1.5/100,000. Non-traumatic cause in 46%-88%	Demonstrates very poor quality of the primary evidence. Not stated whether any age restrictions or diagnostic limits.
Van Erp et al, 2014. [30]	**Systematic** review. Prevalence of vegetative state.	**Fourteen** studies included. Reporting of methodology in most studies poor with major uncertainties. Terms not used correctly or used inconsistently. Figures varied from 0.2 to 6.1 / 100,000 population. Not clear if limited to acute conditions.	Demonstrates very poor quality of the primary evidence.

Tang et al, 2017. [31]	**Systematic** review. Prevalence of 'persistent vegetative state' in people at six months after traumatic brain injury, with focus on change in rate over several decades.	**Twenty-one** cohort studies (in 20 papers). No systematic change in prevalence between 1975 and 2009. Prevalence of vegetative state six months after trauma at 2.8% of cohort studied, but varied from 0.5% to 7.3%	Interpretation difficult: nature of inception cohort unclear and age range included in each study not stated.

Table two

Studies focused on disordered consciousness.

Author, year, country, reference no.	Method	Results	Comment
Kodama and Suziki, 1976. Japan. [33]	Survey of Japanese neurosurgical units (90% response) 1973, 74, 75. Also figures from Miyagi prefecture (pop approx. 2M)	End 1975: 494 survivors (trauma, stroke and brain tumour were main causes). Nationally 243 and in Miyagi 37 new cases over 2 years.	**Incidence** 1.8/100,000/year; estimated **prevalence** (Japanese pop 113M) 0.45 / 100,000. Diagnosis not checked; number missed not estimated
Higashi et al, 1977, Japan. [34]	'Simple inquiries' in 269 hospitals in 16 prefectures, all examined. Relatively complete ascertainment Yamaguchi prefecture (pop 1.5M)	110 cases in total (37 in Yamaguchi): trauma 38, stroke 21, developmental 14, anoxia 12, tumour 10, inflammatory disorder 7, other 8	**Prevalence** (incorrectly labelled incidence in paper) of 2.5/100,000. Only cases in hospital.

Sato et al, 1978 Japan. [35]	Postal survey, and administrative data to identify patients; questionnaire on clinical data; population of 11.6M	219 patients identified. Causes: cerebrovascular 128, head trauma 53, tumour 12, others 26. All ages.	**Prevalence** = 1.9/100,000; only patients in hospital settings. Response rate 65%-87%; therefore an under-estimate.
Tresch et al, 1991. United States. [26]	Survey of 1611 residents of four **nursing homes**. Identified patients assessed.	Sixty-two considered in prolonged disorder of consciousness; 51 in permanent vegetative state: stroke (n = 17), dementia (n = 14), cerebral anoxia (n = 10), brain trauma (n = 7), other (n = 4). Ages 19 – 96 years, mean age 64 years	About 4% of residents in nursing homes. Emphasises range of underlying medical diagnoses
Wilson et al, 2002. Northern Ireland. [36]	Retrospective review of cases seen in specialist centre and survey of neuroscience and rehabilitation senior doctors. Population covered = 1.7M (2001)	Thirty-five cases of prolonged disorder of consciousness identified. Locations: home = 2, acute hospital = 6, care home = 6, NHS long-term care home = 6	Estimated **prevalence** of prolonged disorder of consciousness = 2.1 / 100,000. Highlights wide range of causes, and occurrence of care at home.

		Unknown = 15. Eight separate diagnostic causes, only two were trauma.	Identification likely to have been incomplete and biased
Stepan et al, 2004 Vienna, Austria. [37]	Survey on 28-Nov-2001 of all hospitals and nursing homes in Vienna (pop 1.6M); limited prevalence to patients living in Vienna.	78 patients identified (including 7 at home). 36 considered 'full apallic syndrome'. 32 residents of Vienna in apallic state identified, 25 having non-traumatic cases.	**Prevalence** in nursing homes or hospital = 1.9/100,000. Report unclear on exact 'loss' of patients from 78 to 32.
Lavrijsen et al, 2005. The Netherlands. [38]	Cross-sectional survey of all Dutch **nursing homes**. Initial postal contact; detailed data collected by phone; examination of uncertain cases. September 2003	Thirty-two patients in vegetative state more than four weeks. 8 aged 61-80 years, 4 aged over 80 years. Causes: stroke (n = 14), trauma (n = 8), anoxia (n = 7), other (n = 1)	**Prevalence** in nursing homes of 0.2/100,000. Low prevalence attributed to cultural and legal context in the Netherlands. [25]
Stephan et al, 2006. Vienna, Austria. [39]	Postal questionnaire with follow-up examination of all Viennese hospitals and nursing homes.	28 people with Apallic syndrome (vegetative state) identified on 27-Nov-2003.	**Prevalence** in hospitals and nursing homes = 1.7/100,000 (not significantly changed from 2001)

