

**Bournemouth University,
School of Health & Social Care.**

Report to the Society of British Neurological Surgeons

Saving Lives Is Not Enough?

**Re-evaluating the UK & Ireland Sub-Arachnoid
Haemorrhage National Study (2006): Comparing
'Treatment -as-Usual' with an Enhanced Service**

Professor Colin Pritchard, Research Professor and Dr. Malcolm Cox, Senior Research Fellow, School of Health & Social Care, Bournemouth University; Lesley Foulkes, Neuro-vascular Specialist Nurse, Wessex Neurological Centre, and, Mr. Kenneth Lindsay, Consultant Neurosurgeon, Southern General Hospital, Glasgow

September 2009.

Report to the Society of British Neurological Surgeons August 2009

Saving Lives Is Not Enough? Re-evaluating the UK & Ireland Sub-Arachnoid Haemorrhage National Study (2006): Comparing ‘Treatment -as-Usual’ with an Enhanced Service

Professor Colin Pritchard, Research Professor in Psychiatric Social Work, School of Health & Social Care, Bournemouth University, and, Visiting Professor, Dept of Psychiatry, University of Southampton, Dr. Malcolm Cox, Senior Visiting Research Fellow, SHSC, Bournemouth University; Lesley Foulkes, Neurovascular Nurse Wessex Neurological Centre, Southampton General Hospital and Mr Ken Lindsay, Consultant Neuro-surgeon, Department of Neurosurgery, Southern General Hospital Glasgow.

Executive Summary of a Report to the Society of British Neurological Surgeons Sept 2009

Background

There is increasing interest across specialities, including neurosurgery, in ‘Patient-Related-Outcome-Measures’ (PROM’s) research. The main difference in this approach is that instead of following just the professional’s outcome agenda, the focus is upon what the patient and their carers consider important. This requires that we place the patient and carers at the centre of the evaluation and see the patient as ‘expert’ in identifying their key outcomes. Such an approach was carried out in a two-year retrospective study of a cohort of sub-arachnoid-haemorrhage (SAH) patients in the Wessex region (Pritchard et al, 2001). Respondents identified strengths and weaknesses of their treatment in hospital. As many had a post-traumatic-stress-disorder (PTSD), often associated with a SAH, they highlighted the importance of a continuum of care into the immediate discharge period, and recommended more individualised continued contact with the hospital, which was translated into the establishment of a Neuro-Vascular-Special-Nurse (NVSN) to deal with the linked psychosocial issues that proved to be so costly and disruptive to the service and families.

We evaluated the implementation of a NVNS service’s in a two-year prospective outcome study to determine whether it was possible to reduce the PTSD problems that follow a SAH (Pritchard et al, 2004a). The initial ‘Treatment-As-Usual’ (TAU) Wessex results were used as a control group to be compared with the new NVSN service’ clinical, psychosocial and fiscal outcomes. We found highly significant gains stemming from the NVSN service. As well as improved psychosocial outcomes for patients and families there were major fiscal benefits to the service, to the families and the wider economy.

Following publication of the UK and Ireland National SAH study (National Study 2006) we wished to explore what clinical and fiscal benefits might accrue nationally if there had been a NVSN service in every UK and Ireland neurosurgical unit.

The Study

Objectives

[1] To estimate the fiscal and psycho-socio costs of the impact of a SAH upon a national cohort of ‘Treated-as-Usual’ (TAU) patients, their carers, and, the wider community.

[2] To estimate nationally, the potential clinical, fiscal and psychosocial benefits to the families and service that might accrue from a Neuro-Vascular-Specialist-Nurse (NVSN) service to reduce the associated Post-Traumatic-Stress-Disorder.

[3] To demonstrate the contribution that comprehensive treatment of SAH makes to the wider economy.

Methodology

Utilising the data from the Wessex retrospective TAU and prospective NVSN studies, the psychosocial data was *projected* onto clinically matched patients from the national cohort, all of which had been collected at the same time period, 2001-2003. Clinical data was common to both the Wessex regional and National studies. The additional projected psycho-socio-economic data included family details, occupational status as well as patients and carers perspectives of the service.

Matching the Cohorts. Before having access to the national data all individual and unit identifications were removed to ensure total anonymity and confidentiality, ensuring that no individual patient or unit could be identified. The Wessex PROM data was then attached to clinically matched patients in the national study to form the equivalent of national TAU and NVSN cohorts. Out of the National 2,397 confirmed SAH patients, 2,380 could be adequately match against the Wessex cases, to create the equivalent of national TAU and NVSN cohort outcomes, enabling us to estimate the psychosocial clinical, fiscal and psychosocial outcomes of patient and carer in the comparative cohorts.

Fiscal Analysis: Knowing patients' employment status from the Wessex studies, it was possible to calculate national estimates of salary of patients and carers, to under-take a cost-analyses of any loss of employment by patient or/and carer, during the time of hospitalisation and post-discharge recovery period. The latest confirmed average labour costs up to 2007 were used (Social Trends, 2008; World Salaries 2009). Costs to the NHS were based upon the daily cost of a neurosurgical bed and the length of stay of the TAU and NVSN patients approximately between £544-1,000 per day. Thus it was possible to calculate differential costs between TAU and NVSN cohort's potential savings, to patients, carers, the service and the wider economy.

Findings

Clinical: National NVSN v TAU cohorts: The NVSN patients had a measurably shorter length-of-stay in the Units than their TAU counter-parts. The NVSN patients had a markedly quicker post-discharge recovery, with lower levels of self-reported physical and psychosocial problems than TAU patients and families. Furthermore the NVSN contributed to the earlier identification of complications such as hydrocephalus, often overlooked in general health care, leading to earlier resolution.

In effect the NVSN approach enabled patients who would have been considered on the GOS as having some 'disability' to take up their family, and where appropriate, their employment responsibilities much earlier.

In parenthesis, it was noted males had significantly more anterior circulatory aneurysms than women, with women having more posterior circulatory aneurysms than men.

Psychosocial: As would be expected, estimates of the national NVSN patients and carers had a significantly better psychosocial outcome than did TAU who in effect were left to cope with a generally unrelieved and unnecessarily prolonged PTSD. As a third of the cohorts had school-aged children, and a majority were aged <55, these are people who are at the peak of their family and employment responsibilities. Consequently there are self-evident major gains if we are able to reduce the PTSD associated with a SAH.

As people have differing responsibilities through life, the cohorts were compared in age-bands and by gender, ranging from <44, 45-54 and 55-64 and 65+years. Whilst all NVSN patients in all age-bands had better outcomes than the TAU, this was especially so for the under 64 year olds.

Anonymous and non-attributable views of NVSN service by patients and carers were highly complimentary, not least because the NVSN enhanced what was generally a somewhat inadequate community service that often appeared apprehensive of dealing with neurosurgical patients. Both TAU and NVSN cohorts reported far higher levels of satisfaction with their in-patient neurosurgical care than with the care provided by the community-based services.

Role of NVSN: The role of the NVSN was succinctly described by a senior military person:-

"Unusually I remember much of my in-patient experience- I was fortunate to have had surgery of the very highest international level. But the second outstanding feature was the NVSN. She was available to deal with all those little questions, which if they had not been dealt with would have become major barriers to my recovery, adding to my family's distress"

Fiscal – Costs & Benefits: All costs estimates are deliberately a cautious under-estimate.

NHS Costs: Based upon length of stay, the NVSN patients cost the service an average £30,685 per patient, compared to £34,850 for the TAU cohort. Ten percent of the neurosurgical costs were added to the total service bill to include possible post-discharge NHS costs. The NVSN cohort of patients cost an estimated £27.74million compared to £30.24million for TAU, a potential direct saving of £2.5million to the NHS if there had been an effective NVSN service in the UK and Ireland.

Costs to Patients & Carers:

In-Patient Costs: Time off work when in hospital cost NVSN patients an estimated total of £3.69 million, compared to £4.19 million for TAU patients, a 'saving' of £506,411 to NVSN families.

Post Discharge Costs: The *biggest potential savings* came from the better post-discharge recovery. In terms of time off work for NVSN patients and carers, total estimated costs were £18.39 million and £5.09million respectively. This compares with the £22.38 million and £6.98 million for TAU patients and their carers, which would be a further potential saving of £5.88 to NVSN families.

Overall a NVSN service would save the NHS and patients and their carers, an estimated £7.87million, *not* including savings from reduced need for welfare benefits, or the fiscal equivalents of patients resuming their family responsibilities earlier.

Wider Economy Savings: When discussing NHS services, usually it is only the costs of the service that are considered, not the potential economic benefit, when effective treatment returns people of work-age to employment. Based upon patient's age, occupation and life expectancy, there were 1,365 work-aged eligible NVSN patients, for whom it was estimated that the value of their overall future contribution to the national economy was £629 million at 2007 prices.

Future Research

Irrespective of the size of any bleed, it was noted that in the Wessex cohorts there were no significant psychosocial difference between clipped or coiled patients, probably because the trauma and the 'emergency' life-threatening nature of the SAH, invariably led to a degree of PTSD - so disruptive to family life, that far exceeded any potential difference between the two treatments. There was however, indicative evidence that patients treated by coiling require relatively more of the NVSN service than did the clipped patients, which *may* result from the need for coiled patients to return for more follow-ups and angiograms than clipped patients, reactivating any fears about possible re-bleeds. In any further debate about the merits of coiling versus clipping, it is argued that research needs to also include a consideration of the relative psychosocial outcomes of coiled and clipped patients.

Conclusions

The modern treatment of SAH 'saves lives' but this is insufficient if patients undergo unnecessarily prolonged PTSD, with all its impact upon the family. A NVSN type service can reduce the level of extended psychosocial disruption in a cost-effective self-funding form of care. Finally, what is often ignored, although a comprehensive treatment of SAH is expensive, there are major **financial**, as well as ethical, clinical and psychosocial gains, of returning citizens back to health.

Key References

Pritchard C, Foulkes L, Lang D, & Neil-Dwyer G (2001) Psychosocial outcomes for patients and carers after aneurysmal sub arachnoid haemorrhage patients. *British Journal of Neurosurgery*. 15. 456-463.

National Study of Sub Arachnoid Haemorrhage.(2006) London, Clinical effectiveness Unit. *Royal College of Surgeons of England* (February) 1-56.

Pritchard C, Foulkes L, Lang D & Neil-Dwyer G. (2004c) Two year prospective study of psychosocial outcomes and a cost-analysis of 'Treatment-As-Usual' versus an 'enhanced' (specialist liaison nurse) service for aneurysmal sub arachnoid haemorrhage [ASAH] patients and families *British Journal of Neurosurgery* 18: 347-356

Pritchard C, Foulkes L, Lang D.A. & Neil-Dwyer G (2004d) Cost-benefit analysis of an integrated approach to reduce psychosocial trauma following neurosurgery compared with standard care: Two-year prospective comparative study of enhanced specialist liaison nurse service for aneurysmal subarachnoid haemorrhage patients and carers. *Surgical Neurology* 62: 17-27

Acknowledgements: It is recognised that should the study could not have proceeded without the active work and collaboration of a number of colleagues - Neurosurgical Consultants Jonathan Drifill, Dorothy Lang, Glen Neil-Dwyer, Owen Sparrow, and Sister Beryl Pritchard, all of the Wessex Regional Neurological Unit, Professor John Pickard, University of Cambridge and Dr. Langham of the Health Improvement Unit at the RCS but, most of all, the patients and carers who contributed to the original questionnaires and all former patients and their carers who completed them. Finally we are greatly indebted to the *Glasgow Patient Trust Fund* for financially supporting the project.

Saving Lives Is Not Enough? Re-evaluating the UK & Ireland National Study (2006): Comparing ‘Treatment -as-Usual’ with an Enhanced Service

Introduction

1.1 Aims. It is proposed to determine the clinical, fiscal and psycho-social impact of a Sub-Arachnoid-Haemorrhage [SAH] upon patients, their families and the service and to explore whether a Patient-Related-Outcome-Measure (PROM) recommendation for a Neurovascular-Specialist -Nurse (NVSN) can reduce these problems, compared with the assumed ‘Treatment-as-Usual’ standard care.

Utilising a previously successful methodological approach enabled a calculation of: -

[a] the economic costs of the subsequent psychosocial impact of a SAH to patients, families and the wider economy,

[b] the potential psycho-socio-economic gains of a cost-effective patient-carer recommended enhanced service i.e. Specialist-Neuro-Vascular-Nurse (NVSN),

and,

[c] demonstrate the economic benefits of neurosurgical treatment to the wider economy of the economic gains of successfully returning people to work, which over-time offsets their initial cost to the NHS.

1.2 Background. Aneurysmal subarachnoid haemorrhage (SAH) has a UK incidence of approximately 8 per 100,000 people and asymptomatic un-ruptured aneurysms may exist in about 1% of the general population and contributes around 5% of all strokes (National Study, 2006). Almost fifty-percent of post SAH patients are left severely disabled, although a few decades ago, few survived and far more died than those who recovered, indeed an early report of a person surviving a SAH expressed surprise at the patient’s recovery (Hutchinson & Baille, 1932), although in modern terms the person was left both physically and psychosocially disabled (Teasdale et al, 1988; Hutter et al, 1996; Hop et al, 1998; Noble & Schenke, 2008; Noble et al, 2009).

There has been an increasing interest in patient’s perception of outcomes (Banks, 1998; Rowlands, 1998, H.o.C.S.C., 2001), including studies concerning neurosurgical patients (Hutter et al, 1996; Hop et al, 1998; Pound et al, 1999; Bateman et al, 2000; Da Cruz et al, 2000; Hellowell et al, 2001; Powell et al, 2002; Mezuue et al, 2004; Verhaeghe et al, 2005; Tooth et al, 2005; Langham et al, 2006;). These studies examined clinical outcomes and some quality of life measures, but with some notable exceptions, few actively involved the impact of the SAH and its sequel upon the *carers* (Watanabe et al, 2000; Hellowell, et al 2001; Pritchard et al, 2001, 2004a,b, c; Armstrong & Kerns, 2002).

Indeed this new ‘consumer’ orientation will be reflected in the proposed re-validation of consultants, where some form of ‘Patient-Related-Outcome-Measures’ (PROM) will be incorporated into the process (RCS, 2008) and this study is rightly concerned with such an integrated approach, not least because it enables a consideration of the often ‘hidden’ costs of acute illness, as well as the potential savings.

From many studies on SAH patients it is clear that many experience considerable levels of psychosocial dysfunction and economic disruption, many months after discharge. Indeed, Berry et al

(1998) suggested that many suffer a degree of 'Post-Traumatic-Stress-Disorder' (PTSD), which often follows other cerebral traumas (Hop, et al 1998; Hutter, 1998; Thorn hill et al, 2000; Greenwood et al 2003; Turner-Stokes, 2003, Tooth et al, 2005; Verhaege et al, 2005; Noble & Schenke, 2008; Noble et al, 2009) and there is convincing evidence that the general cognitive and social dis-cohesion following a SAH can rightly be defined as a PTSD (Noble & Schenke, 2008; Noble et al, 2009). Good neurobiological evidence exists as to why PTSD follows major trauma, whose core features include low basal cortisol secretion, enhanced negative feedback control of the HPA axis, increased autonomic responsiveness as well as CNS noradrenergic activity (Heim & Nemeroff, 2009). Equally important however, in a range of differing traumas with a PTSD sequel, it has been found that various psychosocial interventions can provide substantial relief (Cloitre, 2009; Zahar et al, 2009), which of course creates a positive feed-back upon the patients family that speeds up their re-integration into full responsible citizenship. How much PTSD following a SAH can be prevented or reduced is still at issue (Noble & Schenke, 2008; Zahar et al, 2009) but there is growing evidence that even following the traumas and suddenness of a SAH, PTSD can be reduced and/or better managed (Pritchard et al, 2004a,b, Cloitre et al, 2009; Zahar et al, 2009)

The almost inevitable dramatic emergency situation that an SAH creates, imploding into busy lives, as the majority of SAH patients are under 55 years old (National Study, 2006). With the major insult the brain receives plus any harmful effect of treatment, (whether endovascular coiling i.e. coil embolisation, or aneurysm clipping via a craniotomy), a degree of cognitive and psychosocial dysfunction is virtually inevitable. This is compounded by the impact of the patients incapacity upon their family and work responsibilities; so that for many clinicians the expectation is that people after clinical recovery might well be off work six, nine, twelve or more months, but what is often not seen by hospital based staff is the considerable degree of distress patients and family experience (Lapotaire J, 2003; Wertheimer, 2008). However, this study will show that with a substantial proportion of surviving SAH patients, such assumptions are challenged.

1.2 Identifying Patient/Carer's agendas. This emerged when in 2001 a research Sister asked why, if the majority of the SAH patients with single aneurysms were clinically 'cured', 83% being 'clipped' via a craniotomy and 17% coiled, did patients seek to return to the unit for advice. The traditional explanation was offered i.e. major brain insult and operation was inevitably linked to cognitive changes but the research team decided to try to further understand the process. This led to a retrospective study of a 2year cohort of de facto 'Treatment-as-Usual' (TAU) SAH patients, but unusually, we treated the patients and their carers as 'experts'. Whilst the unit performed neurosurgery, only they experienced the procedures, so in effect rather than examining the 'professional's' agenda, the patient and carers agenda perspectives were sought. This led to identifying the psychosocial and economic costs to patients and carers, as well as the clinical outcomes (Pritchard et al, 2001). The key difference being the main outcomes were identified by patients and their carers, who not only highlighted the accumulative problems but also offered a solution, in effect a Neuro-Vascular-Specialist-Nurse' (NVSN) to deal with the psychosocial problems and be an active liaison between the Unit and patient, their family and community based services. The later often being absent, in part because they were

apprehensive of dealing with former neurosurgical patients, summed up by a community based Sister saying 'sorry we don't do neuro!' The cohort highlighted the considerable psychological dysfunction and socio-economic costs borne by patients and families, as well as previously hidden costs to the service. Paradoxically, the majority of patients and carers were very satisfied with the clinical service they had received as in-patients, their main complaints centring upon communication difficulties and an unnecessary sense of confusion. No one was able to deal with the anxieties not only whilst in hospital, but also especially after returning home. Their biggest problems after discharge was that the vast majority felt lost and isolated and an inability to determine what might be thought of as 'reasonable' symptoms and would they 'ever be normal again?' The GP potentially was an important resource, and where the GP actively tried to offer support, there was some measured improvement, but as many GP's will probably see less than half a dozen SAH patients in their careers, frankly they were like the community sister, at a loss (Pritchard et al, 2001).

The extent of the hidden fiscal cost was enormous which led to the Trust funding a 2year prospective cohort study of all SAH patients in the Wessex region and trying out the patient recommended solution by introducing a NVSN.

1.4 Effective Patient/Carer recommended solution. In an attempt to determine whether the psycho-socio-economic stresses could be reduced, the approach recommended by patients and carers was implemented, a NVSN was appointed to deal with patient and family concerns and evaluated, using the initial retrospective cohort as a control to compare clinical, fiscal and psychosocial outcomes of the prospective NVSN enhanced cohort (Pritchard et al, 2004b,c).

It was found that the NVSN cohort had significantly better clinical, fiscal and psycho-socio-economic outcomes, with measurable additional benefits to the NHS and families (Pritchard et al, 2004a,b).

These included reduced length of stay in hospital, fewer re-admissions, less demand on consultant neurosurgeons and GP's time and a reduced need for psycho-pharmacological drugs. Furthermore, families had reduced post-discharge stress associated with the SAH event, with both patient and carers returning to work much earlier than the TAU cohort, with lower unemployment because of the SAH that reduced the need for welfare benefits. As 30% of both TAU and NVSN cohorts had school-aged children, the NVSN supported parents were more able to resume their family responsibilities.

A conservative cost-analysis identified 'savings' in excess of £155,000p.a related to NHS and economic savings to the families, but no attempt was made to estimate any fiscal value for reducing family stress, or from potentially saved welfare benefits, so the estimated level of 'savings' is probably an under-estimate.

One highly notable feature was that in both TAU and NVSN studies 17% of the patients were treated by an endovascular approach i.e. coil embolisation, but no significant differences were found between clipped and coiled patients in respect to either clinical or psychosocial outcomes.

Conterminously with the NSVN prospective study, the Society of British Neurological Surgeons (SBNS) and the Clinical Effectiveness Unit of the Royal College of Surgeons of England undertook a major national study of clinical outcomes of SAH patients in the UK (National Study, 2006), referred to here as the 'National Study'. The study contained valuable clinical data, with forthcoming quality of

life data to be published later, but as yet there has been no estimates made of the fiscal costs of post-operative psycho-socio-economic outcomes to patients, carers and the service.

