The Long-Term (Five-Year) Neuropsychological and Functional Outcomes of Primary Intracerebral Haemorrhage.
A Population-Based Study.

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Abstract

This study examined the long-term (5-year) neuropsychological and functional outcomes of primary intracerebral haemorrhage (ICH) using a population-based sample. The World Health Organisation's model of health outcomes; the International Classification of Functioning (ICF), was used to identify areas for consideration in characterising outcomes. The specific aims of the study were to explore outcomes, in a comparison with matched healthy controls, in ICH survivors in neurological and neuropsychological functioning, mood, ADLs and HRQoL. In addition, the study sought to explore: whether there is evidence of recovery in mood, ADLs, and HRQoL in the ICH group over time; whether there are relationships between the different outcomes and, whether demographic variables such as age, gender and education play a role in outcomes from an ICH. In a population-based incidence study of stroke undertaken in Auckland, New Zealand (Auckland Regional Community Stroke Study [ARCOS]), 19 participants were recruited of whom 77 had experienced a primary ICH during a period of one year, from March 1st 2002 to February 28th 2003. This represented 25% of the original population sample from ARCOS and 42% of those alive, contactable and able to take part at a five year follow up. A healthy control group was also recruited, and was matched to the ICH group on age, gender, ethnicity, and education. Both the ICH and control group were examined on a series of measures considering neurological and neuropsychological functioning, mood, activities of daily living (ADLs), and health related quality of life (HRQoL). As there was also available data from the ARCOS study in regard to outcomes relating to function, mood and HRQoL, this data was also used to examine the change in outcomes over a period of five years.

The results indicate that ICH survivors continued to experience impairment in neurological and neuropsychological functioning, performing significantly worse in comparison with the matched control group at five years post-ICH. They were also likely to experience significantly more symptoms of depression. In addition, they were more likely to experience limitations in ADLs. However, the ICH survivors enjoyed a relatively similar

HRQoL to that of the matched controls, differing significantly only in the areas where physical functioning had a role. There were relationships between outcomes; poorer neurological functioning was significantly correlated with deficits in information processing speed and greater overall cognitive impairment. In addition, deficits in information processing speed and executive functioning were associated with reduced HRQoL, and those with depressed mood were more likely to have difficulties in ALDs and a poorer HRQoL in some areas of their lives. There were no differences in performance on any of the measures associated with age or gender. However, education was associated with better overall cognitive function. When considering performance on measures over time there was generally an improvement in the level of engagement with ADLs, however there was no change in HRQoL. To summarise, at five years post ICH survivors experience significantly poorer neurological neuropsychological, mood and functional than the matched controls. However, their quality of life is similar to that of the matched controls except in the aspects of living where their physical functioning plays a role.

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List of Abbreviations

Abbreviation	Full Expression
ADLs	Activities of Daily Living
AVM	Arteriole Venus Malformation
ARCOS	Auckland Regional Community Stroke Study 2002/3
ASTRO	Auckland Stroke Outcomes Study
BI	Barthel Index
BD	Block Design
BNT	Boston Naming Test
BP	Body Pain (Outcome domain of the Short Form-36)
CAA	Cerebral amyloid angiopathy
COWA	Controlled Oral Word Association
CVLT-II	Californian Verbal Leaning Task – II
FAI	Frenchay Activity Index
GCS	Glasgow Coma Score
GDS-SF	Geriatric Depression Scale-Short Form
GHQ-28	General Health Questionnaire-28
HRQoL	Health Related Quality of Life
IADLs	Instrumental Activities of Daily Living
ICD	International Classification of Disease
ICF	International Classification of Functioning Disability and Health
ICH	Intracerebral Haemorrhage
ICIDH	International Classification of Impairments Disabilities and Handicaps
IS	Ischemic stroke
IVA-CPT	Integrated Visual and Auditory Continuous Performance Test
LHS	London Handicap Scale
LM	Logical Memory
MCS	Mental Component Score (Outcome domain of the Short Form-36)
MH	Mental Health (Outcome domain of the Short Form-36)
MR	Matrix Reasoning
MRS	Modified Rankin Scale
NIHSS	National Institute of Health Stroke Scale
PF	Physical Functioning (Outcome domain of the Short Form-36)
PSA	Post Stroke Anxiety
PSD	Post Stroke Depression
RE	Role Emotional (Outcome domain of the Short Form-36 [limitations due to emotional health])
RP	Role Physical (Outcome domain of the Short Form-36 [limitations due to physical health])
ROCF	Rey-Osterrieth Complex Figure
SAH	Subarachnoid haemorrhage
SF	Social Functioning (Outcome domain of the Short Form-36)
SF-36	Short Form-36
TMT	Trail Making Test
VPA	Verbal Paired Associates
VT	Vitality (Outcome domain of the Short Form-36)
WAIS-III	Wechsler Adult Intelligence Scale-III
WHO	World Health Organisation
WMS-III	Wechsler Memory Scale-III