Jaul & Calderon Margalit, 2007. Israel. [40]	Cohort study on elderly patients admitted to a **Skilled Geriatric Department** with skin pressure ulcers, nasogastric tube feeding, tracheostomy, haemodialysis, or cancer. Diagnosed on Disability Rating Scale.	Eighty-eight admissions; 31 (35%) were in permanent vegetative state. Mean age 78 years. Diagnoses: Alzheimer' disease, 11; stroke, 10; Parkinson's disease, 5, 'acute', 5. Twenty-five had Glasgow Coma Score of 9 or less	Demonstrates high frequency of vegetative state/minimally conscious state in elderly population admitted to hospital (or nursing homes) for long-term nursing care.
Beis et al, 2009. France. [41]	Retrospective review of admissions in prolonged disorder of consciousness to a **specialist unit** in Lorraine, 1988-2006.	47 patients. 5-15 request/year (2.4 admitted per year). 41 from Lorraine (pop. 2.1M) = **incidence** approximately 0.1/100,000/year	Paper does not define population, nor total number referred and their status; minimum estimate. Half due to trauma. Not a dependable estimate.
Saout et al, 2010. France. [42]	Survey with examination of all people with a prolonged disorder	13 patients (4 PVS, 9 MCS); 6 months to 15 years post-onset. All	Well described, well conducted study. Clinical and care data.

	of consciousness in all settings in a population of 800,000.	had severe spasticity and contractures	Gave relative frequency of MCS and PVS.; **prevalence** 1.8/100,000
Donis & Kräftner, 2011 Austria. [43]	Postal and then telephone survey of 889 long-term care facilities in Austria 2007-2009.	269 people in vegetative state and 120 people in minimally conscious state identified.	**Prevalence** = 3.37/100,000 for VS and 1.5/100,000 for MCS. No examination or validation
Giovannetti et al, 2013. Italy. [44]	Carers of people with PDOC recruited by 'snowball methodology' from 78 centres in Italy covering 16/20 Regions. Data from patients used here.	The data from the 487 patients showed: 345/487 patients over one year from onset; in long-term group, 58/345 at home. 147 were minimally conscious, 340 were in vegetative state	After one year of PDOC, 58/345 (17%) are at home. Also gives relative frequency of PVS (340) & MCS (147)
Van Erp et al, 2015. The Netherlands. [45]	National survey of all hospitals, nursing homes, and senior doctors in relevant specialities. All identified patients examined. Concerned people unconscious	Fifty-three reported; 46 gave permission; 2 recovered before seen. Of 44, 40 in prolonged disorder of consciousness: 24 in vegetative state, 20 for over one	**Prevalence** of prolonged disorder of consciousness = 0.24 / 100,000. **Note**: most patients have support withdrawn in the Netherlands.[25]

	four or more weeks after acute-onset condition. Population = 16.7 M in 2012	year; 16 in minimally conscious state. Of patients in VS: 8 traumatic, 11 hypoxic, 5 other causes	
Shimamura et al, 2015 Japan. [46]	Questionnaires to 682 'medical institutions in Aomori prefecture (pop 1.4M); replies from 217 (32%).	381 men and 817 women identified. 63% were aged over 80 years; cerebrovascular disease most common cause (64%)	Abstract states calculated **prevalence** of 86.9/100,000. **Note**: limited abstract, only 30% response rate, paper in Japanese
Pichler & Fazekas, 2016, State of Styria, Austria. [47]	Prospective, cohort study from ITU, neuro-sciences and rehabilitation settings. 2011-12. Assessed at four weeks. Diagnosis of prolonged disorder of consciousness. Population = 1.01M	Thirty patients at 4 weeks; 5 died before examination; 25 confirmed (19 VS, 6 MCS). Causes: hypoxia = 15, trauma = 4, stroke = 6	**Incidence** of new prolonged disorder of consciousness from an acute onset cause at four weeks = 2.5/100,000/year; 40% over age 60 years