This study seeks to correct this deficit, however, before dealing with the main comparative TAU versus the enhanced NVSN study, it will be helpful to place in context something of the nature of SAH and how the disruptive impact of the emergency situation that SAH brings, compared with elective neurosurgical treatment.

1.5 Differences between 'Emergency' and 'Elective' neurosurgical patients. The initial TAU study outcomes led to ENT and neurosurgical consultant colleagues to ask whether other patients undergoing craniotomies had similar psycho-socio-economic results, in this case Acoustic Neuroma (AN) patients. Using similar PROM orientated methodology a 2year retrospective study of AN was undertaken (Pritchard et al, 2004c). The results highlighted similarities but with key differences and that these TAU results of AN and SAH cohorts, enabled a comparison to be made between craniotomy treated patients who were essentially elective versus predominately 'emergency' patients. It was found that despite the AN cohort being objectively more *physically* impaired than the SAH patients, the AN patients and carers had significantly *better psycho-social and economic* outcomes than the 'emergency' TAU subarachnoid haemorrhage patients (Pritchard, et al 2004d), notwithstanding the fact that the Wessex TAU cohort's clinical outcomes were as good if not better than national average results (Molyneux et al, 2002). This led to the conclusion that a contributing factor to the PTSD of the SAH was the emergency nature of their condition, despite the fact that on balance the craniotomy operations for the AN patients often took longer than craniotomies for the SAH. This is not to ignore the contribution of the site and size of the aneurysm and bleed in the SAH patients, but the key psychosocial difference being that unlike most SAH patients, the AN patients and their families had ample time to prepare for their admission, enabling them to make any necessary domestic and/or employment arrangements prior to treatment. It is suggested that the emergency and urgency of the SAH condition adds an additional element to PTSD. This has been found in other acute life-threatening situations such as myocardial infarcts, which also adds particular stresses upon patient's families (Sheldrick et al, 2006; Rocha et al, 2008).

2. The Study

Neurosurgical treatment of SAH 'saves lives' but the current TAU does not go far enough as generally the underlying PTSD is ignored. It will be shown that with relatively little additional cost, more effective outcomes can be achieved, relieving patients and families from unnecessarily prolonged PTSD reactions. This study, utilising the National SAH Study data (2006), will extend the evaluation of the National SAH Study, to estimate the wider psychosocial and economic impact associated with a SAH event, to include the costs of standard 'Treatment-as-Usual' (TAU) and contrast this with potential benefits from an enhanced SAH treatment service of a 'Specialist Neuro-Vascular-Nurse' (NVSN) service to the benefit of patients, families, the service and the wider economy.

2.1 Objectives.

[1] To estimate the psycho-socio-economic 'costs' of a Subarachnoid Haemorrhage upon patients and their families, and the wider economy.

[2] To estimate the potential psycho-socio-economic 'savings' that might accrue by reducing these psycho-socio-economic stresses to benefit patients and the wider economy.

[3] To demonstrate the contribution that effective treatment of SAH makes to the wider economy.

3. Methodology.

Although it is recognised that rehabilitation of neurosurgical patients is somewhat uneven in England & Wales (Pickard et al, 2004), and there may be other neurosurgical Units who use something similar to the Wessex based NVSN service. The Wessex standard (TAU) and enhanced (NVSN) patient and carers data will be projected onto matched clinical data of individual patients drawn from the National SAH study data. All personal identification data had been removed before we received the data to ensure complete anonymity and maintain total confidentiality, thus no individual or the Unit in which they were treated can be identified and none can be identified in this report.

The NVSN data was collected at the same time of the National Study (2006) (2001-2002, thus the NVSN data is a temporal match. To obtain the estimated outcomes however we need to match as closely as possible the Wessex and National Study databases. This might be considered an unusual approach but in a recent BMJ paper were able to show that recognising the need for a mixed-method approach that utilises qualitative observations in the different levels of activity provides a more appropriate method to give a more complete picture of a service delivery than just quantitative methods alone (Brown & Lilford, 2008). As will be seen, we appropriately merge quantitative and qualitative approaches to examine and measure the fiscal and psychosocial outcomes of a standard TAU service against an enhanced NVSN service. .

3.1 Common data with the TAU, SAH and National cohorts. The common data collected makes the TAU and SAH cohort's reasonably reliable representative sample of the National Study cohort of SAH patients and is as

follows:-

- 1] Age *
- 2] Gender *,
- 3] Confirmed aneurysms *,
- 4] Dates of haemorrhage and time to admission,
- 5] National 'CT blood' Light, Medium, Heavy matched Wessex Risk Group 1,2,3.
- 6] Size of bleed,
- 7] Details of the repair –clipping or coiling,
- 8] Medical Complications.
- 9] Glasgow Outcome Score (GOS).
- [10] Location of aneurysm
- 11] Post-operative deterioration.
- 12] Post-operative re-bleed.
- 13] Hospitals outcomes and

14] All patients GOS at six months and all patients being surveyed within the same time frame 2001-2003.

For a TAU or NVSN patient to be considered a reasonable match with a patient in the National data set, in addition to the three asterisked * items, they must be a match on at least 5 of the other variables. The age and gender matching items were considered to be of special importance in view of the particular focus upon the psychosocial. The rationale for this is best seen when considering likely differing life-styles and responsibilities of men and women, so that whilst most men of working age <65 would be expected to be in full time employment, this is not yet the case for women, whilst despite major social changes for greater female equality, women still take the major burden in regard to children (Social Trends, 2008).

Further rationale for the age and gender being essential for matching patients was that although there were 14 common data items, there was a considerable range of 'missing' data on individual cases in the National Study; see below when discussing the 'limits of the study'. One value of this project lies in opportunity to have a wider understanding of a SAH event.

3.2 Additional data from the fiscal and psychosocial TAU and NVSN studies. The additional psycho-socio-economic data from the TAU and SLN studies included:-

- 1] Marital status,
- 2] Child status and their ages,
- 2] Occupation and estimates of socio-economic class,
- 3] Estimates of 'economic' loss to families and length of time off-work following SAH for both carer and patient,
- 4] Patients structured views of their in-patient experience.
- 5] Carers structured views of their in-patient experience.
- 6] Open-ended information about the patient's and Carers hospital experience,
- 7] Patient self-report of post SAH recovery [speech, limbs, headaches, memory, concentration),
- 8] Patients structured views of their post-discharge experiences.
- 9] Carers structured views of their post-discharge experiences.
- 10] Contact and views of the community based Health services.
- 11 Open-ended responses about their post discharge experience, including links with other hospitals, GP's and Community Services,
- 12] Structured view of the impact of the SAH upon the patient themselves,
- 13]] Structured views of the impact of the SAH upon their partners and family
- 14] From the NVSN cohort their experience of the work of the NVSN and strengths and weaknesses of such a service.
- 15] Recommendations to improve the service

3.3 Missing Data. Both the original Wessex studies and the National Study had missing data on various items. In particular within the responses to the structured WPCQ sometimes a particular question was not answered and this was scored as zero. However no question received less than 95%

responses and all questionnaires received 90% response, otherwise it was declared invalid. There were however in all the studies under review missing clinical data, in particular the Glasgow Coma Scores and the WFNS grades. It had been intended to analyse the psychosocial data along the GCS but this would have reduced the size of sample considerably, lessening the value of the study. Consequently the fiscal and psychosocial outcome analysis is only on a comparison of the TAU and NVSN cohorts.

3.4 Questionnaire & Samples. The original, confidential, anonymous and non-attributable self-administered postal Wessex-Patient-Carer-Questionnaire (WPCQ) was designed with the active co-operation of a small pilot group of patients and carers (Pritchard et al, 2001; 2004a,b.). The WPCQ guaranteed total confidentiality and non-attribution as no one from the Neurosurgical Unit saw the returned WPCQ and the degree of engagement with potential respondents was seen in their response rates. The retrospective cohort had a 77% return rate and the prospective NVSN obtained an effective 89% return rate, far above the usual level of return rates of postal questionnaires and a very strong indicator that respondents were very much engaged and welcomed the opportunity for their voices to be heard. Both TAU and NVSN samples were very similar in background to the National Study profiles.

The National Study also covered the same two years as the original prospective NVSN study. It involved all 34 neurosurgical units and starting from 3,174 of possible SAH patients, after adequately accounting for 777 patients excluded because of non-confirmation of aneurysm (n=718) and co-existing pathology (n=59) the study produced an effective 2,397 cases, or 76% of the original national cohort. These 2,397 cases were matched against the Wessex samples and 2,380 cases matched the comparative inclusion criteria, giving an effective comparative rate of 99% with cases in the original National study.

3.5 Cost-Analysis (annual Wages & Salaries & neurosurgical bed). One feature often omitted in studies related to the NHS is potential costs to patient, family and the wider economy of people being off work because of illness. Yet "*patients who survive in good clinical condition following treatment have a potentially long life expectancy*" (Molyneux et al, 2009 p427), which needs to be considered both in terms of cost to patients and the service and potential gain in terms of the patients future economic value, off-setting costs to the NHS and the wider economy.

A cost-analyses will estimate any loss of employment by patient or/and carer following the SAH based upon the broad type of employment of patients and carers. The Office of National Statistics publish an annual Social Trends, which based upon various official government statistics, provides broad indicators of annual income to various sections of the general population. Based upon the latest weekly incomes but only up to for 2000-07 (Social Trends, 2009) they report that 60% of households average income was £226pw equivalent to £11,752per annum, the median income averaged £19,604pa and the mean income was £463pw or £24,076pa. However as 2.7million people earned £1,000 p.w, "this considerably skews the distribution curve and accounts for the long tail". These three income bands are somewhat insensitive to the data available, which is based upon the type of employment so that we can broadly assign a patient and carer to a more accurate socio-economic group. To obtain a more sensitive

estimate of employment costs a more detailed analysis is drawn from World Salaries that examined UK average salaries by typical occupations (www.world.salaries.org/uk 2008). They provide data on income per month from which annual salaries and wages can be calculated. In 2005 Socio-economic group [1] average salaries was £61,944pa, group- [2] £34,923pa, socio-economic group [3] £25,752pa, group- [4] £16,824pa and group- [5] averaging £13,668pa.

However, neither database includes the 'on-costs' of national insurance and superannuation costs to the employer. However to correct for those patients and carers not in superannuation schemes, the usual 22% on-costs over basic salaries will be estimated at 10% for all those in work. However as a majority of the Wessex patients were 'middle-class' this probably means the costs to patients and carers is a slight under-estimate. Conversely, many middle-class occupations continue to pay full salary up to six months of a persons time off work because of ill-health, hence these costs may not be direct to patients or their families but rather in terms of 'lost production'. To estimate losses post-discharge and to err on the side of caution to reflect the socio-economic bias in the South East, the average of the salaries influenced by the socio-economic groupings of the cohorts will be used, i.e. £125 per working day. Finally, again to err on the side of caution, costs and savings will not be updated to 2009 costs, apart from the current daily cost of a neurosurgical bed in 2008.

It should be noted however that women still receive less than men for comparable jobs and initially it was thought that to correct there ought to be a differential ratio. However, this is in part accounted for as because of the gender bias in SAH, the majority of carers who have time off work to support their patient will often be men and to calculate separately ignores the fact that these are estimates, which again will reduce the estimate of costs. Finally, there were 7% males and 2% females of the NVSN who were unemployed and therefore unclassifiable and 13% and 23% of people who were above retirement age, although not all had retired. Thus when calculating cost of lost production, this will exclude the retired or unemployed 20% males and 25% females.

Each of the TAU and NVSN cohorts had been assigned to a group based upon the occupation of those in work or of working age. There were no significant differences in the socio-economic groupings of the two cohorts so we use the NVSN data to project onto the National Study cases. To correct for the higher levels of incomes in the South East, Groups- [1 & 2] were combined, yielding 59%, with group- [3] at 29% and groups- [4&5] at 11%. Table [1] shows the averages based upon 'Social Trends' (2008) and 'World Salaries' (www.world.salaries.org 2008) data, plus the estimated 10% for the employers on-costs and estimated lost 'production' per day. To err on the side of caution therefore the two sources of average salaries, Social Trends and World Salaries are combined to provide an estimated cost.

Table [1] Estimated Cost of Lost Production per working day (p.w- based on 5day week Plus 10% on-costs)

Socio-Economic Groups	Social Trend – p.w.	World Salaries - p.w.	Combined Average p.w.
Groups 1 & 2	£26,484pa - £102	£53,277 - £205	£39,881 - £153
Group 3	£21,564 - £83	£28,327 - £109	£24,946- - £ 96
Groups 4 & 5	£12,927 - £50	£12,660 - £ 49	£12,794 - £ 49

Groups 1&2 estimated cost was £153 per working day, Group 3 £96pwd and £49pwd for Groups 4&5, which yields an average of £125pwd to reflect the socio-economic grouping of the NVSN cohort.

The occupational groups of the TAU SAH cohorts were slightly but significantly higher than those of the Acoustic Neuroma patients (Pritchard et al, 2004d) for the SAH cohorts 56% in groups 1&2, 32% in group 3 and 12% in groups 4&5 whereas the AN cohorts was 47%, 42% and 11% respectively.

These estimates of the cohorts socio-economic groupings reflect the slightly higher levels found in the South East (Wessex) region compared to the UK (Social Trends, 2009), hence the combining of the groups to off-set this regional weighting.

The authors however, readily acknowledge that they are not health economists, but rather are seeking to present a simple cost and possible benefits analysis. What have been described as common-sense statistics (Pritchard & Sharpies, 2008), which providing the rationale and under-lying assumption are clear, can provide good indicators of simple cost and benefits outcomes (Ausman 2004; Shemilt et al, 2006). Furthermore, Shemilt et al (2006) alerts us to some of the methodological problems faced by health economists, not least by inconsistencies and a lack of transparency in reporting methods, hence it is argued that the cost analysis presented here is transparent, and seeks to be a cautious and conservative estimate. With the emphasis upon potential fiscal savings we have been influenced by Drummond et al, (1997), who cautioned against an over-simplistic market analysis that Cookson et al, (2009) recognise might inadvertently be ageist and de facto under-value the 'worth' to retired people of receiving a comprehensive and appropriate form of care and treatment. It is recognised such an equitable and inclusive approach is not without criticism (Richardson, 2009), though some might consider the critique naïve in a liberal democracy, as if health matters were only concerned economic activity on one dimension. Furthermore, remembering that Sir Alan Walters, Lady Thatcher's economic guru, acknowledged that few macro economic predictions are very accurate, and a narrow view of the economics of health care can easily over-look the wider implications that impact upon the families of sick older or retired people and the cost to the adult sons and daughters (Cassie & Sanders, 2008; Parag et al, 2008; Kwon et al, 2009; Visser-Meiley et al, 2009). Moreover, as the Royal Collage of Surgeons develops their re-validation of consultant programmes, influenced by the notion of 'Patient-Related-Outcome-Measures' (PROM), it must include the cost of the burden of the disease upon families, to include both long-term and acute conditions. Acute conditions, such as cancer as well as SAH, have hidden economic as well as psychosocial costs across the age bands (Kim & Schultz, 2008; Sanders, 2008; Tsiaroppoulos et al, 2009).

3.5 Limits to the Study. The main limitation is that all the results are essentially only estimates of outcome, although based upon matched samples but of course from a far smaller database. Furthermore the original Wessex studies were not randomised trials, though the retrospective study served as a control for the prospective. There were no significant clinical differences between responders and non-responders in either Wessex study, suggesting that the responders are a reasonably reliable representative group of the majority of the cohort.

A classic limitation is that in both the TAU and NVSN studies we do not know whether the non-respondents would have been substantially different from the responders, even though there were

effective 76% and 84 % responses from the TAU and NVSN cohorts respectively. Moreover, in both TAU and NVSN there were no spoilt questionnaires and the extent of their open-ended answers showed that the respondents were very much engaged in the questionnaire, which was demonstrated by having relative few missing variables. The estimates of the socio-economic groups were based upon respondents declared occupation. This was relatively brief and most did not provide the detailed information for a more precise estimation of 'social class', which traditionally requires place of residence, education as well as occupation. Thus the respondents can only be broadly designated into socio-economic groups rather than social class per se, which of course includes cultural assumptions. Seeking estimates of costs to patients/family and the wider community the two source of average salaries might be thought problematic but combining the World Salaries (www.world.salaries.org/ul.shtml) which had far more detailed gradations than those in the ONS Social Trends (2009), gives a reasonable sound estimate of cost of a working day, when coming to compare days off work and the loss of production. Of course if the patient or carer is covered by an employers sickness benefit such a loss is in terms of production but for the proportion of self-employed people it was a direct loss to families.

Another limit was that as both the TAU and NVSN studies took place before the impact of the ISAT studies (Molyneux et al, 2002; National Study 2006) like most extant UK neurosurgical units, the main treatment method was craniotomy, with only 17% of both cohorts treated by coiling. Nonetheless, there were no significant differences between the clinical and psychosocial outcomes between clipped and coiled of both TAU and NVSN patients though of the current SAH patients in Wessex 2009, 74% were treated by coiling. Notwithstanding, this study does seek to compare the National and ISAT work but rather the outcomes that focus upon the need to reduce the PTSD that so often follows a SAH.

A final limitation is regard to patient and families contact with other agencies, especially community based. As Pickard et al (2004) points out there are major variations in range and type of services within the UK and the level of contact based upon the Wessex data may not be typical of other parts of the UK.

3.6 Paradoxical Effect of Projecting Regional on National Data. At the outset of the study it had not been appreciated that the rationale of projecting matched regional data on to national data would have the same effect as projecting national data onto the smaller numbers of cases in the regional study. Because we already know that there are major significant psychosocial differences between the TAU and NVSN cohort's outcomes, when applying that to the much larger National data set, those differences are magnified, so that hitherto non-statistically significant differences, by the effect of the increased size of the sample, can become significant. What this does achieve is to note that those small but non-significant differences, at a 'local' level, may well be indicative of real clinical and psychosocial relevance at national level. A research-based example illustrates the point. In the field of neurology, neurological consultants at a district hospital noticed a slight increase in people with earlier dementia, or some of the rarer of neurological disorders, 'other neurological disease deaths', as defined by the WHO (2008), but it does not look statistically significant. However, based upon national mortality statistics it is clear that there are major statistically significant changes (Retsky et al, 1994;

Pritchard & Evans, 1997; Pritchard et al, 2004e; Noonan et al, 2005). Thus changes which are only just discernable at local or regional level become significantly measurable at national level.

3.7 Samples. There were no significant clinical differences between the original TAU, NVSN cohorts, although the NVSN had slightly more high risk aneurysms (45% to 65%) (Pritchard et al, 2004a,b).

4. Findings

General Characteristics of TAU, NVSN & National Study Cohorts

4.1 Site & Gender It is believed that there are few explorations in the literature in regard to any differences between the sexes in respect to the site of the aneurysm. As was noted in the NVSN study (Pritchard et al, 2004) and confirmed here, there are significant differences between the sexes, males having significantly more ACA aneurysms and females having significantly more posterior sited aneurysm.

Table [2] Site of Aneurysm by Gender (excluding 228 missing replies)

Site	ACA	MCA	ICA	Posterior
Males n=773	58%	13%	4%	25%
Females N=1376	39%	23%	8%	30%

Chi square = 80.8812 3 d/f p<0.00001

4.2 Socio-Economic Factors: Costs of In-patient & Post-Discharge Related Time-off-Work & Neurosurgical bed costs.

Length of Stay & costs-off work per day. The equivalent national NVSN cohort stayed in the Neuro Unit approximately a total of 35,703 days. It should be noted we did not have any data for those patients who were transferred back to their referring hospitals so it is not possible to calculate for any post neurosurgical unit hospital admissions. Hence these costs will be an *under-estimate* of total real cost. However, the TAU total length of stay was approximately 40,602 days, a 'saving' in favour of the NVSN cohort of 4,899 days.

Table [3] In-Patient Time. Estimate of Wages & Salaries of those in Work by Gender & Socio-Economic Group per days off work.

Group & Cost	No: Males	No: Females	No days NVSN- TAU	Total Cost NVSN £'s	Total Cost TAU £'s
1&2 p.day	461 £153	620	16,252 – 18,609	2,486,556	2,847,177
3 p.day	163 £96	369	10,559- 11,775	1,013,664	1,130,400
4&5 p.day	72 £49	133	3,874 – 4,466	189,826	218,834
Total	696	1122	30,685- 34,850days	£3,690,046	4,196,411

The estimated cost of 'lost production' via wages & salaries of those SAH working-aged NVSN patients is cautiously estimated at £3.41m compared to £4.20m for the TAU working-aged patient a 'saving' to the enhanced cohort of approximately £506,365.