Chapter 1: Introduction

The purpose of this thesis was to examine the five-year neurological, neuropsychological, mood, functional and health related quality of life outcomes of a group of survivors of an intracerebral haemorrhage (ICH) by comparing them to a group of matched controls. As such, the first part of the introduction reviews descriptions and epidemiology of stroke and ICH literature that is relevant to the study. The second part considers models used to conceptualise health conditions, such as stroke and ICH, with reference to the World Health Organisation's (WHO) models of outcomes. The third part considers common outcomes of stroke and ICH using the framework provided by the WHO model and delineates the purpose of the present study.

1.1 Stroke and Intracerebral Haemorrhage

The first part of this introductory chapter considers the nature of stroke and ICH. Definitions of stroke and its subtypes are provided, with particular attention to ICH. As ICH is the focus of this thesis, the definition, aetiology, mechanisms of damage, clinical presentation, and relevant assessment and treatment procedures for ICH are also described. Also reviewed is the epidemiology of stroke and ICH, with particular attention to data concerning New Zealand.

1.1.1. Definition of Stroke

Historically stroke was called 'apoplexy' or an 'apoplectic attack' (Lezak, 2004). These days it is more commonly known as a cerebral vascular accident (CVA) or stroke (Lezak, 2004). In recent years there has been a movement towards using the phrase 'brain attack', similar to 'heart attack', in order to develop an awareness of the need for urgent medical intervention when stroke first develops (Caramata et al. 1994). Within the scientific literature, one of the most frequently used definitions of stroke has been developed by the World Health Organisation (WHO). The WHO defines stroke as follows: "rapidly developing

signs of focal (or global) disturbance of cerebral function, with symptoms lasting 24 hours or longer (or interrupted by death), with no apparent cause other than of vascular origin" (Aho, Harmsen, Hatamo, Marquardsen, & Strasser, 1980 p. 113).

This definition is quite broad. However, it excludes similar neurological disturbances such as transient ischemic attacks (which are episodes of focal ischemia that can cause short-lived neurological deficits lasting less than 24-hours) and subdural (between the dura and arachnoid matter) and extradural (between the skull and the dura matter) haematomas, which are usually caused by trauma to the skull (Bonita, Solomon, & Broad, 1997). Subtypes typically considered within this definition of stroke include ischemic stroke, subarachnoid haemorrhage and ICH.

1.1.2. Ischemic Stroke and Subarachnoid Haemorrhage

According to Robinson (2006), stroke can be divided into different subtypes according to the parenchymal changes that occur in the brain prior to cell death. Robinson (2006) divides stroke into ischemic and haemorrhagic subtypes. An *ischemic stroke* (IS) is essentially caused by the blockage of a blood vessel within the brain (Lezak, 2004). Ischemic disorders include atherosclerotic thrombosis, lacunar infarction, and cerebral embolism. Atherosclerotic thrombosis occurs when hyaline-lipid material (a fatty substance) is deposited on the arterial walls. Over time, these deposits develop into atherosclerotic plaques, which cause a narrowing or blockage of one or more of the arteries and therefore interrupt the blood supply. If this narrowing or blockage occurs in the brain causing the blood supply to an area to be disrupted or stopped, the cells in that area die due to a lack of oxygen and other requirements of life. This area of dead tissue is called an infarct (Robinson, 2006). Another kind of stroke caused by atherosclerosis is lacunar infarction. This is the occlusion of small penetrating cerebral arterioles, where the resulting infarcts may be so small that there are no noticeable disturbances in cerebral function (Robinson, 2006).

In another form of ischemic stroke, cerebral embolism, an artery is blocked by an embolus or 'plug'. The embolus can take a number of forms; it may be a fragment that has come away from a thrombus within the heart that has travelled along the carotid artery, or from an atheromatous plaque from within the lumen of the carotid sinus, or from the distal end of a thrombus within the internal carotid artery. In each case, the fragment enters the brain and becomes lodged within a small vessel blocking the blood supply to the surrounding tissue, causing an infarct. Although the most common form of embolus is a fragment breaking away from a thrombus, an embolus can also consist of bacteria, a gas bubble, or a fragment of a tumour. When a cerebral embolism has occurred, there is usually very little warning other than the onset of disturbance in cerebral functioning, which develops rapidly. The site of the lodged embolism, and therefore infarct, dictates the nature of the neurological and neuropsychological deficits experienced. However, if parts of the embolism break off and travel to other areas of the brain, a pattern of transient cerebral functional deficits can be seen. In some cases, the embolism can be large and may block the middle cerebral artery or internal carotid artery, which can cause severe deficits or death (Robinson, 2006).