M = million

MCS = minimally conscious state

PDOC = prolonged disorder of consciousness

PVS = permanent vegetative state

Table three

Studies focused on specific conditions

Author, year, country, [reference no]	**Method**	**Results**	**Comment**
Young et al, 1996. USA. [48]	Data from a large randomised trial in people with **severe head injury** (Glasgow Coma Scale 8 or less after resuscitation). Base population unknown.	At 3 months, 37/463 in vegetative state, 85/463 severely disabled. At 6 months, 24/463 in vegetative state (108/463 dead, 64/463 severely disabled)	Good data. Outcome assessed on Glasgow Outcome Scale. Equivalent to 7% of all surviving patients vegetative at 6 months, 5% of incident cases.
Engberg et al, 2006. Denmark. [49]	Prospective study of all severe **traumatic brain injuries** in Copenhagen health area, Denmark (pop = 2.4M). 01-Oct-2000 to 30-Sep-2003	117 patients registered: 21 vegetative state at 4 weeks, eight at 3 months, five at 6 months, four at one year	Prolonged disorder of consciousness / 100,000 population / year = 0.29 at one month, and 0.06 at one year

Godbolt et al, 2013. Sweden and Iceland. [50]	Prospective recruitment from rehabilitation doctors of people with 'severe' **traumatic brain injury** (worst Glasgow Coma Scale score 8/15 or less), age 16-65 years only, in Sweden. Follow up 3 weeks, 3 months, 12 months after injury.	103 identified over 18 months (102 followed). Prolonged disorder of consciousness (PDOC) at 3 weeks = 47, at 3 months = 20, at 12 months = 10. Population covered = 4.7 M.	Only included young acute brain trauma. Rate of prolonged disorder of consciousness in people aged 16-65 years with severe head injury was per 100,000/year: 0.7 at three weeks, 0.3 at three months, and 0.15 at one year
Klein et al, 2013. Germany. [51]	Retrospective study on admissions to a specialist rehabilitation centre; all patients with disordered consciousness on admission after **sub-arachnoid haemorrhage** 2005-10	481 admitted after SAH, 63 had disordered consciousness at mean 26 days after onset: 38 (60%) remained disordered at discharge mean 76 days later	Demonstrates a significant frequency (8% at discharge) of prolonged disorder of consciousness after sub-arachnoid haemorrhage. But data not clearly presented or easily interpreted.
Løvstad et al, 2014. Norway. [52]	Prospective study of **traumatic brain injury** recruiting from all four major	359 patients identified over two years (2009, 2010). Prolonged	Incidence = 0.09/100,000/year at 3 months and 0.05/100,000/year at

	trauma centres in Norway. Follow-up at three months. Excluded people who also had alcohol/drug problems (n = 16) psychiatric disorder (n = 11), or progressive disorder (n = 19). Two year cohort. Population = 3.8M	disorder of consciousness: at three months seven, at 12 months four.	12 months. Note that this is a very selected, very unrepresentative sample.
Spiotta et al, 2015. USA [53]	Retrospective analysis of a data-base of all **stroke** patients give thrombectomy for anterior circulation stroke. Modified Rankin Score of 5 equated to PVS	149 patients; 137 had data at 90 days: At 90 days, 23 had died, 9 were in the vegetative state	Patients with modified Rankin scale of 5 not necessarily vegetative, but same clinical and ethical situation.