The following table shows the estimated 'savings' to families in respect to patients and carers being able to return to work earlier in the NVSN group compared to the National TAU cohort.

Table [4a] Post-Discharge Estimated Numbers of Days lost by numbers of patients & costs £'s (averaging £125p.d.) between NVSN and TAU cohorts.

Time Off before Returning to work	NVSN	TAU	Costs £million	
			NVSN	TAU
Patients (x130) SAH led Job loss	Days (24 pnts)	Days (260 pnts)	0.390	4.225
<12 weeks [x40days]	29,815	20,362	3.727	2.545
13-26weeks [x100]	76,356	25,452	9.545	3.182
Continues 26+ weeks [x 130]	37,814	111,080	4.727	13.850
Carers < 4 weeks [x10]	13,453	8,545	1.682	1.068
5-18 [x50]	27,270	47,268	3.408	5.909
Total	184,708	212,707	23.479	30.779

Savings on patients & carers time off work £7.3million

4.3 Length of Stay & Clinical Condition. In an effort to estimate number of 'days saved' influenced by the patient clinical condition, comparisons were made between those with 'complications' and those without. It was found that the greater rate of reduced length of stay concerned those NVSN with non-complications, as days saved amongst the NVSN patients were 44% of the total 4,166 fewer estimated days the NVSN were in the neurosurgical unit.

Table [4b] Length of Stay & Complications (NVSN v TAU)

Days in Hospital	NVSN	TAU	Gains
Complications	15,956	17,773	1,818
No Complications	14,729	17,077	2,348
Totals	30,685	34,850	4,166

$X^2 = 6.5223$ $p < 0.02$

4.4 Estimate Cost of Neurosurgical Bed. A post-op neurosurgical bed cost £544 per day but most patients spend at least one night in either ITC or HDC bed, though often longer. Depending upon the number of organs requiring support, say an average of two would cost £1,000 per day.

We do not have accurate figures for the ITC or HDC lengths of stay so it is estimated that every patients, including those who stay less than 7days, will occupy a ITC.HDC bed at least once, for those staying between 8-14, we estimate 3days at ITC/HDC, for those staying between 15-21, possibly 5days ITC/HDC and those staying longer is estimated at 7days ITC/HDC. In addition, a proportion of patients will not be discharged home but into the care of the referring hospital and it is not know how long they stayed there. Also are the NHS community charges for GP and community nursing services. Consequently in addition to the estimated neurosurgical in-patients costs we add a further 10% to cover possible additional NHS costs. This 10% estimate seeks to account for further hidden NHS costs, but recognises that convalescent type bed are far less costly than an acute bed. However, de facto, the higher the estimated cost of NHS treatment for a SAH, the greater the level of potential 'savings' therefore to err on the side of caution, the 10% estimate for additional cost is prudent.

Table [5] Cost of Neurosurgical In-patient Care + 10% for subsequent NHS Treatment

Length of Stay [+ITC & HDC] No's patient	No. of days NVSN- TAU	Cost £million NVSN	Cost £million TAU
<7 [+1 day] 237	1644 - 1834	1.103	1.216
8-14 [+3days] 1091	9274 - 9630	8.497	8.710
15-21 [+5days] 524	6778 - 9633	6.624	8.333
22+ [+7 days] 528	12 989 - 13753	11.522	11.979
Totals	30685 - 34850	27.746m	30.238m

Thus it is estimated that 2,380 SAH patients dealt with by a NVSN cost the service £27.746 million as opposed to TAU cost of £30.238 million, a potential 'saving' of £2.492 million.

4.5 Other Possible NVSN Savings. The NVSN by taking on approximately 10% of the consultant's out-patient responsibilities it is cautiously estimated to produce a saving of £1,800, a further £1,900 saving from reducing post-discharge unnecessary calls upon the GP. More important were the 12 patients whom the NVSN identified as needing treatment to avoid the need for re-admission, estimated at saving two days hospitalisation, is £13,056, thus in total a further £16,756 saving to the service. Extrapolating this to potentially all the Neurosurgical units would yield approximately a further £569,704 saving annually to be added to the potential savings from reduced length of stay yields a potential direct savings to the NHS of £1.81 million.

4.6 Calculation of estimated cost.: The NVSN < 7 days group. Number patients 237 @ number of ITC days is 237 @ £1,000p.d. = £237,000. Remaining number of days =1407 @ £544 = £765,408, yields £1,002,408 + 10% adjustment, i.e.. £100,248 therefore £1,102,645 in total.

The TAU 8-14 day's group. Number patients 1,091 @ number of 3 ITC days is 1,091 @ £1,000p.d. = £3,273,000. Remaining number of days =8539 @ £544 = £4,645,216 yields £7,918,216 + 10% adjustment £8,710,376 in total. A simple perusal of the in-patient costs between NVSN and TAU it appears that the impact of the NVSN service is on those patients staying between 8-21 days. These NHS costs of must be added to the patient and carer costs in order to calculate a simple cost effectiveness analysis.

4.7 Neurosurgery : Some Benefits? Invariably health care costs as we saw in the in-patient of the bed-occupancy figures. Indeed, almost invariably the key issue debated across the political spectrum is about the 'cost of the NHS' but there is little about the economic benefits it produces, even in the narrow terms of reintegrating the citizen back to full adulthood.

These deliberately 'simple' statistics are based upon a set of assumptions that deliberately under-estimates the level of fiscal benefits brought by returning the patient to full employment.

The estimates are based only upon patients of working age and who we known to be in employment at the time of the SAH. As might be expected middle-aged women had a much lower level of employment. Excluding those who were considered to be permanently unemployed and those who were still off work at 6months, ignoring the fact that they may re-enter the employment market at a later date, reduced patient numbers. Based upon the age-bands males < 44 years, the range was 22-44, it was assumed they would have a further 24 years of work. This also assumes that all would live until

the age of 65, and those women in employment would only work to the age of 60years. The social-economic group to which the patients belonged was ignored so that the `average of £99 per working day, equivalent to £25,740pa), produces a deliberately cautious estimate as 60% of the males belonged to groups 1 & 2, who averaged 153p.w.d. (i.e. £39,780pa), with only 11% belonging to Groups 4&5 with estimated average salaries of £12,740 p.a. (World Salaries, 2008).

Not all these will live but based upon WHO All Causes of Deaths statistics (2008) for 2006, males between 15-44 died at a rate of 1,001per million [pm] females 517pm, the 45-54 males 3585pm and 2326pm for females and finally 883ppm men 55-64 and females 5567pm, which need to be deducted from the SAH cohort of those in work.

Table [6a Gains of those Returning to Work by Age & Gender * averaging £125p.d. =£32,500pa [include on-costs] (millions)

Age & Gender*	Numbers	Years of Work @ £25.7k	Economic Gain £'s million
<44 years- Males	214	24	166.92
Females	256	16	133.12
45-54 Males	222	20	144.30
Females	312	10	101.40
55-64 Males	154	10	50.05
Females	207	5	33.64
Totals	1,365	85	£629.43million

*Assume women stop work at 60years * minus annual England & Wales death rate for the age-band.

Summary of Costs & Savings of NVSN v TAU.

The following Table (6b) list in summary the cost and savings of the two systems and minus' the cost to the NHS is there were a NVSN in every neurosurgical unit. This would cost the NHS approximately £36,300 to include on-costs per NVSN would be £1.23 million a year and for a two year cohort of 2,380 patients £2.46million. However to off-set this would be the gains to reduced costs for patients and families whilst the patient was in hospital; reduced costs by patients and carers returning earlier to work and the reduced length of stay, which whilst not marked at a local level at a national level produces substantial savings.

Table [6b] Summary of Costs & Savings of NVSN v TAU Treated SAH 2 Year Cohorts (millions)

Groups- Costs	NVSN	TAU	`Potential Savings'
Patient/Carers hospitalisation	£3.69m	£4.19m	£0.50m
Cost Post-Discharge-Patients	£18.39m	£23.83m	£5.44m
Cost Post-Discharge- Carers	£ 5.09m	£6.98m	£1.89m
NHS Hospitalisation costs	£27.74m	£30.24m	£2.50m
National NVSN costs	£ 2.46	00	(-£2.46)
Totals	£57.37	£65.24m	£7.87million

Thus over the 2 years a NVSN service would produce estimated savings, minus the £1.23million for the new NVSN a cautiously estimated surplus of £7.875million pounds if the NVSN service was equally effective in all UK and Ireland neurosurgical Units.

However, when the cost of the NHS service is considered, the main focus is upon saving lives, preventing or reducing illness and distress, which is seen of moral worth of itself and reflecting the NHS Act of 1948, reflected in the United Declaration of Human Rights (1948) as an essential in a society that seeks to develop human rights. Indeed, we have made no attempt to estimate the fiscal equivalent of the reduction of psychosocial distress, which itself is of worth (Drummond et al, 1997; Banks, 1998; Kim & Schultz, 2008; Visser-Meiley et al, 2009). Indeed the study could be criticised for over-focusing on 'savings' associated with getting people back to work etc as it appears to ignore the value of people not in the labour market. This is certainly not intended but rather serves to show that Patient-Related-Outcome-Measure can be of clinical and fiscal benefits. However, what needs to be remembered is that even with a cautious estimate of people returning to work and full responsibility, at 2007 price the former 1,365 SAH patients will contribute over the rest of their working lives more than an estimated £629 million pounds, which more than offsets the £30.4 (including new NVSN) service costs. Thus the investment in a comprehensive neurosurgical service for SAH produces a net surplus of £599 million, over the maximum period of 24 years an annual average return of £25 million, which is equivalent of an 82% return on the initial outlay. Thus it would be reasonable to assert in respect to an integrated holistic treatment of SAH patients, treatment is not only life saving it is also wealth producing.

5. FINDINGS STRUCTURED PSYCHOSOCIAL OUTCOMES

Social Factors of SAH Patients

5.1 Age and Sex: The age and sex of the total effective National cohort (2397) distribution was significantly different as the sample contained proportionately more younger (<44years) males than young females and more older (65+) women than males.

Table [7] Age and Sex of National Cohort

Ages & Sex	Male (n=827)	Female (n=1570)
<44	272 (33%)	372 (24%)
45-54	235 (28%)	456 (29%)
55-64	204 (25%)	412 (26%)
65+	116 (14%)	330 (21%)

Based upon the projected Wessex TAU (n=142) and NVSN (n=184) onto cases onto the National study, seventeen cases had to be excluded, as they did not meet the matching criteria, yielding 2,380 patients and their carers to be used in subsequent estimates.

The age and sex of patients have important psycho-social implications in that generally men earn more than women (Social Trends, 2008), which when they are patients make a differential impact upon the family, and when the carer's work is disrupted to care and support their partner, as the majority of carers are likely to be men, the cost is relatively greater.

This age and sex diversion has other implications. Crucially the majority of patients, both men and women were aged < 54years, 61% and 53% respectively, which means the majority of patients and carers would have major family and socio-economic responsibilities, with the majority of the <45-54 year olds having children of school-age.

As previously mentioned the majority of SAH patients belonged to socio-economic groups 1&2, many of whom would have employee's sickness benefit for at least 6 months but this might be very different

from people who were self-employed. There were examples of some families being devastated by the SAH. As a self-employed person this virtually ruined their single-handed or small business. A key aspect of this study is that using a national sample has highlighted the age and sex differences, which are probably obscured in the usual clinical size samples. Hence the importance of separately considering the psychosocial outcomes of the different age bands.

5.2 The Under 44 year olds All none-replies or not applicable responses are excluded from the tables, 42% of the age band were males. The demographic data was based upon the projected Wessex data onto the national NVSN and TAU cohorts, hence these remain estimates.

Table 8 shows the majority of both male and female patients were either married or in a partnership (90%) and 70% and 75% respectively having children, in total an estimated 895 children belonging to the 641 <44years old patients, the majority of whom would likely to be of school-age.

There were significant differences between TAU and NVSN patients in respect to returning to work.

Males: Those NVSN male patients who were in employment had significantly less time off work, although 14% of TAU to 2% NVSN considered themselves permanently off-work having lost their jobs because of the SAH. Those still off-work at 6 months were 54% and 30% respectively though 2% TAU and 24% of the NVSN had returned to work within 3 months ($p < 0.0001$).

Females: Of the females who were in employment 4% and 6% were off work permanently and whilst the NVSN females patients also significantly more often returned to work than the TAU women, it was not as marked as with the men ($p < 0.03$).

Table [8] follows

Table [8] Social Factors by Gender for <44year olds (based upon the projected Wessex demographic data)

Patients Age < 44 years	Males % [n=272]	Females % [n=369]
Single	7	4
Married	70	59
Separated & Divorced	2	7
Partnership	20	30
Children – 0	30	25
1-2	60	56
3-4	10	19
Social Class 1& 2	57	45
3	25	37
4 & 5	11	17
Unemployed [unclassifiable]	7	2
Comparing TAU v NVN	TAU –NVSN %	TAU –NVSN %
Time Off Work – Permanent	14 - 2	4 - 6
> Less than 12 weeks	2 - 24	19 - 24
>12-23 weeks	24 - 32	14 - 28
Still Off Work	54 - 30	44 - 28

Time Off-work TAU v NVSN Males $X^2 = 35.45$ $p < 0.0001$. Females $X^2 = 9.062$ $p < 0.03$

5.3 The 45-54 year olds: Of the 45-54 year old patients, 34% were male. These patients had an estimated 1,243 children of the 885 patients, many of whom would still be at school, which with the sudden impact of the SAH would pose particular problems for the carer as much as the patient. Like the younger age band, the largest socio-economic group were groups 1&2, with only a minority being either single, separated or divorced (22% and 16% respectively).

Males: In regard to subsequent employment 2% of TAU and 4% of males reported they had lost their jobs because of the SAH and 36% and 18% were still off work; whilst the NVSN patients returned to work significantly earlier than the TAU ($p<0.03$) but not to the same extent as the younger (<44years) aged men.

Females: More TAU woken patients reported they had been dismissed because of the SAH, 19% to 6%, with more than a third still being off work, and again the NVSN patients did better than the TAU in respect to return to employment ($p<0.04$).

Table [9] Social Factors by Gender for 45-54 year olds

Social Factors Age 45-54 **	Male % [n=230]	Female % [n=455]	
Single	4	3	
Married	48	70	
Separated & Divorced	18	13	
Partnership	29	13	
Children – 0	15	7	
1-2	78	57	
3-4	7	36	
Social Class 1 & 2	49	41	
3	35	32	
4 & 5	15	26	
Unemployed [unclassifiable]	1	1	
Comparing TAU v NVN	TAU –NVN	TAU –NVN	
Time Off Work – Permanent	2 - 4	6 - 8	
Still off work	36 - 18	34 - 16	
>12 weeks	10 - 18	14 - 20	
13-25 weeks	46 - 52	46 - 52	

Time off-work TAU v NVSN Males $X^2=9.2293$ $p<0.03$. Females $X^2= 8.4715$ $p<0.04$

5.4 The 55-64 Year olds: The group of patient had significantly fewer single, separated or divorced people than the younger age bands. Most had children, 92% males and 83% females, but the estimated number of 1,188 would assume to be beyond school age and may be part of potential support network. Conversely, these patients, especially the women, may well have been key family supports for their grandchildren as their now working children. This is a feature often ignored best summed up in John Donne's 'No Man (or women) is an Island' and the sudden impact of a SAH might well have considerable repercussion outside the patients immediate household.

Table [10] Social Factors by Gender 55-64 year olds

Social Factors Age <55-64 Cohort	Male % [n=199]	Female % [n=411]	
Single	1	1	
Married	88	85	
Separated & Divorced	10	4	
Partnership	4	10	
Children – 0	8	17	
1-2	82	39	
3-4	10	44	
Social Class 1 & 2 (retired)	22 (6)	8 (3)	
3	47 (7)	39 (12)	
4 & 5	21 (3)	29 (8)	
Unemployed / N/A	12	24	

Comparing TAU v NVN	TAU -NVN	TAU -NVN	
Time Off Work – Permanent	12 - 16	6 - 3	
Still off work	42 - 24	14 - 18	
>12 weeks	8 - 12	17 - 9	
13-25 weeks	22 - 42	4 - 19	
No Replies	2 - 4	3 - 6	
No Applicable	n/a - n/a	55 - 45	

Time off-work TAU v NVSN Males $X^2=12.006$ $p<0.007$. Females $X^2= 13.1368$ $p<0.005$

5.5 The 65+ year olds: There were significantly more female 65+ patients than men, most were married or had a partner but % males and 4% females were widowed and 6% males and 20% females had no children. Seven percent of males and 1% of females were still in employment consequently no comparison of return to work was of real relevance. It is noteworthy that this age band contained fewer people in the socio-economic group 1&2 than the other age bands.

Table[11] Social Factors by Gender for 65+ year olds

Social Factors Age 65+ Cohort	Male % [n=115]	Female % [n=329]
Single	1	0
Married	82	80
Separated & Divorced	4	8
Partnership	11	8
Widowed	2	4
Children – 0	6	20
1-2	25	47
3-4 [82%-80%]	68	33
Social Class 1 & 2 [Retired]	10	10
3	52	34
4 & 5	34	44

5.6 The <44 Year old: Hospital & Post-Discharge Experience: As would be expected, there were major statistically significant differences in favour of the Neurovascular-Specialist Nurse psychosocial results as these were based upon the project of regional figures, which had already demonstrated the value of the service over the standard Treatment-As-Usual. Consequently, the focus will be upon the main problems faced by patients and carers and the benefits of the approach. The following tables show the structured responses, based upon the projection of the Wessex data onto the national equivalent NVSN and TAU cohorts.

5.7 In-Patients: Overall the NVSN patients, both men and women, reported better ward communication and confidence in discharge preparation. Moreover, whilst the majority of TAU patients denied that 'nurses were not interested, it's just a job to them', the NVSN patients expressed greater confidence in the ward staff and a greater sense of individualised continuity of care. In regard to the subjective level of post-SAH recovery, there were better scores for the NVSN patients but interestingly, NVSN women had significantly better sense of recovery to return to 'normality' 100-70% than their <44year old male peers, 63% to 53% ($p<0.001$).

5.8 Post-Discharge: Whilst the NVSN patients reported similar but lower rates of physical difficulties (along a 4 point scale) than the TAU patients, it was noted that the <44year old female patients reported

a significantly better rate of subjective recovery, 'On a percentage 0-100% how well do you feel you have recovered since your SAH', for NVSN males 53% indicated between 70-100 to 15% for TAU men 63% NVSN females 30% TAU women. One practical implication of this would be to take pressure off the female patient's carer and possibly their family, facilitating his return to work. Again the NVSN had similar but lower rates of problems at home, fewer NVSN report stress and employment problems although both NVSN sexes reported more than 30% feeling exhausted. The NVSN patients reported less negative pressures on family members in particular 'children found the situation very distressing' for fathers it was 90% to 56% and mother 85% and 75%. Crucially, the TAU patients generally felt less supported and disproportionately needed to call 'unnecessarily' upon GP more than male NVSN patients 19% to 0% and females 31% to 20%, further incurring cost to the service, which also affected the partners of TAU patients more. Male TAU patients reported more sense of "being stressed", 35% to 20% than the NVSN and an even greater gap between female TAU and NVSN patients, 80% to 25%. Furthermore male and female TAU reported feeling more "under serious financial pressure" than NVSN, 30% to 18% males and 36% to 13% females. In regard to male patients 10% of TAU and 38% of NVSN reported that no family member lost work because of them, which would compound some of the above pressures. In brief, whilst many of the SAH patients reflected some of the emotional and physical problems now recognised to be in part related to PTSD (Noble et al, 2008), they affected the NVSN less, which lessened the impact upon their families, especially the children.