In contrast to ischemic strokes, *haemorrhagic strokes* (which comprise about 20% of all strokes) involve blood leaking into the surrounding brain tissue or into the layers of tissue that surround the brain (Robinson, 2006). There are two types of haemorrhagic stroke, subarachnoid haemorrhage (SAH) and intracerebral haemorrhage (ICH).

The most common causes of SAH are ruptured aneurysms and arterial venous malformations (AVM). An aneurysm is caused by developmental deficits in the formation of the arterial wall where a weak area the wall of the artery balloons out and weakens over time. These are usually found at main arterial junctions within the brain. The aneurysms rupture when the arterial wall becomes so weak that it bursts. In contrast, an AVM is a developmental abnormality where there is an intricate linking of dilated blood vessels that cause abnormal communication between the arterial and venous systems, which can spontaneously rupture (Robinson, 2006). In contrast to IS and ICH, in SAH blood leaks into

the membranes outside the brain and as a consequence the mechanism of neural damage is different to IS and ICH. As the focus of this thesis is ICH, the next section will focus in more detail on the definition, aetiology, mechanisms of damage and presentation of ICH.

1.1.3 Intracerebral Haemorrhage

Definition and Aetiologies

ICH accounts for between 6.5% and 19.6% of all strokes, and about 70% of all haemorrhagic strokes (Sacco, Marini, Toni & Olivieri, 2009; Thrift, Dewey, MacDonnell, McNeil & Donnan, 2001). An ICH is defined as an arterial bleed directly into the brain parenchyma (Viswanathan & Greenberg, 2009).

Chronic hypertension is the primary cause of nearly two thirds of ICHs (Sessa, 2008; Squire, 2008). Whilst small changes in arterial blood pressure can be accommodated by autoregulatory changes in cerebrovascular resistance, when there is chronic arterial hypertension, morphological changes in blood vessels can increase arterial resistance. This limits the ability of the vessels to dilate in the presence of increased acute hypertension and constrict during acute hypotension in the brain (Squire, 2008). These morphological changes usually occur in end arteries with small diameters of 100-400µm, particularly the lenticulostriate and thalamoperforate arteries and the paramedian branches of the basilar artery. As these arteries arise directly from the large arteries of the brain, it is thought that this may cause higher pressures in these smaller sized arteries than in similar sized arteries in other parts of the brain that are connected to medium sized vessels (Squire, 2008). The putamen, through which these arteries travel, is the most common site for an ICH, accounting for 50% of all cases. A further 30% of ICHs occur in the subcortical white matter, 10-15% in the thalamus, 15% in the cerebellum and 10% in the pons (Squire, 2008). Hypertension is thought to be the cause in 50% of lobar and 40-70% of putamen and globus pallidus, most of the thalamic, and 50-70% of cerebella haemorrhages (Squire, 2008). ICH can also be caused by sympathomimetic drugs; (i.e. cocaine, amphetamine and

phenylpropanolamina), as they can also cause acute hypertension (Ronning, Sorteberg, Nakstad, Russel & Helseth, 2008).

Another common cause of ICH is cerebral amyloid angiopathy (CAA), which usually only occurs in older adults. In CAA, amyloid β proteins, particularly apoliproprotien E2 and E4 (Ronning, et al. 2008), are deposited in the cerebral arteries and arterioles and weaken the arterial walls. Consequently, a haemorrhage can occur spontaneously, or after minor trauma or surgery. Older adults are particularly at risk, with studies showing a prevalence rate of CAA in 15-10% of ICH amongst 60-69 year olds in comparison to 43-58% in adults over the age of 90 (Ronning et al. 2008).

Another cause of ICH is the development of new blood vessels from primary brain tumours (such as in oligodendroglioma, meningioma, high-grade astrocytoma and pituitary tumours) that are fragile in nature and rupture causing a bleed; or, when existing arteries are penetrated by neoplasms from tumours, and so begin to bleed (Squire, 2008).

People with acquired coagulation deficiencies that have difficulty developing blood clots to stem the flow of blood due to pathological or iatrogenic causes are also vulnerable to ICH. Types of coagulation deficiencies can include; platelet dysfunction and thrombocytopenia; while people undergoing anticoagulant therapy such as Warfarin are also at higher risk of developing a haemorrhage, this is because the arteries are more likely to rupture, and they are more at risk of bleeding out when the rupture occurs (Cavallini, Fanucchi & Persico, 2008; Ronning et al. 2008; Squire, 2008).