Appendix one

Table one

List of primary data sources compiled from reviews and searching, giving how each was identified

Year, Author	Title	Source	Comment
1976 Kodama & Suziki	Vegetative state patients in Japan	C	***Table 2***. *National survey of neurosurgery units (90% response). 494 alive 1975. 108-135 new each year. Trauma, stroke and brain tumour main causes. Miyagi prefecture (pop 2M) had 37 new cases over 2 years*
1977 Higashi et al	Epidemiological studies on patients with a persistent vegetative state.	A, B, C	***Table 2*** *Response to 'simple inquiries' in 16 prefectures in 1973; said to be complete in Yamaguchi prefecture (pop 1.5M) where 37 identified. Prevalence 2.5/100,000. Of 110 total, causes trauma 28, stroke 21, developmental 14, anoxia 12, tumour 10, inflammatory disorder 7, others 8*
1978 Sato et al	Epidemiological survey of vegetative state patients in Tohoku district in Japan.	A, C	***Table 2.*** *Recruited by postal survey and administrative data; clinical data collect by questionnaire; response rate 65%-87%. 219 patients; prevalence 1.9/100,000*
1985 Minderhoud & Braakman	The vegetative existence	A, C	***Not included in main table.*** *Paper in Dutch.* ***Report*** *by van Erp et al says: methods very unclear and diagnosis uncertain. 53 cases found, prevalence of 0.37/100,000.*
1991 Tresch et al	Clinical characteristics of patients in the persistent vegetative state.	A	***Table 2.*** *Survey of four nursing homes (1611 residents): 62 in PDOC, of whom 51 in permanent vegetative state. Stroke, dementia and anoxia main causes. (Ages 19-92 years)*

Year, Author	Title	Source	Comment
1996 Young et al	Effects of Pegorgotein on Neurologic Outcome of Patients With Severe Head Injury: A Multicenter, Randomized Controlled Trial.	F	***Table 3*** *Considers frequency of PDOC after severe head injury. Selection and base population unknown. 5% of incident severe head injuries vegetative at 1 year.*
2002 Wilson et al	Vegetative state and minimally responsive patients -- Regional survey, long-term case outcomes and service recommendations.	D	***Table 2.*** *Survey of doctors and follow-up of patients discharged from unit. 35 cases identified from population 1.7M. Prevalence 2.1/100,000*
2004 Stepan et al	Prevalence of persistent vegetative state/apallic syndrome in Vienna.	B, E	***Table 2.*** *Survey on 28-Nov-2001 of all people from Vienna (pop 1.6M) in a nursing home or hospital. 78 people identified: 36 'full-stage apallic syndrome', four not from Vienna. [Note that seven of 78 were at home.] Prevalence = 2/100,000 (Viennese residents). 25/32 (75%) were non-traumatic*
2004 Engberg & Teasdale	A population-based study of survival and discharge status for survivors after head injury	C, E	***Not included in main tables.*** *Random retrospective sample of admissions in Denmark with head trauma 1979-1993.* ***No specific analysis of vegetative state.*** *Not a prevalence or incidence study.*
2005 Lavrijsen et al	Prevalence and characteristics of patients in a vegetative state in Dutch nursing homes.	B, E	***Table 2.*** *Survey of all nursing homes in the Netherlands (pop 16.2M). 32 cases identified of people in vegetative state four weeks or more. Prevalence 0.2/100,000*
2006 Stepan et al	Prevalence of Apallic Syndrome (Vegetative State) in Vienna – Comparison with results found in 2001	C	***Table 2.*** *Text in German; all data from English abstract. Prevalence in Vienna 27-Nov-2003 (same population as Stephan (2004). 28 patients. Prevalence = 1.7/100,000*

Year, Author	Title	Source	Comment
2006 Engberg et al	Centralized rehabilitation after severe traumatic brain injury - a population-based study.	F	***Table 3.*** *Prospective study in Copenhagen health area (pop 2.4M) of all severe traumatic head injuries over 3 years 2000-03. Of 117 recorded, 21 vegetative at 4 weeks, four at one year. Incidence = 0.29/100,000/year and 0.06/100,000/year at 4 weeks and one year.*
2007 Jaul & Calderon-Margalit	Persistent vegetative state and dementia in the elderly.	F	***Table 2.*** *Prospective study of all admissions to a skilled nursing facility for elderly. 31 (35%) of 88 admissions in vegetative state. Many causes.*
2009 Beis et al	Care protocol for persistent vegetative states (PVS) and minimally conscious state (MSC) in Lorraine: Retrospective study over an 18-year period.	F	***Table 2.*** *Retrospective review over 18 years of admissions to a 12 bedded specialist unit of people with PDOC. 41/47 admitted in PDOC. Incidence = 0.1/100,000/year. Very selected admissions (2-3 each year only)*
2010 Saoût et al	Patients in a permanent vegetative state or minimally conscious state in the Maine-et-Loire county of France: A cross-sectional, descriptive study.	B, C	***Table 2.*** *Survey of hospitals and nursing homes in a county in France. 13 patients in PDOC found. Prevalence = 1.8/100,000*
2011 Donis & Kräftner	The prevalence of patients in a vegetative state and minimally conscious state in nursing homes in Austria.	B, C, E	***Table 2.*** *Telephone and questionnaire survey of Austrian long-term care facilities. 269 patients in VS and 120 patients in MCS found. Prevalence = 3.36/100,000 (VS) and 1.5/100,000 (MCS)*
2013, Leonardi et al	An Italian population study on 600 persons in vegetative state and minimally conscious state.	E	***Not included in main tables.*** *Survey (unspecified) of 600 people with PDOC in Italy. 64%-77% were non-traumatic.* ***No specific data****.*