Table 12 follows

**Table [12] Patient Responses Experience [No replies excluded * scored as zero]
Totally & Totally Agree v Disagree v Totally Disagree [no replied excluded]**

<44 year old cohort	Male % [n=272]		Female % [n=369]	
	TAU	NVN	TAU	NVN
Hospital Experience	Agree: Disagree		Agree- Disagree	
Dr explained everything to me	90 v 10	88 v 2	50 - 13	63 - 6
Nurse too busy to explain	80 v 13	13 v 65	63 - 13	13 - 30
Unanswered questions about my prognosis	60 v 10	15 v 70	56 - 19	6 - 44
Best way to cope is to rely on Neuro staff	50 v 10	32 v 25	10 - 10	44 - 25
Lack of continuity in seeing Drs & Nurses	10 v 30	20 v 35	19 - 30	12 - 40
No time for Consultant to answer questions	20 v 50	0 v 64	31 - 25	19 - 45
Patient so 'zapped out' can't remember	70 v 5	44 v 10	75 - 25	44 - 13
Neuro Booklet not specific to my questions	30 v 10	56 v 10	81 - 0	56 - 19
Nurses not interested: Just a job to them	0 v 40	0 v 70	0 - 75	0 - 90
I knew what to expect on discharge	20 v 45	45 v 30	13 - 63	50 - 13
I was discharged too soon	20 v 35	18 v 40	31 - 31	6 - 23
I was treated as an individual	30 v 20	63 v 6	40 - 15	75 - 6
Most of the Time I was:-	TAU	NVSN	TAU	NVSN
Frightened	43v 40	30 v 35	95 - 0	49 - 31
Confident	20 v 20	40 v 30	49 - 13	69 - 6
Depressed	50 v 20	40 v 55	86 - 0	55 - 25
Hopeful	60 v 20	85 v 10	80 - 13	70 - 6
Despair	30 v 50	20 v 70	56 - 25	13 - 63
In Pain	70 v 10	60 v 30	94 - 6	38 - 38
Anxious	80 v 5	40 v 20	87 - 6	50 - 25
#Recovery Post SAH status 100%	0	v 8	0	v 13
90-70	15	v 45	30	v 50
60 -50	65	v 35	40	v 24
> 49%	20	v 11	30	v 13
Difficulties Post SAH (4 point scale]				
Limbs	30 - 70	v 33 - 67	63 - 37	v 28- 69
Speech	20 - 80	v 20 - 80	19 - 50	v 6 - 69
Headaches	30 - 50	v 25 - 65	63 - 23	v 39 - 45
Exhaustion	50 - 30	v 56 - 30	45 - 10	v 38 - 38
Concentration	50 - 50	v 40 - 60	80 - 13	v 38 - 44
Memory	40 - 50	v 30 - 59	63 - 12	v 38 - 40

<44 year old cohort continued	Male % [n=272]		Female % [n=369]	
	TAU -	NVN	TAU -	NVN
Problems at Home post SAH				
Employment [Some – None 4 point scale]	49 - 10	v 20 - 70	50 - 30	v 15 - 56
Exhaustion	56 - 10	v 40 - 40	60 - 20	v 31 - 25
Mobility	26 - 38	v 15 - 70	31 - 31	v 13 - 69
Stress	55 - 6	v 40 - 40	54 - 19	v 12 - 63
General Health	56 - 6	v 30 - 50	69 - 19	v 26 - 63
Patient's Perception				
Doubts about Physical Tasks [3 pt scale]	38 - 35	v 30 - 50	13 - 63	v 31 - 35
Worried Would I be normal again	70 - 30	v 13 - 56	100 - 0	v 31 - 38
No further family stress post discharge	0 - 90	v 25 - 38	56 - 0	v 46 - 6
I worry so much I feel ill	30 - 30	v 20 - 60	53 - 44	v 31 - 20
After discharge I lost touch with the Unit	40 - 30	v 20 - 40	88 - 12	v 13 - 70
Family OK at crises	13 - 38	v 50 - 20	19 - 44	v 37 - 44
After discharge I felt depressed	50 - 0	v 40 - 50	88 - 12	v 56 - 32
Difficult to decide aches & pains 'normal'	70 - 20	v 50 - 31	81 - 12	v 56 - 20
Help if told didn't need Unit after discharge	80 - 10	v 38 - 60	74 - 6	v 31 - 50
Worried about SAH impact on family	80 - 10	v 19 - 44	94 - 0	v 16 - 75
I needed medication for anxiety	20 - 19	v 19 - 70	53 - 44	v 9 - 31
Children found situ very distressing	90 - 0	v 56 - 12	85 - 0	v 75 - 6
I have all the support I need	10 - 63	v 50 - 40	41 - 44	v 50 - 13
Sometimes make unnecessary calls to GP	19 - 44	v 0 - 80	31 - 63	v 20 - 64
No member of family lost work due SAH	10 - 70	v 38 - 19	31 - 63	v 53 - 25
SAH brought family closer together	19 - 38	v 70 - 10	50 - 44	v 56 - 6
Too much fuss about stress after SAH	30 - 60	v 63 - 31	13 - 75	v 80 - 6
Family suffered as much as I	80 - 10	v 44 - 6	75 - 25	v 50 - 10
SAH Impact on Partner				
Lost time to care for me	80 - 6	v 16 - 80	13 - 40	v 6 - 48
Was physically ill more often	13 - 16	v 20 - 80	19 - 77	v 19 - 80
Felt emotionally vulnerable	30 - 70	v 13 - 46	38 - 62	v 5 - 90
Needed extra visits to GP	20 - 80	v 9 - 75	80 - 0	v 13 - 87
More family stress	19 - 7	v 20 - 80	20 - 12	v 19 - 41
Generally had difficulty in coping	32 - 63	v 20 - 80	13 - 87	v 12 - 88
Felt under serious financial pressures.	30 - 70	v 18 - 40	36 - 60	v 13 - 87
Experience After Returning home				
Frightened [3 point scale]	40 - 20	v 13 - 33	90 - 6	v 50 - 25
Confident	50 - 30	v 56 - 12	55 - 44	v 47 - 37
Angry	50 - 50	v 31 - 23	45 - 25	v 30 - 13
Depressed	40 - 6	v 40 - 38	78 - 6	v 20 - 35
Cared for	31 - 38	v 70 - 20	74 - 10	v 80 - 19
In Pain	40 - 50	v 19 - 13	40 - 50	v 20 - 25
Stressed	35 - 10	v 20 - 37	80 - 6	v 25 - 50
Hopeful	19 - 31	v 80 - 20	75 - 13	v 50 - 18
Anxious	50 - 30	v 15 - 40	76 - 0	v 18 - 50
GP Knew about SAH	38 - 30	v 50 - 25	38 - 44	v 45 - 20

One practical point was that the NVSN liaising with the families GP to improved collaboration by contributing to appropriate prescribing thus enhancing the GP's role, which the initial TAU study had found was an element in reducing PTSD, but of course most GP's will have had relatively few SAH patients in their careers.

Other Agencies & Post-Discharge Help: Asked about family and other agencies with whom they may have had contact, the family was the mainstay, as would be expected, though again, this was stronger in the NVSN patients than TAU. There were some interesting variations but notably more than 65% of both cohorts said they had had no contact with Community Nurse, those that that did most found them helpful. Whether this reflects something of the situation in the Wessex region and not typical of the rest of the UK, reflects the marked variation found in head-trauma post-discharge care (Pickard et al, 2004). GP's were important and generally reported as being helpful, but as with all the contacts, the NVSN respondents seemed to have lower 'unhelpful' scores than TA patients, though not in regard to any continuing contact with the neurosurgical unit. There are detailed comments about a range of agencies outlined in Appendix 1.

Table [14] Agency Contacts (<44's) post-discharge. How Helpful – Unhelpful Were they? (No = no contact)

Agency Contacts	TAU (n=644) %	NVSN (n=644)%
Agencies	No: Helpful-Unhelpful	No: Helpful- Unhelpful
Community Nurse	65: 65 - 25	76: 57 - 40
GP	9: 72 - 20	21: 84 - 12
Family	1: 84 - 4	1: 96 - 0
Social Worker	75: 54 - 44	84: 89 - 11
Benefits Agency	47: 28 - 75	60: 34 - 60
Consultant @ O.P.	42: 60 - 33	65: 90 - 4
Neighbours	11: 78 - 22	20: 92 - 8
Employers	24 70 - 24	18: 86 - 10

5.9 The 45-54 years. Again the NVSN results were generally significantly better than the majority of TAU patients. Nonetheless both cohorts were generally very positive about the hospital care they received, especially in regard to the Nurses.

As with the <44year olds, females NVSN had a higher reported level of subjective (100-70%) recovery than the males 80% to 71%.

5.10 Post-Discharge: Looking at the physical problems faced by patients on a three point scale it was notable that the females in both groups 'complained' less, although the highest reported NVSN male rate concerned exhaustion 44%, which was actually very similar to the TAU men, whilst 22% denied having such a problem. However, the NVSN men and women reported less being 'stressed' and less problems for their partner. However, in this age band, there was little difference in their children finding the situation distressing. Crucially the NVSN patients reported far less "serious financial pressure" though of course it was a factor in 10% and 12% of men and women patients respectively. In regard to family members losing time off work 35% of TAU and 46% of male NVSN so reported as opposed to the female patients families 21% for TAU and 30% for NVSN.

Finally there was evidence that the GP's were more able to contribute to their patient's rehabilitation as the NVSN people had greater confidence in their GP than the TAU.

Table[15] Totally & Totally Agree v Disagree v Totally Disagree [no replied excluded]

<45-54 year olds	Male %[n=230]		Female % [n=455]	
	TAU	NVN	TAU	NVN
Hospital Experience	Agree: Disagree		Agree- Disagree	
Dr explained everything to me	67 - 8	v 75 - 3	34 - 16	v 71 - 20
Nurse too busy to explain	56 - 40	v 7 - 70	78 - 14	v 10 - 58
Unanswered questions about my prognosis	44 - 22	v 18 - 44	67 - 31	v 20 - 52
Best way to cope is to rely on Neuro staff	44 - 22	v 59 - 7	71 - 20	v 60 - 10
Lack of continuity in seeing Drs & Nurses	33 - 33	v 11 - 57	49 - 16	v 29 - 48
No time for Consultant to answer questions	39 - 33	v 15 - 57	39 - 42	v 13 - 55
Patient so 'zapped out' can't remember	55 - 11	v 44 - 33	57 - 21	v 39 - 29
Neuro Booklet not specific to my questions	60 - 11	v 4 - 22	50 - 25	v 23 - 62
Nurses not interested: Just a job to them	5 - 70	v 5 - 88	3 - 65	v 0 - 86
I knew what to expect on discharge	22 - 67	v 40 - 37	21 - 61	v 48 - 29
I was discharged too soon	38 - 44	v 12 - 65	29 - 64	v 10 - 48
I was treated as an individual	67 - 11	v 80 - 8	71 - 12	v 78 - 8
Most of the Time I was:-Frightened	55 - 33	v 33 - 37	60 - 24	v 35 - 40
Confident	55 - 33	v 64 - 15	48 - 38	v 40 - 29
Depressed	33 - 33	v 22 - 47	35 - 35	v 24 - 36
Hopeful	89 - 11	v 68 - 23	53 - 18	v 58 - 7

Despair	22 - 44 v 11 - 55	34 - 32 v 10 - 60
In Pain	66 - 22 v 36 - 33	46 - 24 v 15 - 55
Anxious	55 - 11 v 22 - 41	52 - 22 v 30 - 36
Recovery Post SAH status 100%	0 v 15	0 v 10
90-70	44 v 56	58 v 70
60 -50	18 v 14	20 v 6
> 49%	38 v 15	22 v 14
Difficulties Post SAH (4 point scale]		
Limbs	33 - 56 v 15 - 58	50 - 43 v 10 - 65
Speech	28 - 68 v 10 - 70	23 - 68 v 3 - 67
Headaches	55 - 22 v 30 - 22	64 - 36 v 32 - 38
Exhaustion	40 - 20 v 44 - 22	42 - 25 v 32 - 36
Concentration	54 - 32 v 30 - 33	67 - 24 v 36 - 36
Memory	67 - 22 v 35 - 20	67 - 31 v 40 - 37
Problems at Home (45-54yrs)		
Employment [Some – None 4 point scale]	44 - 22 v 15 - 60	42 - 57 v 18 - 58
Exhaustion	46 - 20 v 26 - 43	38 - 30 v 32 - 38
Mobility	33 - 44 v 15 - 59	46 - 52 v 19 - 78
Stress	33 - 37 v 18 - 49	66 - 30 v 20 - 44
General Health	33 - 56 v 15 - 58	46 - 52 v 18 - 52
Patient's Perception		
Doubts about Physical Tasks [3 pt scale]	60 - 22 v 52 - 15	57 - 40 v 39 - 48
Worried Would I be normal again	67 - 33 v 26 - 30	71 - 29 v 18 - 68
No further family stress post discharge	22 - 78 v 25 - 55	12 - 86 v 13 - 58
I worry so much I feel ill	22 - 78 v 20 - 48	28 - 64 v 19 - 44
After discharge I lost touch with the Unit	56 - 22 v 7 - 67	71 - 21 v 22 - 55
Family OK at crises	22 - 56 v 20 - 22	19 - 36 v 78 - 21
After discharge I felt depressed	70 - 20 v 33 - 44	64 - 29 v 55 - 37
Difficult to decide aches & pains 'normal'	78 - 11 v 50 - 25	79 - 14 v 51 - 25
Help if told didn't need Unit after discharge	56 - 28 v 40 - 50	64 - 28 v 38 - 42
Worried about SAH impact on family	78 - 0 v 15 - 65	79 - 21 v 19 - 54
I needed medication for anxiety	20 - 55 v 11 - 60	48 - 12 v 32 - 57
Children found situ very distressing	60 - 5 v 59 - 4	70 - 5 v 75 - 0
I have all the support I need	10 - 66 v 67 - 15	19 - 58 v 64 - 21
Sometimes make unnecessary calls to GP	37 - 30 v 12 - 78	46 - 43 v 10 - 71
No member of family lost work due SAH	33 - 56 v 46 - 30	21 - 71 v 30 - 70
SAH brought family closer together	60 - 22 v 67 - 20	71 - 24 v 58 - 18
Too much fuss about stress after SAH	22 - 67 v 52 - 10	24 - 64 v 67 - 7
Family suffered as much as I	77 - 4 v 41 - 56	57 - 29 v 55 - 45
SAH Impact on Partner		
Lost time to care for me	12 - 88 v 15 - 80	17 - 42 v 10 - 78
Was physically ill more often	22 - 78 v 11 - 88	40 - 54 v 21 - 79
Felt emotionally vulnerable	33 - 66 v 4 - 50	71 - 29 v 24 - 45
Needed extra visits to GP	22 - 66 v 19 - 70	21 - 79 v 32 - 64
More family stress	66 - 11 v 7 - 56	36 - 64 v 19 - 77
Generally had difficulty in coping	22 - 66 v 18 - 78	21 - 79 v 18 - 80
Felt under serious financial pressures.	22 - 67 v 10 - 66	29 - 71 v 12 - 80
Experience After Returning home		
Frightened [3 point scale]	55 - 45 v 33 - 60	36 - 50 v 40 - 50
Confident	15 - 30 v 67 - 10	10 - 61 v 36 - 14
Angry	43 - 30 v 16 - 67	41 - 36 v 13 - 50
Depressed	63 - 11 v 25 - 67	36 - 50 v 13 - 61
Cared for	30 - 44 v 89 - 11	44 - 36 v 90 - 5
In Pain	26 - 30 v 16 - 66	44 - 44 v 29 - 46
Stressed	63 - 11 v 15 - 46	58 - 28 v 20 - 64
Hopeful	38 - 48 v 78 - 11	39 - 35 v 61 - 28
Anxious	66 - 11 v 15 - 56	67 - 10 v 12 - 67
GP Knew About SAH [3 point scale]	33 - 44 v 52 - 29	39 - 33 v 57 - 29

In regard to the 45-54 year group's post-discharge contact, as with the youngest group of patients, the NVSN had a more helpful response from family, neighbours and the home unit, but proportionally less contact with other agencies as it appeared that the NVSN was far better equipped to deal with the SAH family's needs.

Table [16] Agency Contact (45-54) How Helpful - Unhelpful

<45-54 Agencies & How Helpful	TAU (n=691)%		NVSN (n=691)%	
	None.	Helpful- Unhelpful	None.	Helpful- Unhelpful
Community Nurse	62:	68 - 22	74:	60 - 40
GP	9:	80 - 20	16:	88 - 12
Family	2:	83 - 6	1:	96 - 1
Social Worker	76:	54 - 43	90:	92 - 8
Benefits Agency	55:	36 - 60	64:	32 - 64
Consultant @ O.P.	38:	70 - 28	54:	88 - 8
Neighbours	8:	80 - 15	18:	94 - 2
Employers	30:	80 - 20	32:	85 - 12

5.11 The 55-64 year olds: Whilst both male and female NVSN patients had a significantly better reported post SAH recovery than the TAU patients, it was noteworthy that this age band had higher rates of recovery than the younger age bands. This perhaps might be expected because of possible generational aspects and established life-styles and resilience (Pritchard, 1999). Moreover both sexes had relatively low post-discharge stress and less financial pressures. Interestingly the NVSN males reported relatively high levels of 'children's distress', 71%, reminding us that acute illness in a family member can impact upon even adult children. Nonetheless, whilst not as high as TAU, employment problems were an issue, seen in patients reporting family members losing time off work. With 66% of TAU and 71% of male NVSN Not being off work but for female 55-64 patients 44% of TAU and 31% of NVSN having economic problems added to their psychosocial pressures.

Table [17]Totally & Totally Agree v Disagree v Totally Disagree [no replied excluded]

<55-64 year olds	Male % [n=199]		Female % [n=411]	
	TAU -	NVN	TAU -	NVN
Hospital Experience	Agree: Disagree		Agree- Disagree	
Dr explained everything to me	59 - 24	80 - 20	44- 30	67 - 11
Nurse too busy to explain	60 - 20	12 - 65	65 - 30	6 - 60
Unanswered questions about my prognosis	60 - 20	29 -49	43 - 33	10 - 48
Best way to cope is to rely on Neuro staff	59 - 30	59 - 33	72 - 10	40 - 47
Lack of continuity in seeing Drs & Nurses	80 - 20	24 - 69	43 - 39	20 - 47
No time for Consultant to answer questions	50 - 40	24 - 34	39 - 27	13 - 41
Patient so 'zapped out' can't remember	80 - 20	58 - 22	83 - 10	44 - 32
Neuro Booklet not specific to my questions	40 - 40	71 - 22	50 - 11	38 - 44
Nurses not interested: Just a job to them	10 - 40	8 - 79	8 - 85	3 - 90
I knew what to expect on discharge	40 - 50	48 - 41	11 - 49	13 - 67
I was discharged too soon	20 - 80	24 - 70	35 - 59	13 - 57
I was treated as an individual	70 - 12	90 - 10	42 - 23	61 - 10
Most of the Time I was:-				
Frightened	40 - 60	36 - 36	43 - 27	21 - 38
Confident	40 - 60	40 - 34	28 - 38	35 - 20
Depressed	60 - 20	22 - 31	29 - 33	19 - 30
Hopeful	60 - 40	66 - 18	38 - 23	50 - 28
Despair	80 - 20	22 - 47	24 - 39	16 - 40
In Pain	70 - 20	22 - 57	28 - 39	16 - 28
Anxious	60 - 40	30 - 39	48 - 21	25 - 35
Recovery Post SAH status 100%	0	v 20	5	v 18
90-70	50	v 55	25	v 46
60-50	30	v 15	45	v 24
> 49%	20	v 10	25	v 12

Problems at Home (55-64)		
Employment [Some – None 4 point scale]	40 - 60 v 35 - 52	6 - 40 v 10 - 53
Exhaustion	30 - 50 v 27 - 63	28 - 55 v 28 - 53
Mobility	50 - 50 v 22 - 72	33 - 53 v 22 - 41
Stress	60 - 4- v 22 - 63	37 - 43 v 17 - 45
General Health	50 - 50 v 36 - 58	40 - 49 v 23 - 40
Patient's Perception		
Doubts about Physical Tasks [3 pt scale]	30 - 50 v 35 - 48	43 - 49 v 31 - 30
Worried Would I be normal again	70 - 30 v 30 - 59	89 - 11 v 35 - 36
No further family stress post discharge	40 - 60 v 60 - 40	30 - 69 v 16 - 50
I worry so much I feel ill	50 - 50 v 41 - 38	27 - 72 v 25 - 65
After discharge I lost touch with the Unit	70 - 30 v 29 - 63	67 - 33 v 10 - 55
Family OK at crises	50 - 50 v 49 - 40	37 - 40 v 56 - 36
After discharge I felt depressed	60 - 40 v 57 - 22	56 - 44 v 34 - 45
Difficult to decide aches & pains 'normal'	90 - 10 v 53 - 29	83 - 11 v 41 - 21
Help if told didn't need Unit after discharge	30 - 50 v 40 - 40	38 - 44 v 19 - 43
Worried about SAH impact on family	70 - 30 v 71 - 10	67 - 17 v 19 - 50
I needed medication for anxiety	40 - 50 v 29 - 39	30 - 66 v 25 - 48
Children found situ very distressing	40 - 40 v 71 - 20	25 - 65 v 30 - 43
I have all the support I need	19 - 80 v 60 - 30	10 - 59 v 66 - 33
Sometimes make unnecessary calls to GP	40 - 60 v 41 - 56	19 - 72 v 28 - 58
No member of family lost work due SAH	60 - 40 v 71 - 18	44 - 50 v 31 - 35
SAH brought family closer together	40 - 40 v 71 - 11	30 - 50 v 72 - 22
Too much fuss about stress after SAH	30 - 60 v 70 - 11	25 - 61 v 18 - 40
Family suffered as much as I	70 - 30 v 53 - 47	72 - 18 v 19 - 20
SAH Impact on Partner		
Lost time to care for me	30 - 70 v 10 - 90	28 - 72 v 10 - 90
Was physically ill more often	20 - 80 v 29 - 70	22 - 78 v 25 - 75
Felt emotionally vulnerable	40 - 60 v 35 - 60	45 - 55 v 16 - 43
Needed extra visits to GP	10 - 90 v 12 - 72	22 - 78 v 10 - 90
More family stress	30 - 70 v 12 - 60	22 - 78 v 19 - 71
Generally had difficulty in coping	53 - 47 v 10 - 80	12 - 88 v 7 - 93
Felt under serious financial pressures.	20 - 80 v 0 - 90	17 - 83 v 13 - 87
Experience After Returning home		
Frightened [3 point scale]	30 - 30 v 45 - 35	58 - 31 v 38 - 48
Confident	24 - 52 v 50 - 50	10 - 50 v 48 - 39
Angry	60 - 30 v 24 - 53	28 - 50 v 20 - 52
Depressed	50 - 30 v 60 - 40	48 - 42 v 40 - 38
Cared for	76 - 24 v 90 - 0	78 - 22 v 73 - 20
In Pain	80 - 10 v 40 - 43	24 - 56 v 16 - 54
Stressed	63 - 37 v 40 - 45	44 - 42 v 30 - 55
Hopeful	64 - 18 v 70 - 20	34 - 44 v 67 - 13
Anxious	40 - 40 v 25 - 45	43 - 33 v 23 - 67
GP Knew About SAH [3 point scale]	50 - 48 v 60 - 20	47 - 40 v 58 - 38

As with the other age bands, families and neighbours scored highly and with greater expressions of satisfaction with the home unit in the NVSN, but the availability of the NVSN was preferred to the community services, but as with all the work-aged patient there was marked criticism of the Benefits Agencies. However as all patients apparently did not use the Benefit Agency facilities it might reflect the disproportionate 'middle-class' weighting in the cohorts, and they had forms of employment, which enabled them to be independent.

Table [18] follows

Table [18] Post-Discharge Agency Contact: How Helpful -Unhelpful

Agency Contact 55-64	TAU (n=626) %	NVSN (n=626)%
	None. Helpful - Unhelpful	None. Helpful - Unhelpful

How Helpful ?	No: Helpful-Unhelpful	No: Helpful- Unhelpful
Community Nurse	60: 63 - 33	77: 60 - 40
GP	5: 81 - 18	15: 88 - 12
Family	2: 83 - 6	1: 96 - 0
Social Worker	74: 50 - 38	84: 90 - 5
Benefits Agency	60: 34 - 66	66: 35 - 65
Consultant @ O.P.	42: 70 - 24	58: 90 - 2
Neighbours	7 : 82 - 18	18: 94 - 0
Employers	35: 79 - 18	34: 86 - 14

5.12 The 65years + : It was noteworthy that this age band reported the most satisfied post SAH recovery levels. However, this may be a generational factor as older people are less likely to 'complain' (Pound et al, 1999) and appear to have either an extra level of resilience or acceptance as 87% of male and 70% of female NVSN reported a 70-100% recovery level and of the TAU man and women 63% and 50% respectively between 70-100% recovery.

Both cohorts were relatively positive about their hospital experience. Whilst all were over retirement age, some were still in employment but on average both NVSN and TAU patients reported over 10% that some family members lost time off work due to their SAH, a reminder that illness has implications for families, even or especially with elderly relatives.

At this stage some of the open-ended comments are valuable as the NVSN respondents valued the fact of being treated with dignity and not being thought

Table [19] Totally & Totally Agree v Disagree v Totally Disagree [no replied excluded]

65+ year olds	Male % [n=115]	Female % [n=329]
	TAU - NVN	TAU - NVN
Hospital Experience	Agree: Disagree	Agree- Disagree
Dr explained everything to me	42 - 36 v 50 - 10	27 - 33 v 68 - 14
Nurse too busy to explain	21 - 35 v 23 - 60	67 - 13 v 4 - 68
Unanswered questions about my prognosis	42 - 28 v 10 - 37	43 - 26 v 24 - 64
Best way to cope is to rely on Neuro staff	49 - 21 v 12 - 25	60 - 10 v 68 - 8
Lack of continuity in seeing Drs & Nurses	30 - 42 v 7 - 40	37 - 37 v 24 - 60
No time for Consultant to answer questions	28 - 42 v 20 - 40	33 - 40 v 14 - 62
Patient so 'zapped out' can't remember	71 - 14 v 15 - 30	61 - 14 v 36 - 30
Neuro Booklet not specific to my questions	28 - 14 v 12 - 20	27 - 13 v 52 - 24
Nurses not interested: Just a job to them	0 - 85 v 0 - 80	0 - 64 v 0 - 76
I knew what to expect on discharge	28 - 42 v 31 - 20	37 - 37 v 50 - 24
I was discharged too soon	28 - 10 v 35 - 28	33 - 33 v 8 - 64
I was treated as an individual	57 - 14 v 50 - 5	80 - 7 v 72 - 0
Most of the Time I was:- Frightened	28 - 49 v 20 - 38	37 - 43 v 14 - 62
Confident	31 - 20 v 28 - 24	57 - 23 v 58 - 12
Depressed	20 - 20 v 29 - 43	37 - 50 v 12 - 60
Hopeful	33 - 30 v 50 - 20	70 - 5 v 64 - 6
Despair	29 - 70 v 12 - 60	13 - 77 v 8 - 74
In Pain	21 - 49 v 13 - 40	20 - 40 v 16 - 52
Anxious	28 - 42 v 20 - 32	37 - 33 v 24 - 48
Recovery Post SAH status 100%	5 v 13	10 v 20
90-70	58 v 74	40 v 50
60-50	20 v 10	35 v 22
> 49%	17 v 3	15 v 8

65+ year olds continued	Male % [n=115]		Female % [n=329]	
	TAU	NVN	TAU	NVN
Difficulties post SAH (point scale)				
Limbs	14 - 77	v 5 - 63	60 - 13	v 30 - 44
Speech	10 - 71	v 14 - 65	27 - 54	v 20 - 64
Headaches	29 - 43	v 14 - 45	50 - 40	v 28 - 56
Exhaustion	28 - 48	v 23 - 50	34 - 30	v 42 - 42
Concentration	34 - 48	v 25 - 38	60 - 33	v 22 - 52
Memory	57 - 21	v 35 - 48	60 - 27	v 36 - 54
Problems at Home (65+)				
Employment [Some – None 4 point scale]	0 - 71	v 6 - 68	6 - 67	v 4 - 64
Exhaustion	24 - 43	v 20 - 40	36 - 36	v 34 - 38
Mobility	28 - 54	v 13 - 50	50 - 37	v 20 - 54
Stress	14 - 71	v 18 - 68	27 - 53	v 20 - 60
General Health	21 - 57	v 13 - 50	43 - 53	v 32 - 48
Patient's Perception				
Doubts about Physical Tasks [3 pt scale]	34 - 49	v 50 - 44	56 - 39	v 60 - 36
Worried Would I be normal again	50 - 36	v 30 - 36	50 - 37	v 36 - 44
No further family stress post discharge	13 - 62	v 43 - 43	12 - 68	v 23 - 46
I worry so much I feel ill	50 - 37	v 24 - 71	44 - 36	v 20 - 74
After discharge I lost touch with the Unit	33 - 48	v 5 - 63	47 - 40	v 4 - 80
Family OK at crises	29 - 57	v 25 - 38	24 - 58	v 46 - 39
After discharge I felt depressed	29 - 57	v 13 - 50	52 - 32	v 33 - 30
Difficult to decide aches & pains 'normal'	50 - 36	v 38 - 35	60 - 27	v 36 - 48
Help if told didn't need Unit after discharge	25 - 38	v 28 - 56	54 - 34	v 24 - 58
Worried about SAH impact on family	50 - 35	v 13 - 50	54 - 33	v 12 - 74
I needed medication for anxiety	14 - 71	v 13 - 70	60 - 12	v 13 - 63
Children found situ very distressing	81 - 2	v 64 - 0	58 - 4	v 64 - 12
I have all the support I need	38 - 62	v 71 - 14	14 - 74	v 66 - 20
Sometimes make unnecessary calls to GP	49 - 20	v 38 - 15	62 - 24	v 7 - 70
No member of family lost work due SAH	71 - 14	v 55 - 10	47 - 13	v 72 - 8
SAH brought family closer together	63 - 10	v 71 - 14	76 - 20	v 68 - 30
Too much fuss about stress after SAH	71 - 20	v 58 - 15	30 - 64	v 72 - 24
Family suffered as much as I	67 - 29	v 25 v 35	46 - 49	v 12 - 30
SAH Impact on Partner				
Lost time to care for me	14 - 86	v 20 - 78	0 - 80	v 4 - 70
Was physically ill more often	14 - 85	v 20 - 75	13 - 80	v 14 - 80
Felt emotionally vulnerable	14 - 86	v 5 - 80	27 - 67	v 4 - 70
Needed extra visits to GP	57 - 43	v 13 - 47	7 - 86	v 12 - 80
More family stress	29 - 70	v 13 - 60	15 - 80	v 12 - 88
Generally had difficulty in coping	29 - 71	v 10 - 60	13 - 80	v 8 - 78
Felt under serious financial pressures.	14 - 86	v 13 - 80	13 - 80	v 20 - 76
Experience After Returning home				
Frightened [3 point scale]	38 - 38	v 40 - 50	60 - 27	v 54 - 20
Confident	60	v 38 v 85 - 14	14 - 72	v 67 - 20
Angry	13 - 87	v 13 - 74	67 - 23	v 24 - 60
Depressed	63 - 37	v 34 - 54	68 - 30	v 46 - 40
Cared for	63 - 10	v 78 - 14	67 - 13	v 56 - 4
In Pain	43 - 21	v 13 - 50	13 - 60	v 24 - 56
Stressed	38 - 28	v 40 - 50	60 - 24	v 30 - 40
Hopeful	85 - 10	v 80 - 10	80 - 10	v 76 - 14
Anxious	14 - 71	v 13 - 80	67 - 27	v 14 - 67-
GP Knew About SAH [3 point scale]	48 - 34	v 50 - 13	60 - 20	v 56 - 38

The post-discharge contact in this post-work age group was especially heavy upon families, neighbours and the GP, virtually none reporting that they were not in contact with the GP. The demands upon carers have over the past decade increasingly been recognised (Drummond et al, 1997; Henman, 1998; Hop et al, 1998; Hutter et al, 1998; Rowlands 1998) and of course with women being more involved in employment than 20 or more years ago, there are in effect, new fiscal costs to families who respond to their family member, often a parent, than ever before.

Table [20] follows

Table [20] Agency Contact: How Helpful Unhelpful

65+ year olds continued	TAU[n=446] None. Helpful -Unhelpful	NVSN (446) % None. Helpful- Unhelpful
How Helpful ?	No: Helpful-Unhelpful	No: Helpful- Unhelpful
Community Nurse	40: 63 - 18	61: 63 - 33
GP	0: 77 - 11	2: 78 - 9
Family	5: 80 - 5	4: 88 - 2
Social Worker	61: 55 - 18	64: 79 - 2
Benefits Agency	12: 47 - 33	11: 42 - 39
Consultant @ O.P.	28: 77 - 11	27: 81 - 0
Neighbours	4: 84 - 3	7: 83 - 2
Employers	97: 92 - 0	100: n/a

Finally, the role of the NVSN is succinctly summarised by a patient who gave permission to quote him. *"Unusually I remember much of my in-patient experience- I was fortunate to have had surgery of the very highest international level. But the second outstanding feature was the NVSN. She was available to deal with all those little questions, which if they had not been dealt with would have become major barriers to my recovery, adding to my families distress"* A' Patient's Voice (A Senior Military Person).

6. CARERS PSYCHOSOCIAL FINDINGS

6.1 Social Factors . The key difference between patients and their carers was the majority of carers, especially in the early weeks, were mainly men. Moreover as men earn more than women (Social Trends, 2008) the earlier estimates of lost wages and salaries means this was a deliberate cautious under-estimate.

Most primary carers were the patient's spouse or live in partner or a family member. Sometimes, whilst the man would be the primary carer he had some help from female members of the wider family, such as mother-in-law, sisters and sister-in-laws

Table 21 indicates the patient's primary carer, out of the 152 non-partner carers, all but 20 were women, these being mothers or sisters or sisters-in-law. There were 1,476 primary carers who were men and 901 women. Thus 62% of men were carers and 38% were women, which when compared with the sex breakdown of patients, 816 men to 1564 females is statistically significantly different, in that proportionately females relatives significantly more often cared for men not their husbands or a female relatives, especially in the older age bands, than did men.

Table [21] The Sex and Age of Carers of Patients

Age & Sex [Not Partner]	Males [n.p]	Females [n.p]
<44	361 [4]	252 [24]
45-54	428 [3]	226 [28]
55-64	393 [5]	190 [22]
65+	274 [8]	101 [58]
Totals	1456 [20*]	769 [132*]

n.p.= not partner, other family member. $X^2= 89.01$ 9 f/f $p<0.0001$

6.2 Carers Age Bands and Psychosocial Outcomes. As would be expected from projecting the Wessex outcomes onto the National cases, overall the carers served by the NVSN had significant better psychosocial outcomes than the TAU carers. It must be stressed that whilst some problems remained

for the SNVN families, issues of communication both in and post hospital were greatly superior, as was having lower levels of stress and financial problems, and generally the adverse impact of the SAH was less than TAU carers, but some difficulties remain, but crucially they were resolved earlier.

Overall, as with the patients, the NVSN outcomes were slightly better in the two younger age groups, <55, whilst the oldest age band 65+, whilst having less marked problems than their TAU peers, had proportionately more 'unsure' responses and were slightly less 'definite' in either total agreement or total disagreement..

6.3 Community Services. What might be considered surprising was the relative low contact these SAH families had with a number of the Community Services. The probable reason for this comes from the 'opened-ended response', when for example a number of Community Nurses told the families "we don't do neuro", indeed a little more than a third saw a Community Nurse. The impress was given that some staff lacked confidence in dealing with neurosurgical patients, perhaps in part because of the relative infrequency.

However, the importance of care in the community was seen in the original Wessex study focus upon the family's views of the GP service. Where they had expressed 'confidence' in the GP's knowledge "about SAH", they had a small but significant better psychosocial outcome, and as became clear from the open-ended response. Their GP had engaged and supported them through the difficult times, which lessened the TAU profound sense of isolation. The advent of the NVSN paradoxically, apart from the GP, meant that the other services were used slightly less but the families satisfaction with those services improved, not least because the NVSN were able to liaise and utilise them where appropriate. The most striking finding was the relatively high level of families who found the Benefits Agency 'unhelpful', which as virtually half the families had used the service, is a matter of concern. Equally the fact that more than half had not bothered to use the Benefits Agency is a further indicator of the socio-economic grouping to which most patients belonged.

6.4 The Under 44 year olds. As would be expected the NVSN carers psychosocial outcomes were markedly better for the <44-age band. Salient features was that the NVSN carers did not 'feel left out' of the treatment and care of their relative and were more positive in hopeful outcome. Nonetheless even amongst the NVSN men more than 20% felt stressed and had financial pressures, higher than the female carers, which as the majority would have children, reminds us of the continuing impact upon more than adults of a SAH incident.

When patients returned home, again nearly a quarter of men and women carers felt the pressure of caring for their relative, even though they reported they had significantly "all the support we need", reflected in 28% male and 30% female carer reporting they felt stressed.

In terms of other agency help, it is noteworthy that more than half (53%) of male carers had contact with the Benefits agency and for the most part found to be unhelpful (75%, 60%female).

Finally whilst the GP was the most frequent 'professional' support and the NVSN carers gave the GP higher 'helpful' scores, 12% were graded as 'unhelpful'..

**Table [22] Carers Experience [No replies excluded * scored as zero]
Totally & Totally Agree v Disagree v Totally Disagree [no replied excluded]**

<44 year old cohort	Male % [n=365] TAU - NVN	Female % [n=276] TAU - NVN
Hospital Experience	Agree: Disagree	Agree- Disagree
Failed to prepare us for what was happening	63 - 24 v 15- 75	58 - 31 v 7 - 76
It would have helped if we'd been asked how were we' going to cope at home	85 - 12 v 0 - 65	80 - 14 v 0 - 64
Information about medication was also made clear to us	45 - 42 v 74 - 6	40- 6 v 64 - 10
Only way to stop worrying was to depend upon neuro staff	72 - 12 v 58 - 40	72 - 20 v 52 - 34
Consultants never had enough time with relatives	74 - 18 v 32 - 68	70 - 12 v 36 - 56
I knew what to expect when my relative left hospital	12 - 73 v 48 - 36	10 - 84 v 39 - 24
My relative left neuro far too soon	81 - 10 v 30 - 54	72 - 8 v 36 - 48
Patients can't remember so relatives need to be informed	52 - 28 v 88 - 2	76- 12 v 64 - 10
Booklet helpful but we needed specific answers	60 - 14 v 80 - 2	72 - 12 v 70 - 26
Communication between staff & relative mainly very good	24 - 56 v 88 - 4	32 - 44 v 72 - 6
Most of the Time I was:- Hopeful	75 - 10 v 84 - 0	78 - 4 v 86 - 0
Felt Left Out	24 - 48 v 2 - 78	22 - 58 v 4 - 72
Anxious	76 - 4 v 84 - 1	82 - 6 v 79 - 0
My Problems Post SAH (4 point scale]		
Finance	32 - 48 v 24 - 38	40 - 52 v 32 - 48
Mobility	19 - 70 v 12 - 78	24 - 68 v 18 - 74
Stress	52 - 22 v 21 - 58	58 - 12 v 24 - 48
General Health	32 - 40 v 12 - 64	28 - 44 v 20 - 58
Post-Discharge		
Confident in our GP re SAH	30 - 30 v 48 - 20	39 - 28 v 50 - 18
I felt no stress when relative returned	25 - 40 v 22- 30	40 - 44 v 30 - 54
After the crisis there was no further family stress	18 - 40 v 78 - 10	22 - 56 v 66 - 18
Worries about my relative affected my work	78- 8 v 30 - 52	66 - 10 v 28 - 56
We made extra calls on GP for reassurance	56 - 30 v 10 - 84	58 - 15 v 10 - 84
Being unsupported put extra strains on family	58 - 22 v 24 - 70	54 - 30 v 26 - 78
It would helped knowing consultant had discharged us		
I needed medication for the worry	72- 18 v 22 - 60	68 - 28 v 20 - 54
Unresolved worries interfered with relatives recovery	26 - 40 v 8 - 90	40- 44 v 28 - 52
My family had all the support we need		
Too much fuss is made about stress with SAH	56 - 34 v 25 - 60	58 - 38 v 28 - 58
	10 - 80 v 64 - 20	15 - 72 v 64 - 18
	35 - 55 v 10 - 78	45 - 52 v 5 - 68
Emotional State at Home (<44yrs)		
Confident	54 - 36 v 66 - 20	48 - 30 v 70- 28
Stressed	42 - 24 v 28 - 64	46 - 26 v 30 - 58

6.5 The 45-54 year age band: Table [18] shows the specific results for the 45-54 year group with the NVSN carers doing better than TAU carers. Notable features were their involvement with the treatment and care plan for their relative. However more than 20% of both genders had financial pressures linked to the SAH and more than a quarter, 31% and 26% felt that unresolved worries interfered with their relative recovery and whilst almost 66% of NVSN carers to 25% of TAU carers did not feel 'stress at home', it is a reminder of the ongoing the implications of a SAH upon other members of the family. In respect to other agencies, Benefits Agency was predominately found unhelpful though NVSN carers found their GP more helpful, only 12% expressing negatives. However in this age band of the quarter that had contact with the Community Nurse, 40% did not find them helpful.