Year, Author	Title	Source	Comment
2013 Godbolt et al	Disorders of consciousness after severe traumatic brain injury: A Swedish-Icelandic study of incidence, outcomes and implications for optimizing care pathways.	E	***Table 3.*** *Prospective observational study of severe traumatic brain injury over 18 months. 102 patients: 32 PDOC at 3 weeks, 6 at one year. Incidence of PDOC at ; at 3 weeks = 0.7 and at 1 year = 0.15/100,000/year*
2013 Giovannetti et al	Burden of caregivers of patients in Vegetative State and Minimally Conscious State	E	***Table 2.*** *Snowball method of recruitment from 16/20 Italian Regions. 487 caregivers - 17% of patients were at home.*
2013 Klein et al	Rehabilitation outcome of patients with severe and prolonged disorders of consciousness after aneurysmal subarachnoid hemorrhage (aSAH).	F	***Table 3.*** *Retrospective data analysis from rehabilitation centre of patients with subarachnoid haemorrhage. 38/481 (8%) in PDOC at discharge*
2014 Løvstad et al	Rate of Disorders of Consciousness in a Prospective Population-Based Study of Adults With Traumatic Brain Injury	E	***Table 3.*** *National prospective survey in Norway of all severe head injuries. Excluded many patients likely to develop PDOC; incidence of PDOC 0.09 and 0.05/100,000/year at 3 and 12 months respectively.*
2015 Van Erp et al	The Vegetative State: Prevalence, Misdiagnosis, and Treatment Limitations.	E	***Table 2.*** *National survey; all patients assessed using Coma Recovery Scale – Revised. 53 patients identified in 16.7M population. PDOC prevalence 0.2/100,000*
2015 Spiotta et al	Impact of the ASPECT scores and distribution on outcome among patients undergoing thrombectomy for acute ischemic stroke.	F	***Table 3.*** *Retrospective data analysis of a stroke population having thrombectomy. 9/149 in vegetative state at 90 days*
2015 Shimamura et al	Epidemiological Investigation of Patients in Persistent Vegetative States in Aomori, Japan	E	***Table 2***. *Japanese; English Abstract used. Questionnaire to all 682 'medical institutions' in Aomori prefecture. Prevalence calculated 86.9/100,000*

Year, Author	Title	Source	Comment
2016 Pichler & Fazekas	Cardiopulmonary arrest is the most frequent cause of the unresponsive wakefulness syndrome: A prospective population-based cohort study in Austria.	F	***Table 2.*** *Prospective 12 month cohort study (2011-12) in an Austrian state (pop 1.0M). 25 in PDOC 30-50 days after onset. Incidence 2.5/100,000/year*

Abbreviations:

M = million
MCS = minimally conscious state
PDOC = prolonged disorder of consciousness
pop = population
VS = vegetative state

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A = Multi-Society Task Force on PVS.
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Table two

Search strategy: Medline Database (07-Apr-2018)

N	Search Terms	Number
1	(Prevalence OR Incidence OR Frequency).ti,ab	1,763,502
2	(state AND (vegetative OR (minimal* AND conscious*))).ti,ab	4,021
3	(1 AND 2)	316
	Selected	15

Report on a survey of Health Commissioners about patients with prolonged disorder of consciousness.
Number funded, care location, and cost.