**Table [23] Carers Experience [No replies excluded * scored as zero]
Totally & Totally Agree v Disagree v Totally Disagree [no replied excluded]**

<45-54 year old cohort	Male % [n=431] TAU - NVN	Female % [n=254] TAU - NVN
Hospital Experience	Agree: Disagree	Agree- Disagree
Failed to prepare us for what was happening	59- 27 v 12 - 75	60 - 30 v 14 - 80
It would have helped if we'd been asked how were we' going to cope at home	80 - 10 v 0 - 24	81 - 12 v 0 - 38
Information about medication was also made clear to us	40 - 50 v 72 - 18	44 - 48 v 67 - 15

Only way to stop worrying was to depend upon neuro staff	64 - 14 v 40 - 44	68 - 15 v 44 - 36
Consultants never had enough time with relatives	62 - 20 v 48 - 40	66- 18 v 52 - 40
I knew what to expect when my relative left hospital	13 - 68 v 54 - 32	14 - 70 v 50 - 34
My relative left neuro far too soon	86 - 12 v 30 - 58	88 - 10 v 28 - 62
Patients can't remember so relatives need to be informed	50- 40 v 92 - 2	46- 44 v 88 - 8
Booklet helpful but we needed specific answers	55- 21 v 92 - 5	57 - 22 v 85 - 10
Communication between staff & relative mainly very good	34 - 58 v 92 - 4	40 - 56 v 88 - 6
Most of the Time I was:- Hopeful	76 - 14 v 90 - 0	70 - 12 v 92 - 1
Felt Left Out	26 - 64 v 5 - 80	30 - 60 v 10 - 82
Anxious	77 - 6 v 84 - 0	80 - 10 v 78 - 0
My Problems Post SAH (4 point scale]		
Finance	30 - 58 v 24 - 40	34 - 56 v 23 - 38
Mobility	19 - 68 v 20 - 54	20 - 60 v 22 - 48
Stress	34 - 40 v 14 - 64	38 - 38 v 12 - 60
General Health	24 - 48 v 11 - 64	30 - 40 v 16 - 61
Post-Discharge		
Confident in our GP re SAH	36 - 38 v 49 - 26	38 - 34 v 45 - 25
I felt no stress when relative returned	40 - 30 v 30 - 60	34 - 30 v 22 - 58
After the crisis there was no further family stress	22- 34 v 80 - 12	18 - 34 v 70 - 16
Worries about my relative affected my work	68 - 24 v 40 - 52	76 - 20 v 36 - 40
We made extra calls on GP for reassurance	39 - 40 v 8 - 80	54 - 36 v 12 - 86
Being unsupported put extra strains on family	44 - 30 v 28 - 66	54 - 32 v 34 - 58
It would help knowing consultant had discharged us		
I needed medication for the worry	72 - 18 v 20 - 54	68 - 24 v 26 - 44
Unresolved worries interfered with relatives recovery	18 - 48 v 8 - 90	38 - 56 v 15 - 74
My family had all the support we need		
Too much fuss is made about stress with SAH	56 - 40 v 31 - 58	50 - 38 v 26 - 59
	10 - 64 v 60 - 20	12 - 74 - v 52 - 24
	40 - 40 v 10 - 73	44 - 54 v 7 - 84
Emotional State at Home (<45-54yrs)		
Confident	66 - 18 v 88 - 0	64 - 22 v 86 - 10
Stressed	34 - 24 v 30 - 68	39 - 30 v 36 - 61

6.6 The 55-64year age band.: Table [19] outlines their structured responses to the psychosocial outcomes.

This age band felt very involved and the males expressed the lowest level of being “stressed at home”, but 30% expressed concern at financial pressures, with more than 20% for both gender finding unresolved worries impairing their relatives rehabilitation.

Again the Benefits Agency were criticised but it is noted here that of all the ‘other’ supports in this and all the age bands neighbours and employers scored highly on being ‘helpful’, even though a small proportion of SAH patients became unemployed because of their SAH, although at a lower rate than the TAU.

**Table [24] Carer Experience [No replies excluded * scored as zero]
Totally & Totally Agree v Disagree v Totally Disagree [no replied excluded]**

Carers 54-64 old cohort	Male % [n=398]	Female % [n=212]
	TAU - NVN	TAU - NVN
Hospital Experience	Agree: Disagree	Agree- Disagree
Failed to prepare us for what was happening	60 - 30 v 12 - 74	56 - 28 v 8 - 80
It would have helped if we'd been asked how were we' going to cope at home	74 - 12 v 0 - 54	80 - 8 v 0 - 48
Information about medication was also made clear to us	40 - 46 v 72 - 15	40 - 44 v 70 - 12
Only way to stop worrying was to depend upon neuro staff	70 - 10 v 38 - 40	72 - 11 v 35 - 33
Consultants never had enough time with relatives	55- 18 v 20 - 70	52 - 20 v 15 - 66
I knew what to expect when my relative left hospital	10 - 64 v 54 - 33	12 - 54 v 54 - 40
My relative left neuro far too soon	80 - 5 v 25 - 60	82 - 10 v 17 - 55
Patients can't remember so relatives need to be informed	48 - 39 v 92 - 2	38 - 42 v 90 - 2

Booklet helpful but we needed specific answers	57 - 20 v 80 - 5	56 - 17 v 84 - 2
Communication between staff & relative mainly very good	30 - 50 v 88 - 3	33 - 48 v 89 - 4
Most of the Time I was:- Hopeful	78 - 8 v 94 - 0	74 - 10 v 90 - 0
Felt Left Out	12 - 58 v 0 - 80	17 - 60 v 3 - 66
Anxious	70 - 5 v 78 - 0	74 - 8 v 88 - 0
My Problems Post SAH (4 point scale]		
Finance	30 - 54 v 30 - 40	32 - 56 v 30 - 36
Mobility	15 - 64 v 12 - 88	20 - 70 v 7 - 86
Stress	50 - 14 v 20 - 60	56 - 18 v 24 - 55
General Health	29 - 40 v 12 - 66	30 - 45 v 13 - 62
Post-Discharge		
Confident in our GP re SAH	36 - 30 v 44 - 24	37 - 32 v 50 - 27
I felt no stress when relative returned	39 - 51 v 24 - 63	36 - 48 v 24 - 69
After the crisis there was no further family stress	20 - 33 v 68 - 16	22 - 38 v 71 - 17
Worries about my relative affected my work	69 - 20 v 34 - 48	71 - 24 v 38 - 54
We made extra calls on GP for reassurance	49 - 40 v 9 - 84	51 - 35 v 12 - 79
Being unsupported put extra strains on family	48 - 33 v 28 - 70	52 - 30 v 32 - 61
It would helped knowing consultant had discharged us		
I needed medication for the worry	70 - 18 v 25 - 52	63 - 21 v 24 - 44
Unresolved worries interfered with relatives recovery	25 - 60 v 7 - 90	35 - 55 v 12 - 83
My family had all the support we need		
Too much fuss is made about stress with SAH	55 - 40 v 23 - 60	50 - 44 v 28 - 49
	12 - 70 v 56 - 18	15 - 73 v 56 - 23
	44 - 40 v 2 v 78	39 - 52 v 7 - 83
Emotional State at Home (<55-64)		
Confident	62 - 20 v 86 - 2	59 - 22 v 81 - 0
Stressed	30 - 33 v 24 - 70	39 - 30 v 34 - 63

6.7 The 65+ year group: Table [20] provide the detailed results for the 65+ year olds. Apart from the NVSN doing better than the TAU carers, but not so highly significant as the younger age groups, the notable feature in this age band was relative their high 'unsure/don't know' scores.

Both male and female 65+ carers expressed higher stress levels than the NVSN carers and they were not significantly different from the TAU carers on this dimension. The impression was that they were less inclined to feel strongly either way although they scored the highest 'my relative left Neuro too soon' than any other NVSN group but significantly less than the TAU carers.

If we focus upon the TAU 65 year olds, there are some areas of serious concern due to their apparent continued isolation; e.g. almost half felt unprepared for what was happening; more than 70% had no one ask how they were going to manage at home once the relative returned; most felt 'left out' anxious, stressed and feelings that their general help was negatively affected; barely half felt confidence in their GP; yet many made unnecessary calls upon the GP's service, nearly two-thirds felt their patient had continued worries undermining their recovery and feeling 'unsupported put extra strains on the family, which was reflected in their greater level of contact with other services.

[25] Carer Experience [No replies excluded * scored as zero]

Totally & Totally Agree v Disagree v Totally Disagree [no replied excluded]

65+ cohort	Male % [n=282]	Female % [n=159]
	TAU - NVN	TAU - NVN
Hospital Experience	Agree: Disagree	Agree- Disagree
Failed to prepare us for what was happening	44 - 30 v 8 - 62	50 - 20 v 7 - 64
It would have helped if we'd been asked how were we' going to cope at home	69 - 12 v 0 - 34	79 - 7 v 0 - 36
Information about medication was also made clear to us	34 - 36 v 58 - 20	42 - 30 v 52 - 10
Only way to stop worrying was to depend upon neuro staff	80 - 5 v 64 - 15	88 - 2 v 55 - 30
Consultants never had enough time with relatives	50 - 15 v 18 - 50	48 - 20 v 20 - 66
I knew what to expect when my relative left hospital	12 - 55 v 30 - 20	13 - 40 v 34 - 30
My relative left neuro far too soon	90 - 3 v 40 - 40	92 - 2 v 33 - 36

Patients can't remember so relatives need to be informed	44 - 38 v 78 - 8	41 - 41 v 78 - 1
Booklet helpful but we needed specific answers	58 - 16 v 74 - 0	45 - 28 v 68 - 1
Communication between staff & relative mainly very good		
	33 - 44 v 78 - 12	36 - 48 v 80 - 2
Most of the Time I was:-		
Hopeful	72 - 3 v 76 - 0	70 - 2 v 77 - 0
Felt Left Out	20 - 45 v 4 - 58	17 - 58 v 3 - 55
Anxious	74 - 3 v 81 - 0	80 - 0 v 66 - 0
My Problems Post SAH (4 point scale]		
Finance	28 - 44 v 20 - 33	23 - 43 v 20 - 58
Mobility	28 - 59 v 14 - 76	26 - 68 v 22 - 72
Stress	55 - 17 v 32 - 40	68 - 8 v 36 - 36
General Health	38 - 36 v 24 - 54	42 - 28 v 30 - 49
Post-Discharge		
Confident in our GP re SAH	48 - 20 v 56 - 18	55 - 15 v 60 - 11
I felt no stress when relative returned	28 - 66 v 18 - 44	23 - 17 v 15 - 37
After the crisis there was no further family stress	15 - 43 v 36 - 28	9 - 47 v 33 - 26
Worries about my relative affected my work	5 - 88 v 5 - 90	10 - 84 v 12 - 76
We made extra calls on GP for reassurance	59 - 20 v 22 - 76	63 - 12 v 24 - 68
Being unsupported put extra strains on family	68 - 18 v 33 - 58	67 - 11 v 37 - 55
It would helped knowing consultant had discharged us		
I needed medication for the worry	56 - 12 v 30 - 40	57 - 9 v 24 - 38
Unresolved worries interfered with relatives recovery	38 - 32 v 17 - 49	42 - 29 v 21 - 58
My family had all the support we need		
Too much fuss is made about stress with SAH	66 - 28 v 34 - 41	71 - 7 v 40 - 36
	10 - 58 v 36 - 34	12 - 52 v 33 - 30
	28 - 38 v 2 - 54	22 - 34 v 1 - 37
Emotional State at Home (<65+yrs)		
Confident	44 - 40 v 51 - 5	49 - 28 v 63 - 7
Stressed	42 - 12 v 39 - 48	55 - 5 v 41 - 37

6.8 General Comments about Carers' Experiences.

It is reiterated that so many 'consumer' orientated studies do not include the carers, despite the knowledge that in a range of psycho-medical conditions, carers carry a great burden (e.g. Albert et al, 2002; Hop et al, 2002; Mezue et al, 2004; Tooth et al, 2005; Wikman et al, 2008; Cookson et al, 2009). This can be perhaps best highlighted by considering the TAU carer results for the 45-54 year olds, people, almost by definition at the height of their family and work responsibilities. Bearing in mind males are less likely to complain about psychosocial matters 80% complained that no one had asked how they would cope with their relative at discharge; 86% felt the patients had returned too soon; 86% felt left out, nearly 66% complained about poor communication between staff and relative; less than a third felt confident in their GP; two-thirds felt their work had suffered because of worries about their relative; and 33% felt stressed and of the other services with whom they had contact more than 20% found them unhelpful. Not surprising that in the open ended responses they complained about a sense of isolation and being unsupported by a partner whose demands were considerable, no matter how good their original relationship was; an act of active imagination at the plight of these TAU families exposes the often forgotten fact that for many patients of serious acute conditions their problems for them and their families really impact after the life-saving surgery and medical intervention. Perhaps the most salient feature, which is often forgotten because the treatment and care of NHS patients is 'free at the point of delivery' - is that there are often substantial fiscal costs to families struggling to help their SAH patient return to normal life. It is suggested that there is little doubt that this study, along with those mentioned above, have identified the level of need. It is argued that the integrated and inclusive approach of a NVSN type service can deliver real clinical, fiscal and psychosocial benefits, not only for patients who are the surgeons first responsibility, but taking a

'Patient-Related-Outcome-Measure' (PROM) approach, contribute to improving post-treatment care of the whole family, with benefits for the service and the wider community.

6.9 Differentiating Patient & Carer's Emphasis: Within the structured and open-ended responses, whilst the focus has been upon the differences between TAU and NVSN cohorts, readers may have noticed a differing emphasis between patients and their carers. Whilst it was noticeable that both TAU patients and carers made proportionally more open-ended comments than did the NVSN cohort, suggesting, despite they being a retrospective sample, they still had much to say and needed to say it. However as table [21] shows, there were highly significant differences in the emphasise that patients and carers placed upon their experience. On reflection this seems common sense, as the patient and carers face shared but differing pressures. Of particular importance however is to remember that patients, 'playing the role' of being a patient can be 'socially excused'- whereas this is far less the case for the relative and carer who is expected to fulfil their 'social obligations' despite what is going on at home. It is the carers who have to live through the agony of not knowing whether their relative will live or die, be handicapped, disabled or even become mentally unstable. Their need and anxieties are reflected in the different emphasis they make upon post-discharge care.

Table [26] Comparing Open-Ended Responses TAU v NVSN, Patients v Carers.

Problematic Issues	Patients TAU [Av:=7.5]	Patients NVSN [Av:=6.4]	Carers TAU [Av:=12.1]	Carers NVSN [Av:7.1]
Communication	166	29	276	39
Practice	132	41	151	35
Impact on Family	105	117	29	48
Psychological	96	82	315	152
Post-Discharge	89	74	134	45
Comments on Staff {Negative = - }	87 + 11 -	320+ 7- [111 (6-) NVSN]	252 + 14-	314+ 6- [129 (2-) NVSN]
Physical Problems	73	65	55	78

TAU v NVSN Patients $X^2 = 170.67$ 6d/f $p < 0.00001$ # : TAU v NVSN Carers $X^2 = 210.15$ 6d/f $p < 0.00001$ #:
TAU Patients v Carers $X^2 = 177.08$ 6d/f $p < 0.00001$: NVSN Patients v Carers $X^2 = 95.66$ 6d/f $p < 0.00001$: [#
Excluding comments re NVSN]

It can be seen from the numbers of comments that TAU patients and carers wrote more than the NVSN, suggesting they were more concerned with their experiences and had more to report.

This has important practice implications and there is a need for the NVSN to appreciate the potential conflict of interests between them, with their possible different emphasis and priorities, pressures and needs between patient and carer, which can create potential tension, which could further undermine their post-SAH adjustment. This needs to be understood and on occasions sensitively dealt with as in the last analysis the family is likely to be the major source of support, which the NVSN needs to support and enhance.

Viewing the above over-all results, as would be expected the NVSN psychosocial outcomes, were better than the TAU. A major benefit however has been the ability to expand a regional data base to illicit what previously would have been relatively 'hidden' namely the differences between the age groups and how the impact of the SAH played out on their families and the influence of the NVSN

service. It would appear the service speeded up those less physically impaired by the SAH the WFNS Grades 1 and 2, and probably assisted patients at Grade 3 to function closer to WFNS grade 2. This can only be an assumption as there were too many missing GCS and WFNS in the original data. What needs to be borne in mind is the speedier reduction of the PTSD following a SAH, produces its own positive impetus, with beneficial interactions upon the family, facilitating both patients and carers return to work and therefore normal family life.

6.10 Views of the Work of the Neuro-Vascular-Specialist-Nurse. In the prospective study were questions about patient's responses to the NVSN service. Generally it was very highly complimentary and the liaison functions, the accessibility, the relatively individualised service, all were valued across the age bands. Table [27] list the structured answers about their views on the NVSN for patients and carers in the four separate age-bands. It should be noted of the 7 comments about the NVSN, three were posed negatively to avoid the Hawthorn effect.

Table [27] Patient & Carers Views of the NVSN Service

Response to NVN Service	Patient Agree v Disagree	Carer Agree v Disagree
<44year group		
Specialist Nurse did not work in practice	7 v 78	5 v 76
I seldom saw Specialist Nurse	11 v 67	18 v 69
Specialist Nurse was little help to family	2 v 91	5 v 86
Specialist Nurse was an important link between home & hospital	92 v 0	88 v 7
GP should be more willing to seek advice from Specialist Nurse	55 v 8	61 v 8
Specialist Nurse provided all the information we needed	77 v 9	83 v 2
Specialist Nurse invaluable support to family	72 v 9	77 v 8
<45-54year group		
Specialist Nurse did not work in practice	4 v 79	7 v 81
I seldom saw Specialist Nurse	12 v 66	15 v 72
Specialist Nurse was little help to family	3 v 89	3 v 92
Specialist Nurse was Not an important link between home & hospital	93 v 1	93 v 0
GP should be more willing to seek advice from Specialist Nurse	61 v 9	59 v 5
Specialist Nurse provided all the information we needed	80 v 6	82 v 7
Specialist Nurse invaluable support to family	77 v 9	81 v 6
<55-64year group		
Specialist Nurse did not work in practice	9 v 78	8 v 79
I seldom saw Specialist Nurse	17 v 66	19 v 68
Specialist Nurse was little help to family	5 v 87	4 v 93
Specialist Nurse was an important link between home & hospital	86 v 7	89 v 5
GP should be more willing to seek advice from Specialist Nurse	56 v 11	61 v 9
Specialist Nurse provided all the information we needed	82 v 7	83 v 7
Specialist Nurse invaluable support to family	76 v 9	77 v 6
65+year group		
Specialist Nurse did not work in practice	8 v 70	11 v 71
I seldom saw Specialist Nurse	20 v 58	22 v 60
Specialist Nurse was little help to family	11 v 78	13 v 72
Specialist Nurse was Not an important link between home & hospital	80 v 11	78 v 12
GP should be more willing to seek advice from Specialist Nurse	43 v 20	45 v 15
Specialist Nurse provided all the information we needed	77 v 8	78 v 7
Specialist Nurse invaluable support to family	69 v 7	71 v 9

As can be seen both patients and carers valued the work of the NVSN. In regard to the core question “Specialist Nurse was little help to the family” except the 65+ respondents, only 2% of people agreed with the proposition; whereas it was positively rejected by never less than 86%, and somewhat surprisingly the 65year olds were least enthusiastic, although 78% of patients and 72% of carers rejected the idea. It is reiterated that the surveys were totally anonymous, non-attributable and respondents were guaranteed that no one from the Unit saw the questionnaires.

7. Outline of Current NVSN Service

7.1 The NVSN role. The NVSN is available to both patient and carers, and whilst she makes an early introduction, the main work starts in preparation and after discharge. He/she provides an individualised explanation and answers questions about the recovery process in the context of specific patients lives and outlines a more personalised plan that includes patients and carers. A crucial element to the NVSN service is being able to give a real sense of continuity of interest and care.

The initial home visits had to be abandoned because of the size of the caseload (currently 200 p.a. as there are not only SAH patients but also all new neuro-vascular conditions receive the service) so a telephone and where feasible an email system was devised.

7.2 Telephone & Email Patients and families have the NVSN work telephone number to make contact for advice about any physical or psychosocial problem, including discovering early indications of such problems as hydrocephalus, which leads to earlier investigations thus reducing the impact of possible complications and often avoiding the crisis becoming an emergency, as it is a complication that is often over-looked in general health care, as it can be mistaken for the PTSD reaction and not investigated early enough. Whilst patients can always be re-referred to the consultant, patients are happy to have the easier contact with the NVSN, who acts as both ‘gate-keeper and bridge’.