Data from Sanchia Berg

Introduction.
In 2016 a court case about a patient in a prolonged disorder of consciousness was heard. Among other issues raised was the prolonged delay in bringing the case. [1][2] The matter was investigated by Sanchia Berg, a BBC reporter, and it was discussed on the Victoria Derbyshire programme on BBC on 23 September 2016. As part of the background investigation, Sanchia Berg initiated a Freedom of Investigation request to determine the number of people with a prolonged disorder of consciousness being whose care was being funded by the NHS.

Method.
The Clinical Commissioning Groups (in England), Local Health Boards (in Wales), Health and Social Care Trusts (in Northern Ireland), and local NHS organisations in Scotland responsible for administering Continuing Healthcare funding [3] in the UK were identified. Each was contacted asking for information about the patients with a prolonged disorder of consciousness they were responsible for. Data requested included:

1. Numbers cared for (funded)
    a. total, **and**
    b. number within the first six months since onset
2. Location of patients cared for:
    a. NHS hospital
    b. Residential care/nursing home
    c. Own home
    d. Other
3. Cost:
    a. total
    b. as percentage of continuing healthcare budget
4. Length of funding up to that point

Data were entered into an Excel spreadsheet, and analysed descriptively. As the return rate was very low in Wales, Scotland and Northern Ireland, and so only the data from England were analysed.

Results.
Replies with data were received from 45 (21%) of 213 clinical commissioning groups. Much of the information was imprecise, making it difficult even to estimate numbers. However, it has been assumed that "less than five" refers to one person unless the associated funding suggested a higher number. The data are shown in the table, **table three**, at the end. The main features are:

- a total of 114 people (but actual number uncertain)
    - 5 in hospital
    - 66 in nursing homes
    - 10 at home
    - 7 in 'other'
    - 26 not specified or data too unclear
- a total expenditure of £9.8M per year
- 11/45 groups stated that they were not funding any patients with a prolonged disorder of consciousness

The huge variation, including many specifically reporting no patients (which is not credible) suggests the data are not valid except as a minimum.

However, three clinical commissioning groups appeared to have good data:

- Gloucester: population = 635,000; number = 11 (including 5 at home); prevalence = 1.17/100,000
- Lambeth; population = 370,000; number = 11; prevalence = 2.98/100,000
- Southwark; population = 285,000; number = 11; prevalence = 3.85/100,000

Cost data were given on an estimated 105 patients, which gives an average expenditure of £92,168 each year in care costs.

Discussion
The majority of commissioning organisations did not respond, and a significant number responded stating that they did not spend any money and they had no such patients. The data suggest a prevalence of 1.17 - 3.85 people with a prolonged disorder of consciousness being funded through continuing healthcare in each 100,000 of the population. Around 8%-10% are cared for at home.

The failure to respond by 80% of commissioners is not surprising. The replies stating that a clinical commissioning group did not fund any either means that they did not look, or that they had no way of identifying such patients. The zero responses from 11 commissioners of the 45 who did reply should not be treated as meaning that they had no such patients, or that they were not funding such patients.

Information was difficult to interpret. A significant minority of funding organisations stated that they had '<5' (less than five) patients. The number has been guessed, and this is indicated by a '?' by the number. Occasionally they have given the duration that individuals have been funded, without admitting their number; again, an estimated number has been used

The cost being paid per case per year is roughly similar to the estimate made in a recent economic paper. [4] However the data do suggest quite considerable variation. Some of the variation must be secondary to clinical needs, which can differ considerably, and the rest probably arises from variation in cost in proving care in different geographic areas. This would suggest that the figures given are accurate, and that the economic assumptions made in the paper were reasonable.

Whilst it is obviously difficult to know anything about the sources of data, and thus it is difficult to know with any certainty what the actual numbers are, it is notable that the minority of commissioning authorities that gave detailed information tended to have the higher numbers of patients. The combination of (a) taking the trouble to provide better data and (b) the credibility of their figures when judged against the research-based estimated suggests that their data is reasonably dependable.

Thus, the figures from three commissioning groups - Gloucester, Lambeth, and Southwark - giving the most plausible information have been used to estimate prevalence of people with a prolonged disorder of consciousness **who are funded** by the NHS continuing care budget. This will inevitably be only a proportion, probably a minority of all patients in this clinical state. Nevertheless the figures are consistent with the suggested estimates in the main paper.