As with other ‘telephone based’ services, when having the possibility to seek professional help, they often do not use it, with increasing evidence from other fields, that an appropriate use of IT and telephones in reaching patients under stress, can be very effective in reducing the need for emergency services (Vaiva et al, 2006; Tam et al, 2007; Wider & De Leop, 2007; Hailey et al, 2008), as well as in other neurological conditions (Bell et al, 2008; Bombardier et al, 2008), cancer patients cancer (Huang et al, 2006; Kornblith et al, 2006; Kimman et al, 2007) and following cardiac surgery (Hartford et al, 2002; Hartford, 2005).

7.3 Patient/Carer NVSN Group There is a NVSN led monthly patient and carer support group, which again adds to the continuity of care, with families being able to offer mutual support as their period of rehabilitation evolves.

7.4 Requirements of a NVSN Whilst the researchers recognised the outstanding personal qualities of the original NVSN, it was her role that was of importance; viz need to have a high level of relevant experience, be able to think about acute and psychosocial situations and how each family responds in its own way to the initial crisis. Furthermore, the NVSN requires, tact, understanding of human relations, the ability to engage in a wide range of professional relationship and to develop counselling skills, which always benefits from professional supervision/ mentoring

7.5 The NVSN Duties. What does the NVSN do?

- [1] Ward contact to advise and offer support and information to begin the preparation for discharge.
 - 2] Contributes to earlier discharge.
 - 3] Provides a telephone and e-mail support service after discharge and to facilitate liaison between patient/carers, community services and the neurosurgical unit.
 - 4] Provide information via a web site available on the Trust website.
 - 5] The NVSN leads weekly outpatient clinics and a monthly support group of current and recent patients and carers,
 - 6] The NVSN is the key referral point for the patient GP's whose neurosurgical experience is invariably relatively less and who often welcome advice and guidance about their specific patient.
 - 7] Sees all patients routinely 3 months and one year after discharge to review neurosurgical progress and outcome, whilst offering patients and carers opportunity to ask questions about their progress and recovery, most of whom are especially grateful for the additional time to discuss any psychosocial problems they may have, which is usually longer than the average medical led appointment, this is experienced as reassurance by families and markedly reduced DNA at outpatients.
 - 8] NVSN undertakes consent for follow-up 6/12 angiograms for coiled patients.
 - 9] Produces and supplies written information to other Health Care Professionals about SAH and other cerebral vascular conditions, as well as analgesia guidelines.
 - 10] The NVSN has designed and produced a DVD for patients and families to borrow, in addition the NVSN has their own web site used by both new patients and other Health Care Professionals.
 - 11] Initiated a National Neurovascular forum for 8 other units, which becomes a mutual supervision/support service.
- NVSN Reduces DNA.
- 12] The NVSN is increasingly used by patients to contribute to court and employment tribunals.
 - 13] NVSN Seen as vital and continuing part of Neuro team and weekly meetings to discuss progress, any clinical problems and discharge and contributes to the development of the policies of the unit.
 - 14] All consultants refer patients, saving Consultant time as NVSN reviews all Coiled patients.
 - 15] NVSN runs charity fund to support neurovascular patient care and provide a little help in particular circumstances.
 - 16] Very important for GP, Unit and patient and families, early identification of problems, thus reducing need for long term care and / or readmission,
 - 17] Acts as adviser to GP in regard to monitoring prescribing

How did this service meet the needs of the NVSN cohort of patients and carers? The open-end responses provide a flavour of their experience.

Finally, the NVSN role and its development are given in greater detail in Appendix 1. Sister Foulkes, the original NVSN, would be happy to respond to any queries about the work and can be contacted at Southampton University Hospital Trust.

8. In Parenthesis: Practical Issues on Clipped v Coiled. What may appear to be diversion has practical implications for future treatment of SAH irrespective of whether it is by clipping or the now majority treatment, endovascular coiling (Molyneux et al, 2009) is ongoing debate on the issue as to

the benefits of coiled versus clipped treatment. Although in both Wessex 1 and 2 studies there were no significant differences in the psychosocial outcomes of clipped or coiled patients, although there were only 15% of patients coiled, intuitively it might be thought that an apparent less invasive non-surgical treatment would have been measurably superior to the clipping, more so in regard to psychosocial outcomes, yet this was not the case. Initially craniotomies were the majority treatment in Wessex but after the ISAT study, currently they, like most other Neurosurgical Units in the UK have increased its endovascular treatments (coiling) and currently only 26% of Wessex patients are clipped, the remainder are coiled.

The original National Study however focused very much upon comparing clipped and coiled outcomes and concluded that there was little significant clinical difference between them, with pluses and minus for each e.g. coiled did better on post-op deterioration, clipped better in regard to re-bleeds (National Study, 2006). Recently Molyneux et al (2009) at 5year post SAH explored subsequent deaths and dependency after clipping and coiling. Whilst relatively there were not many re-bleeds, there were more re-bleeds and associated deaths amongst the coiled than clipped patients, but because of cumulative mortality and numbers at risk they concluded that the risk of death at 5years was eventually lower in the coiled group. More important however is that the new Molyneux et al study (2009) also looked at dependency five years on and found 23% of coiled scoring 3-6 to slightly more clipped at 26%, or an alternative perspective is that 77% and 74% respectively had a good outcome, in a condition in which death had been the majority outcome (Walton, 1993). However, bearing in mind the emergency nature of an SAH, irrespective of treatment, there are inevitably major psychosocial impact upon patient and family. We have shown that the associated PTSD reaction (e.g. Berry et al, 1998; Noble & Schneck, 2008) can be reduced by a NVSN type service (Cloitre et al, 2009; Zarah et al 2009, which should not be lost in the clipped versus coiling debate. Moreover, as it appeared that the early intervention of the NVSN speeded up the recovery from PTSD, creating a 'virtuous circle', it appeared to us that the NVSN service helped the patients at boarder-line 'moderate recovery' to be more independent and function at a good recovery level. Hence it is argued that whilst the primary treatment of a SAH is self-evidently 'technical' it is not the only factor in effective recovery of patient and their family and the service should also be concerned about wider psychosocial factors.

We are somewhat diffident in raising this but when the current NVSN service was asked whether there were any apparent psychosocial differences between coiled and clipped patients, she was most cautious, as the question had not been raised before. Furthermore, there had been no subsequent study and the only current information available is the number of contacts with the NVSN and who initiated them.

Impressionistically, it seems that coiled patients and families contact the NVSN service more this *may* be because due to the need for 6/12 follow-up and the potential for further treatment, this *perhaps* gives rise to anxiety as inevitably their initial trauma is recalled, something that few professional staff, unless they themselves have been a patient, realise. They often exhibit a degree of anxiety when facing an investigation that they are told carries a risk of stroke, re-reminding them of the trauma, when they had felt 'all was over' but now may feel anxious about what the angiogram result will show. Thus 56% of the current coiled patients to 45% of clipped patient sought additional help, suggesting a possible

continued psychosocial need. However, whilst this result was not significant (chi square 1.1215 $p < 0.3$), but if projected onto the National patients (905 coiled v 1269 clipped patients) the difference would become highly significant (chi square 25.6901 1 d/f $p < 0.0001$), a feature that requires future consideration.

Table [28] shows the patient and carer initiated NVSN contact and possibly linked to coil compaction about 20% required further treatment and therefore further reassurance. One somewhat paradoxical finding emerged, coiled unlike clipped patients, have no 'scar' or their treatment is not noticeable and therefore appear 'normal' which leads to some employers and others apparently being less understanding about the nature of the life-threatening condition these people have endured. However, this is an impressionistic observation and there is a case for considering whether there are any psychosocial different outcomes between coiled and clipped patients.

Table [28] SAH Patient/Care Generated Contacts – T/phone, email & O.P.C per patient (2007)

Group	Patient - Ratio	Carer – Ratio	OPC - Ratio
Clipped n=31	18 = 0.58	11 = 0.35	18 = 0.58
28 contacted NVSN	0.64	0.39	0.64
Coiled n=89	134 = 1.51	23 = 0.26	123 = 1.38
73 contacted NVSN	1.84	0.32	1.68

9. Recommendations

1] It is recommended that Units recognise that PTSD almost invariably follows a SAH and impacts negatively upon the family (Berry et al, 1998; Curtiss et al, 2000; Hop et al, 2002; Powell et al, 2004; Tooth et al, 2005; Noble & Schenk, 2008) and that this has become *legitimate area of treatment and responsibility* for those treating a SAH. There is growing evidence that the earlier PTSD is dealt with the quicker it can be reduced (Cloitre et al, 2009; Zahar et al, 2009).

2] That a NVSN type service be developed in every Unit that deals with SAH. For effective intervention, bearing in mind that within a year most Units 'collect' approximately 150 neurovascular patients, of which about 70-74 are SAH, suggests that 1.5 f.t.e staff are required, with at least minimal administrative support, and an area of privacy for interviewing.

Thus the Unit would offer a comprehensive service providing the community with the expertise it lacks. Over-time the NVSN would 'educate' the community services by making more intelligible, the ramifications of neurological conditions.

3] There is a need to develop IT and specific email facilities for patients and carers to make easy access with the NVSN staff.

4] The NVSN deals with highly emotive situations, in an environment of the rush and bustle of high tech medicine. There should be available opportunities for regular case supervision

5] It is believed that currently there are 9 NVSN type posts in the UK Neurological Units.

Consequently there would be real value in a national study to compare these units' outcomes directly with standard units.

9.1. The Role of the Neurosurgeon & Neuro-Endovascular Surgeon: It is not being recommended that neurosurgeons or neuro-endovascular surgeons become 'counsellors', though traditional clinical skills, sometimes dismissively described as a 'good bedside manner', are recognised as a core skill in

the best surgical consultants (Giddings & Williamson, 2007). As recommended by the RCS, a comprehensive 'Patient-Related-Outcome-Measure' inclusive view of the patients treatment and care means that whilst the consultant is the unequivocal leader of the team, with high technical and scientific skill being paramount, the consultant should ensure that their team is equipped to meet the total needs of the patients (Giddings & Williamson, 2007). Thus whilst neurosurgery is a highly regarded form of high-tech medicine and demands a high level of scientific knowledge, understanding new research and techniques, it is still like all medicine a science based art. Moreover, there is evidence from a survey of the Association of Surgeons of Great Britain & Ireland (Pritchard et al, 2009), that the majority of consultants will actually welcome this approach, as it reflects their core patient centred aspirations that brought people into medicine in the first place. Thus, every consultant should ensure that their Neurovascular Specialist Nurse is a central member of their team to ensure comprehensive treatment and care of their patients.

10. Conclusions

There has been some debate about the value of 'Specialist Liaison' nurses in the various specialities (Hobbs & Murray, 1999) but in fiscal terms alone the NVSN is very cost effective, quite apart from helping to reduce the subsequent PTSD stresses. Moreover, the service appeared to strengthen the ability of the families to cope as well as improve liaison with the local community services, thus lessening the vicious circle of serious illness followed by psychosocial demoralisation. The damaging knock-on effect of PTSD on patients and their families suggests that in any acute life-threatening emergency, not only in neurosurgery, the treatment team that is able to respond early, is far more likely to have a more effective outcome. One problem may be, especially at a time of economic uncertainty, that budget managers only consider their own Unit costs and not consider the 'psychosocial' in the 'high-tech' arena has having a high enough priority? Such an approach is shortsighted as an inadequately treated PTSD is costly to all concerned. It is recognised that traditionally 'high-tech' medicine gives the impression that the psychosocial aspects are on the periphery, yet whichever clinical treatment approaches are used for a SAH, at the core the consultant is a physician, with traditional responsibilities for the total care of their patient (Giddings & Williamson, 2007). Thus a NVSN type service is not a simple bolt on but reflects the very best in comprehensive medical care.

At the heart of the NVSN activity is it's individualising of the patient and family situation. It provides easy access so that the doubts and niggles can quickly resolved as well as identifying those situations in which there is real deterioration before further damage ensues.

The epitome of the service was described by a military person, who had seen active service and who whilst highly valuing the skills of the consultant and surgical team said "*she was available to deal with all those little questions, which if they had not been dealt with would have become major barriers to my recovery, adding to my families distress*". As the project started with listening to patients, so it ends with the apparent paradox, that though the time in hospital is vitally important, for the vast majority of patients, it is but an interlude in their lives and their real problems often start after discharge. It is when the patient is at home that they begin to measure the real value of the service they have received and can judge the extent to which they can reasonably resume a normal quality of life; a Neurovascular

Specialist Nurse service can make a real contribution to enhance the life saving skills of neurosurgery, so that the patient can return to 'normal' life. Finally it is argued that a modern comprehensive treatment of SAH the service is both wealth producing and more effectively 'saving lives'.

Acknowledgements

It is recognised that should the study could not have proceeded without the active work and collaboration of a number of colleagues including Neurosurgical Consultants Jonathan Duffil, Dorothy Lang, Glen Neil-Dwyer, Owen Sparrow, and Sister Beryl Pritchard all of the Wessex Regional Neurological Unit; to Professor John Pickard, University of Cambridge and Dr. Julia Langham of the Health Improvement Unit at the RCS but most of all to the patients and carers who gave of their time in contributing to the original questionnaires and to all former patients and their carers who completed them. Finally we are deeply indebted to the Glasgow Patient Trust Fund for financially supporting this project.

References

- Al-Shahi R, White PM, Lindsay KW (2006) Subarachnoid haemorrhage: A clinical review. *BMJ* 333, 235-240
- Albert, SM, Brenner, L, Smith, M. & Waxman, R (2002) Effect of a social work liaison programme on family caregivers to people with brain injury. *J. Head Trauma Rehab.* 2, 175-189
- Alfieri A, Unterhuber V, Pircher M et al & Widmer HR (2008) Psychosocial and neuro-cognitive performance after spontaneous non-aneurysmal subarachnoid haemorrhage related to the APOE-epsilon-4 genotype: A prospective 5 year follow-up study. *J. Neurosurgery.* 109,1019-26.
- Armstrong, K & Kerns, KA. (2002) The assessment of parent needs following paediatric traumatic brain injury. *Paediatric Rehab.* 3, 149-160.
- Bell KR, Hoffman JM, Temkin NR, Powell JM et al Dikmen S (2008) The effect of a telephone counselling on reducing PTSD symptoms after mild traumatic brain injury: A randomised trial. *J.Neuro Neurosurgery Psychiat.*79, 1275-1281
- Baldwin DS & Birtwistle J (2002) *Depression Illustrated* London, Smith Klein
- Berry, E. (1998) Post-traumatic-stress-disorder after subarachnoid haemorrhage. *Neurosurgery.* 37, 365-367
- Bellebaum C, Schafers I, Schoch B, Wanke I et al Daum I (2004) Clipping versus coiling: neuro-psychological follow-up after ASAH. *J Clin Exper Neuropsychol.* 26, 1081-1092.
- Bollinger A & Ruttimann B (2002) Aneurysms in the history of medicine *J. Vascular Dis* 31: 281-286
- Bombardier CH, Cunniffe M, Wadhvani R, Gibbons L & Kraft GH (2008) The efficacy of telephone counselling for health promotion in people with multiple sclerosis: A randomised controlled trail. *Arch Phys Med Rehab.* 89, 1849-1856.
- Brand S & Price R (2000) *The Economic and Social Costs of Crime* Development & Statistics Directorate Research Study 217, London, Home Office
- Bromberg JEC, Rinkel GJE, Algra A et al & Van Gijn J (1995) Familial subarachnoid haemorrhage:

- Distinctive features and patterns of inheritance *Annals Neurology* 38: 929-934
- Brown C & Lilford R (2008) Evaluating services delivery intervention to enhance patient safety. *BMJ* 337, 2764.
- Carr AJ, Gibson B & Robinson PG (2001) Is quality of life determined by expectations or experience? *BMJ* 322: 1240-1243
- Cedzich C & Roth A (2005) Neurological and psychosocial outcome after subarachnoid haemorrhage and the Hunt and Hess scales as a predictor of clinical outcome. *Zentralbl Neurochirurgi.* 66,112-118.
- Cloitre M (2009) Effective psychotherapies for PTSD: A Review and Critique. *Int. J. Neuropsychiat Med.* 14, suppl. 32-43
- Cookson, Drummond MF & Weatherly H (2009) Explicit incorporation of equity considerations into economic evaluation of public health interventions. *Health Econ Policy Law.* 4, 247-254.
- Coulter A. Sharing decisions with patients: is the information good enough? *BMJ.* 1999; 318: 318-22.
- Curtiss, G. Klemz, S. & Vanderploeg, RD. (2000) Acute impact of severe traumatic brain injury of family structure and coping responses. *J Head Trauma Rehab.* 5, 1113-1122.
- Dawes Ha, Doherty T, Traynor I, Gilmore DH & Knill-Jones R (2007) Specialist nurse supported discharge in gynaecology: A randomised comparison and economic evaluation. *Eur J Obset Gynaecol Reprod Biol.* 130, 2620270.
- D.F.E.F (2000) *Labour Statistics* London, Dept for Education & Employment
- Down K, Hughes R, Sinha et al & Leigh N (2005) *Involving Users in Shaping Motor Neurone Disease Services.* York, Joseph Rowntree Foundation.
- Drummond MF, O'Brien D, Stoddart G & Torrance GW (1997) *Methods of Economic Evaluation of Health Care.* New York, Oxford University Press.
- Forbes A, White A, Mathes L & Griffiths P (2006) Evaluation of a MS specialist nurse programme. *Int J Nurse Stud.* 43,985-1000.
- Foulkes L (2008) *Sub Arachnoid Haemorrhage* . Southampton Wessex Neurological Centre.
- Fountas KN, Kapalaki EZ, Lee G et al & Theodosiadis PG (2008) Terson haemorrhage in patients suffering ASAH predisposing factors and prognostic significance. *J Neurosurg* 109,439-444
- Frazer D, Ahuja A, Watkins I & Cipolotti L (2007) Coiling versus clipping for the treatment of ASH: A longitudinal investigation into cognitive outcome. *Neurosurgery.* 60, 434-441.
- Hadjivassiliou M, Tooth CL, Romanowski CAJ et al 7 Sagar JH (2001) Aneurysmal SAH: Cognitive outcome and structural damage after clipping or coiling *Neurology* 56: 1672-1677
- Harris, JKJ. Godfrey, HPD. Partridge, FM. & Knight, RG. (2001) Caregiver depression following TBI: A consequence of adverse effects on family members. *Brian Injury.* 3, 223-238.
- Hartford K, Wong C & Zakaria D (2002) Randomised controlled trial of a telephone intervention by nurses to provide information and support to patients and their partners after elective coronary artery bypass surgery: Effects of anxiety. *Heart Lung* 31, 199-206
- Hartford K (2005) Tele-nursing and patients recovery from bypass surgery. *Journal Advanced Nursing* 50, 459-468
- Heim C & Nemeroff CB (2009) Neurobiology of Posttraumatic Stress Disorder. *Int J. Neuropsychiat Med.* 14, suppl1. 13-24

Hellawell, DJ. & Pentland, B. (2001) Relatives reports of long-term problems following traumatic brain injury or subarachnoid haemorrhage. *Disability Rehabil.* 23, 300-305.

Henwood M (1998) Ignored and Invisible? *Carer's experience of the NHS*. London, Carers National Association.

Hibbard, MR, Cantor, J, Charatz, H. et al & Gartner, A. (2002) Peer support in the community: Initial findings of a mentoring program for individuals with traumatic brain injury and their families. *J. Head Trauma Rehab.* 2, 112-131

Hobbs R & Murray ET (1999) Specialist liaison nurses: Evidence for their effectiveness is limited *BMJ* 318: 683-684

Hop JW, Rinkel GJ, Algra A van Gijn (1998) Quality of life in patients and partners after ASAH. *Stroke.* 29,798-804.

Hop JW, Rinkel GJ, Algra A & Gijn J (2002) Changes in functional outcomes and quality of life in patients and caregivers after ASAH. *J Neurosurg* 97, 741-742.

Haug T, Sorteberg A, Sorteberg W, Lindegaard K & Finset A (2009) Cognitive functioning and health related quality of life after rupture of aneurysm *Brit J Neurosurgery.* 19, 1-9.

Huang F, Liu SC, Shih SM, Tao YH & Chang P (2006) Reducing anxiety of surgical patients families access short message service. *AMIA Annual Symposium Proceedings.* 957.

Hutchinson GF & Baille MB (1932) A case of subarachnoid haemorrhage with recovery. *Can Med Ass* 27, 509-512.

Hutter BO, Gilsbach JM & Kreitschmann I (1995) Quality of life and cognitive deficits after SAH. *Brit J Neurosurgery.* 9, 465-475.