If the prevalence of funded care is 3.0/100,000 across England and Wales, the cost to NHS England and NHS Wales is £160,000,000 each year

I think that these figures provide reasonable evidence that the NHS is probably spending very large sums of money on caring for people with a prolonged disorder of consciousness, often for very many years. It is also notable that there is a significant variation in the cost per case. It is quite probable that this simply reflects variation in patient need, and variations in local care costs but this may be worth investigating.

Last, the severe lack of available data, for whatever reason, again highlights the need for prospective registration of all patients if only to identify the number of people being supported by the NHS, the cost of that care, and where they are being supported.

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Re: S
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Table three

Data of people with a prolonged disorder of consciousness from a survey of commissioning authorities in England

CCG	No.	Hosp/NH	Home/other	Cost	comment
Barnsley	1	1	0	123,343	Two years; 0.08 %(? Budget = £12M)
Basildon	1-**2**	2	0	227,698	
Bexley	1	-	-	-	
Blackpool	5	5	0	427,857	2/12 to 7 yrs; 4.0% (budget = £10M)
Bolton	0				
Bury	5	-	-	498,420	Over 3 years; 6% (budget = £M8.3)
Cambridge	2	1	1	-	
Camden	0				
Central London	<5 (?1)			?	2 – 8 years; average cost £120,000/year
Dartford	4	3	1	329,588	1 – 7 years; 4.39% (budget = £7.5M)
Ealing	6	6 (1,5)	0	356,695	1 – 6 years; 2.4% (budget = £14.9M)
Gloucester	11	5	6	960,460	1 – 17yrs; 1.26% (budget = £76M)
Great Yarmouth	6	6 (3,3)	0	366,438	NK; 1.64% (budget = £22.3M)
Huddersfield	<5 (?3)	-	-	294,229	NK; 1% (budget = £29M)
Greenwich	7	-	-	804,813	NK; 4.8% (budget = £16.7)
Guildford	0				
Halton	0				
Hammersmith	<5 (?1)	-	-	?	2 – 8 years
Hereford	0				
Heywood	1(?)	-	-	98,992	NK; 1.5% (budget = £6.6M)
Ipswich	1	1	0	?	55 days
Isle of Wight	0				
Kingston	<5 (?4)	-	-	470,719	2 and 7 years; 6% (budget = £7.8M)
Knowsley	0				
Lambeth	11	11	0	1,131,936	1 – 5 yrs; 7.5% (budget = £15.0M)
Luton	0				

Medway	4	2	2 (0,2)	427,419	3-11 yrs; 4.59% (budget = £9.3M)
Milton Keynes	5	5	0	410,307	Upto 10yrs; 3.59 (budget = £11.4M)
N Lincoln	1 (?)	1	0	127,193	3yrs; 0.89% (budget = £14M)
N Norfolk	1 (?)	-	-	61,906	NK; 0.03% (budget = £207M)
Norwich	1 (?)	-	-	131.508	NK; 0.06% (budget = £220M)
Nottingham	5	5	0	292,502	1 – 8 yrs; 2% (budget = £14.6M)
Somerset	0				
S Norfolk	0				
Southampton	2 (?)	-	-	198,886	NK
Southend	1 (?)	1	0	97,770	NK
Southwark	11	11	0	1,068,957	NK; 9% (budget = £11.9M)
Swale	1	0	1 (0,1)	139,880	4 yrs; 2.25% (budget = £6.2M)
Tameside	3	1	2 (0,2)	335,235	1-2yrs; 3.76% (budget = £8.9M)
Telford	1 (?)	1	0	146,143	NK; 4% (budget = £3.6M)
Warrington	4	1	3 (2,1)	148,763	1-4 yrs; 1.23% (budget = £12.1M)
W London	?			?	2 – 8 years
W Norfolk	0				
W Suffolk	1	0	1	?	1 year
Wigan	1 (?)	0	1 (0,1)	102,870	NK; 0,48% (budget = £21.5M)
totals	114	5 + 66	10 + 7	£9,677,657	= 92,000 per person per year

CCG = Clinical Commissioning Group
M = million
N = North
NH = Nursing home
NK = not known
No = number
S = South
W = West

?n = the estimated number used