Kapfhammer HP, Rothenhausler HB, Krauseneck T & Schelling G (2004) PTSD and health-related quality of life in long-term survivors of acute respiratory distress syndrome. *Am J Psychiatry.* 161, 45-52.

Kapur N (1997) *Injured Brains of Medical Minds: Views from within*. Oxford, University of Oxford Press.

Kornblith AB, Dowell JM, Herndon JE et al Holland JC (2006) Telephone monitoring of distress in patients aged 65 years or older with advanced stage cancer: A cancer and leukaemia group B study. *Cancer* 107, 2706-2714.

Kreitschmann-Andermahr I, Poll E, Hutter BO, Reineke A, Kristes S, Gilsbach JM, Saller B. Quality of life and psychiatric sequel following aneurysmal subarachnoid haemorrhage: does neuroendocrine dysfunction play a role? *Clin Endocrinol.* 63,833-7

Lapotaire J (2003) *Time Out of My Mind*. London, Virago Press.

Leblanc R (1996) Familial cerebral aneurysms: A bias for women *Stroke* 27: 1050-1054

Lindsay KW & Bone I (1997) *Neurology and Neurosurgery Illustrated*. Section IV Edinburgh – Livingstone.

McKenna P, Willison JR, Lowe D & Neil-Dwyer G (1989) Recovery after subarachnoid haemorrhage *BMJ.* 299, 485-487.

Mezue W, Mathew B, Draper P & Watson R (2004) The impact of care on carers of patients treated for ASAH. *Brit J Neurosurgery*. 18,135-137.

Mocco J, Ransom Er, Komotar RJ, Schmidt J et al Connolly ES (2006) Preoperative prediction of long-term outcome in poor grade ASAH. *Neurosurgery* 59, 529-538.

Molyneux, A. Kerr, R. Stretton, I. & Holman, R. (2002) International subarachnoid aneurysm trial [ISAT] of neurosurgical clipping versus endovascular coiling in 2143 patients with ruptured intercranial aneurysms. A randomised trial. *Lancet*. 360, 1267-1274.

Molyneux A, Kerr RS, Birks J et al & Rischmiller J (2009) Risk of recurrent subarachnoid haemorrhage, death or dependence and standardised mortality ratios after clipping or coiling for intercranial aneurysm in the International Subarachnoid Aneurysm Trail (ISAT): Long-term follow up. *Lancet Neurology* 8, 427-433.

Ogden Ja, Utley T & Mee EW (1997) Neurological and psychosocial outcome 4 to 7 years after subarachnoid haemorrhage. *Neurosurgery*. 41,25-34.

National Study of Subarachnoid Haemorrhage.(2006) Clinical effectiveness Unit. Royal College of Surgeon of England (February) London. 1-56.

Neil-Dwyer, G. Lang, DA. Smith, PWF. & Ianotti, F. (1998) Outcome after aneurysmal subarachnoid haemorrhage: The use of a graphic model of assessment of risk factors. *Acta Neurochirurgica*. 140, 1019-1027.

Noble & Schenk (2008) Post traumatic stress disorder in the family and friends of patients who have suffered spontaneous subarachnoid haemorrhage. *Jl Neurosurgery*. 109, 1027-1033.

Pickard J et al (2004) Mapping rehabilitation resources for head injury. *J Roy Soc Med*. 97, 384-389.

Pound P, Tilling K, Rudd AG, Wolfe CDA (1999). Is patient satisfaction an indicator of effective stroke care? *Stroke*; 30. 49-55.

Powell, J. Kitchen, N. Heslin, J & Greenwood, R. (2002) Psychosocial outcomes at 3 and 9 months after good neurosurgical recovery from aneurysmal subarachnoid haemorrhage: Predictors and prognosis. *J Neurol Neurosurgery Psychiat*. 72, 772-781.

Powell J, Kitchen N, Heslin J & Greenwood R (2002) Psychosocial outcomes at three and nine months after good neurological recovery from ASAH: Predictors and prognosis. *J Neurol Neurosurg Pschiatry*. 72, 772-778.

Powell J, Kitchen N, Heslin J & Greenwood R (2004) Psychosocial outcomes at 18 months after good neurological recovery from aneurysmal subarachnoid haemorrhage. *J Neur Neurosurgery Psychiat*. 75, 1119-1124.

Pritchard C, Foulkes L, Lang D, & Neil-Dwyer G (2001) Psychosocial outcomes for patients and carers after aneurysmal subarachnoid haemorrhage patients. *Brit J Neurosurgery* . 15. 456-463

Pritchard C, Chapman L, Davies A, Lang D & Neil-Dwyer G. (2004a) Psycho-socio-economic outcomes in acoustic neuroma patients and their carers related to tumour size. *Clin Otolaryngology* 29: 324-330

Pritchard C, Davies A, Lang D & Neil-Dwyer (2004b) Comparison of cohorts of elective and emergency neurosurgical patients: Psychosocial outcomes of cohorts of acoustic neuroma and aneurysmal sub arachnoid haemorrhage patients and carers. *Surg Neurology*. 62: 7-16

Pritchard C, Foulkes L, Lang D & Neil-Dwyer G. (2004c) Two year prospective study of psychosocial outcomes and a cost-analysis of 'Treatment-As-Usual' versus an 'enhanced' (specialist liaison nurse) service for aneurysmal sub archnoid haemorrhage [ASAH] patients and families *Brit J Neurosurgery* 18: 347-356

Pritchard C, Foulkes L, Lang D.A. & Neil-Dwyer G (2004d) Cost-benefit analysis of an integrated approach to reduce psychosocial trauma following neurosurgery compared with standard care: Two-year prospective comparative study of enhanced specialist liaison nurse service for aneurysmal subarachnoid haemorrhage patients and carers. *Surg Neurology* 62: 17-27

Pritchard C & Hickish T (2008) Changes in cancer incidence & mortality in England & Wales and cancer deaths compared with the Major Developed Countries 1979-2002 in context of GDP expenditure on health. European Institute of Oncology. *ECancerMedicalScience*. 2, 80, 1-18.

Pritchard C, MacFie J & Brackstone J (2009) The Voice of 549 Surgeons on Patient Safety:: Identifying problems and solutions: Study for the Association of Surgeons of Great Britain & Ireland. *Under review*.

Rapaport MH, Endicott J & Clary CM (2002) PTSD and quality of life: Results across 64 weeks of sertraline treatment. *J Clin Psychiat*. 63,59-65.

Richardson J (2009) Is the incorporation of equity considerations into economic evaluations really so simple? A comment on Cookson, Drummond and Weatherly. *Health Econ Policy Law*. 4, 261-263.

Rocha LP, Petersson JC, Meyers B, Boutin-Foster C & Bruce ML (2008) Incidence of PTSD after myocardial infarct and predictors of PTSD symptoms : A brief report. *Int J Psychiat Med* 38,297-306.

Rodholm M, Starmark JE, Ekholm S & Von Essen C (2002) Organic psychiatric disorders after aneurysmal SAH; outcome and associations with age, bleeding severity and arterial hypertension *Acta Neurological Scandinavia* 106: 8-18

Rowlands O (1998) *Informal Carers: An Independent Study Carried Out on Behalf of the Department of Health as Part of the General Household Survey*. London, Stationary Office.

Samra SK, Giordani B, Caveney A, Clarke WR et al Todd MM (2007) Recovery of cognitive function after surgery for ASAH. *Stroke*. 38,1864-1872

Sheldrick R, Tarrier N, Berry E & Kincey J (2006) Post-traumatic-stress-disorder and illness perceptions over-time following myocardial infarction and sub arachnoid haemorrhage *Brit J Health Psychol* 11, 387-400.

Shemilt I, Mugford M, Drummond M, Eisenstein E et al & Walker D (2006) Economics methods in Cochrane systematic reviews of health promotion and public health interventions. *BMC Medical Research Methodologies*. 15,6-55.

Tagay S, Kribben A, Hoenstein A, Mewes R & Senf W (2007) Post traumatic stress disorder in hemodialysis patients. *Am J Kidney Dis*. 50, 594-601

Teasdale GM, Drake CG, Hunt W, Kassell N & Santo N et al (1988) A universal subarachnoid haemorrhage scale: Report of a committee of the World Federation of Neurosurgical Societies. *J Neuro Neurosurgery Psychiat*.51, 1457.

Tooth, L. McKenna, K. Barnett, A, Prescott, C. & Murphy, S. (2005) Caregiver burden, time spent caring and health status in the first 12 months following stroke. *Brain Injury*. 19, 963-974

Tseng M, Hutchinson P, Czosnyka M et al & Pickard JD (2007) Effects of acute pravastatin on intensity of rescue therapy, length of patient stay and 6-month outcomes in patients after aneurysmal subarachnoid haemorrhage. *Stroke*. 38, 1545-1550

Van der Schaaf I, Wermer M, Velthuis B et al & Rinkel GJ (2006) Psychosocial impact of finding small aneurysms that are left untreated in patients previously operated upon for ruptured aneurysms. *J Neuro Neurosurgery Psychiat*. 77,713.

- Visser-Meiley JM, Rhebergen ML, Rinkel GJ & Post MW (2009) Long-term health-related quality of life after ASAH relationship with psychological symptoms and personality characteristics. *Stroke*. 1526-1529.
- Vergaehge S, Defloor T, & Grypdonck (2005) Stress & coping among families of patients with traumatic brain injury: A review. *J Clinical Nursing*. 14;1004-1012
- Walters AA & Matthews K (1998) *Economics and Politics of Money: Selected Essays of Alan Walters*. London, Edward Elgar.
- Walton J. (1993) *Brian's Diseases of the Nervous System 8th / 10th edition*. Oxford University Press.
- Wermer M, Kool H, Albrecht K et al & Rinkel GJ (2007) Subarachnoid haemorrhage treated with clipping: Long-term effects on employment, relationships, personality and mood. *Neurosurgery*. 60,91-97.
- Wertheimer A (2008) *A Dented Image. Journeys of recovery from a subarachnoid haemorrhage*. London, Routledge.
- Wikman A, Bhattacharyya M, Perkins-Porras I & Steptoe A (2008) Persistence of PTSD symptoms 12 and 36 months after acute coronary syndrome. *Psychosom Med* 70, 764-772.
- Zahar J, Sonnio BA, & Cohen A (2009) Can Posttraumatic Stress Disorder be Prevented? *International J Neuropsychiatric Med*. 14, suppl1. 44-51

Appendix [1]

11. The Neurovascular Specialist-Nurse Role & it's Development

11.1 The Experience of Psychosocial problems? The bio-physiological context of SAH is that unlike the majority of illnesses in that there are virtually no prodromal symptoms. This means literally that people busy with their lives and professions (the majority of SAH are under 55 years old) were faced with a sudden dramatic blue-light flashing' emergency as their lives are thrown into a turmoil. Books recently written by former SAH patients tell about their sense of confused isolation, anxiety, despair and catastrophic disruption created by the SAH, quite apart from the pain and trauma which are salutary (Lapotaire, 2003; Wertheimer, 2008). We could not do just to the life-stories of either our respondents in the first Wessex study, and the impact the event had on them and their families. Some open-ended TAU comments, despite the positive technical outcomes, many experienced months or even longer of unnecessarily prolonged PTSD (Albert et al, 2002; Noble & Schenk, 2008b)

11.2 Initial Situation The Wessex Region Neuro Unit approach to the treatment of SAH patients was what might be described as typical standard high tech neurosurgical treatment, but with the pressure upon beds, to seek a speedy safe discharge or return to the local hospital for continued care. The psychosocial and economic outcomes were frankly not considered a primary concern of the Unit although clinical follow-up was offered.

The standard advice to patients was that generally it could be said they were 'cured', as re-bleeds were very unlikely, although they had survived what had previously been a condition with extremely high mortality (Walton, 1993). In effect modern neurosurgery had saved their lives, but they may well

require some months before they were fit to return to work and able to resume normal life (e.g. McKenna et al, 1989; Hutter et al 1995).

The Research Sister however, had raised the question why, unless they had multiple aneurysms, the majority of SAH patients who were now technically 'cured', many returned to the unit for advice? The response was to repeat the 'wisdom of the day' that SAH patients had suffered a major brain insult and irrespective of being either clipped or coiled, it was common for many patients to be psychosocially and cognitively impaired for many months afterwards (McKenna et al, 1989; Ogden et al, 1997; Hop, et al 1998; Hutter et al 1995; Samra et al, 2007) indeed sometimes stretching into years (Kapur, 1997; Wermer et al, 2007; Wertheimer, 2008).

The Sister was not satisfied with the situation, which led to the Wessex retrospective cohort study (Pritchard et al , 2001), where patients identified their problems and recommended a solution, namely a Specialist Neuro-Vascular-Nurse (NVSN) who would be available to deal with the psychosocial impact of the SAH upon family as well as patient from the point of admission.

The result was the retrospective 2year-cohort study of patients and carers views of their experience of the SAH (Pritchard et al, 2001). The extent and magnitude of the psychosocial and economic impact upon patients and their families, led to the Trust funding the prospective two-year cohort study of patients and carers study (Pritchard et al, 2004a) which created the role of the NVSN, with the major psychosocial, economic, clinical and service benefits described above.

In the pilot stage of the retrospective 2year cohort study the principle researcher met patients and their carers who were at least 6 to 12 months post final discharge. He came equipped with clipboard, a series of questions culled from recent research literature which he quickly realised concerned the 'professional's agenda not these patients and their families. Moreover, it was immediately apparent that these randomly invited patients and their carers, had had very post-discharge distressing experiences and appeared to be showing many signs of a 'Post-Traumatic-Stress-Disorder' (PTSD) type reactions. One advantage the principle researcher enjoyed was that in addition to his continuing social psychiatry, both clinically and academically, he had been associated with neurosurgery in the Leeds (1960-67), Bristol (1978-80) as well the Wessex (1981-1998) regions, and had a better understanding of SAH than the average social scientist. This led to changing the focus of the project and responding to the patients and carers, in what is now the 'new' terminology of seeking 'Patient-Related-Outcome-Measures' (PROM). The approach was to respond to patients and carers as the 'experts', to learn from them what happens in neurosurgery, and not following the traditional agenda of the professionals in the research. Thus the pilot group in effect became a patient-carer directed focus group, being guided by them rather than pursuing our pre-conceived notions about what was important.

11,3 Current Situation. The post is equivalent to one f.t.e for a regional Neurosurgical unit covering 9 consultants in all. The role has expanded to include all neuro-vascular patients, such as AVM and AVF patients not just SAH, with an approximate 200 new patients over the year

The focus is to provide a holistic psycho-social service for patients and their carers, the latter in particular are often ignored by the standard 'Treatment-as-Usual' [TAU] services, yet are so important to the fuller recovery of patients. but crucially encourages patient and family to take responsibility for their own health to restore to their normal pre-treatment functioning.

11.4 Patient / Carers Perspectives of the NVSN : Randomised In-depth Interviews

The open-ended comments from the original TAU study highlighted patient and carers experience without a NVSN service, given in Appendix 1, and we can do little justice to the prolonged and unrelieved PTSD, reflected in the virtual 'poetry' of actress Jean Lapotiare (2003) and that of Alison Wertheimer (2008), a professional, both of whom suffered a SAH. These experiences should be mentally juxtaposed when considering that of patients and carers receiving a NVSN service.

To provide an adjunct to better understanding from qualitative material (Brown & Lilford, 2009) and gain a more detailed experiential view of the role of the NVSN, respondents were invited to be individually interviewed, to undertake a small stratified (age, region and socio-economic group) and from amongst 91% who replied positively 21 cases were randomly chosen.. The following briefly sets out their views, which reinforce the value that most found during a very disturbed and disrupting time of their lives, and shed further light on the role of the NVSN, and.

11.5 Socio-Economic Groups - Working-Class-patients appeared less complaining /questioning, but especially valued the time the NVSN could give and to explain things, which helped them to be able to ask appropriate questions of the Medical staff, for example “ *it was really useful when talking to the Dr's- I then knew what they were on about*'.

However diffidence means they may contact NVSN less, "*didn't like to trouble her*" [I advised re GP] who *'was always willing to listen but didn't do much for us'*.

Issue here of need for NVSN to follow-up 'quiet' cases, as this pair needed help, crucially into 2/3 week at home & certainly required physiotherapy.

11.6 Existing Family Dynamics. Families have 'histories' before the traumatic event, which may impact upon an existing psychosocial problem. This was demonstrated on a number of occasions, e.g. conflict centring around a teenager who was convinced the row preceding his father's SAH had nearly killed him. This required a degree of specialist help to deal with the adolescent's suicidal ideation. Other's mean that the NVSN perhaps should be able to refer such cases on to mental health or social services.

11.7 In-Patient Experience. Most respondents were especially impressed by the nurses and in particular how they coped with confused patients who *'abused the nurses'*.

The issue of discussing the Consent form raised unexpected problems for some.

"Was it really necessary to go into all the details of risk- frankly it scared the shit out of me, I realised they had to do it because of all the litigation nonsense but it was not a good time'.

Also many patients felt pressure upon them to be discharged- "*nobody meant it, but there was pressure on the patient to go from a place they felt safe*".

One elderly couple were very graphic in their description of the care they had received.

"When you get to 70 you become accustomed to people thinking you're half-witted. But this didn't happen in Neuro. What was so wonderful, my wife and I were treated like people of worth. We felt valued, which was so different from the one contact we had with the district nurse. The neuro staff never did this and despite the bustle, I never felt afraid that they wouldn't care because they might think my wife was old"

11.8 Hiatus between Neuro & Peripheral Hospital. One problem is the shock of diminished care after high quality Neuro - Theme of 'experience v expectations' very strong- *'I thought everybody would be on the ball like Neuro but when we got home we realised we were on our own'.*

Links with Local hospital *"not up to scratch- couldn't compare with Neuro"* compounded by the impression that the other hospitals had a higher infection rate, which of course which was very worrying. One example of being returned to a local hospital was being given a bed in geriatric unit, *"it was **** horrendous, depressing, the staff tried but, well they hadn't a clue, I was there because of my age, not my condition, I don't know who was most scared, me or the staff" ..*

11.9 General Practitioner. GP's invariably were sympathetic and attentive but *" but didn't really know much about SAH- kept telling us to contact Neuro- fortunately LF was at the end of a t/phone'* A number of informant felt that the NVSN was helpful to the GP helpful and supportive but *"was much too diffident about giving advice- sometimes one wants to be told what to do- I sometimes had the feeling that I knew more about SAH than he did".*

Also had an excellent service from GP - at the initial SAH a deputy visiting Dr recognised the symptoms and had him admitted within an hour [11+] and *'saved my life'.*

11.10 Benefits Agency. Problems with Benefits Agency- a number of respondents were very hostile and complained that the *'letters were inscrutable and offensive'*

Middle Class patients were shocked by the offhandedness of the Benefits agency *"possibly because they're not geared for people like us, and they probably thought we expected too much."*

Practical Issue with Benefits Agency was if the Consultant completes the forms but is not aware of the *'fragile' emotional state* of patients, the BA then say, *'there's no problem'.* A Husband sought *'attendance allowance' 'I've never claimed for anything in my life and was really hurt to be turned down because they'd asked the wrong person', that is the Neuro Doctor who completed form, needed to have up-to-date GP report from community, rather than the 'technical', which was positive but did not take into account the emotional insecurity continued to be felt.*

Benefits agency however could also be very helpful viz self-employed person being able to claim benefit but *'it was a 21 page booklet, it was a maze'.*

11.11 Community Care. After Neuro *'we experienced the desert of community care - without LF 'I don't know where we would have been'.* Was a very common theme, with many were scathing about lack of Community Care *" it's a good thing we don't have to rely upon them- I got the feeling we scared them".*

Community Care- no contact at all- no one checked up on him.

NVSN- Bravo- the *"fact that she was available made an enormous difference- in the early days I'd wake early worrying about a minor problem, but I didn't panic- I could ring Leslie in the morning"*

11.12 Role of NVSN . Identified the importance of NVSN technical knowledge, allied to counselling skills Many examples of simple Practical and Emotional Help *"Not 'seeing anyone from Community Care' 'we were told that they didn't do SAH because that was the job of the specialists'.*

Agreed that whilst LF is *"Outstanding",* but the *"importance to families is her role"* so that it was not person specific but someone who could also be *"patient and happy to go over issues again -- who knew what she was talking about - her role is the thing although she's outstanding."*

Community Care- I didn't need them, thanks to Leslie- but they ought to at least check up that I was all right and not rely entirely upon the family'.

Available on Request to the principal author.

- 1] Patient & Carers Questionnaires
- 2] Clinical Matching of Wessex & National Samples
- 3] National Re-bleeds
- 4] National Deaths