Moya moya disease, encephalitis, malignant hypertension, eclampsia and vasculitides have also been associated with ICH. In these pathologies, haemorrhage is thought to occur due to the performance of collateral blood vessels that become abnormally dilated and have fragile walls, which then rupture (Squire, 2008). The rupturing of new vessels, coagulation deficiencies, and moya moya disease, account for less than 8% of ICH (Viswanathan & Greenberg, 2009). ICH can also be caused by brain trauma (Squire, 2008).

According to Squire (2008), an ICH generally affects only brain function in the location in which it occurs. Small haemorrhages caused by hypertension tend to disrupt tracts of white matter rather than destroying tissue outright and in these cases it is possible to recover from the associated neurological phenomena. Haemorrhages from vascular malformations and tumours often have a good prognosis, as the white matter of the brain is not usually destroyed. In contrast, haemorrhages in the cortex caused by chronic hypertension or amyloid angiopathy do not have a good prognosis (Squire, 2008).

Mechanisms of Damage

When a haemorrhage occurs within the brain it interrupts blood supply to the brain cells depriving them of oxygen and other requirements, the result is cell death. In addition, the brain can also experience secondary injury due to the development of oedema, which is a build up of blood and fluid in the brain, which causes the brain to shift its position; this results in areas of the brain being compressed, and subsequently causes cell death. Oedema occurs in the hours following the haemorrhage and reaches a maximum 24-48 hours after the initial bleed. As the size of the oedema increases, the associated neurological deficits can increase in severity. Of particular concern are; the resulting increase in intracranial pressure and a decrease in level of consciousness, as both are associated with much lower chances of survival. Hydrocephalus also causes damage. This can occur when the haemorrhaged blood leaks into the ventricular system and blocks the discharge of the cerebrospinal fluid (CSF) thorough the fourth ventricle and aqueduct causing the CSF to accumulate. This occurs more often in putaminal and thalamic haemorrhage, as they are proximally located to the third and lateral ventricles. As a result of brain shift due to increasing pressure, compression of the foramen of Monro can result in the drainage from the contralateral ventricle becoming blocked and enlarged (Squire, 2008).

Clinical Presentation

The clinical presentation of an ICH includes the onset of focal cerebral deficits that become progressively worse over minutes to hours (Squire, 2008). The progression is usually smooth and this differentiates ICH from ischemic stroke (IS) and SAH where progression is often acute and rapid. ICH survivors often report experiencing a severe headache, which does not usually occur in IS. However, headache is reported more frequently in SAH (Goldstein, 2006). Other common symptoms include increased blood pressure, vomiting and reduced consciousness; which are indicators of increased intracranial pressure (Goldstein, 2006). Seizures can also occur when the haemorrhage is located in the caudate, but less often when it originates in the thalamus or basal ganglia. ICH as a consequence of tumour is usually associated with headaches that have become increasingly severe in the preceding weeks.

Presentation alone is not enough to differentiate ICH from other sub-types of stroke. The American Heart Association (AHA), in conjunction with the American Stroke Association (ASA), issued a practice standard paper for the initial assessment of ICH (Broderick et al. 2007). They suggest assessment should include the individual's presenting symptoms, risk factors such as age, head trauma, hypertension, prior ischemic stroke, diabetes mellitus, smoking, alcohol and drug consumption including non-prescription and prescription drugs such as aspirin or Warfarin or other antithrombotic medication, blood disorders or other disease processes that can cause bleeding. They further suggest that the physical examination (once basic life support has been established if required) should assess level of consciousness, degree of neurological deficit, blood pressure and include a CT or MRI scan to confirm the nature, location and severity of the haemorrhage. A full blood count and toxicology screening should be undertaken, as an elevated serum glucose level is an indicator of increased risk of death. In addition, if safe for the patient, a lumbar puncture is also recommended to see if blood has leaked into the cerebrospinal fluid. The AHA/ASA maintains that the focus of acute treatment should be the slowing or stopping of the

haemorrhage; this is in order to reduce the level of brain injury caused by the disruption of blood supply to the haemorrhaging area, decrease cerebral profusion and/or increase intracerebral pressure. The AHA/ASA suggests that an ICH can be approached in a variety of ways, including the management of blood pressure, treatment of intracranial pressure, the prevention of deep vein thrombosis and pulmonary embolism, and surgery to remove blood clots. (Butcher & Laidlaw, 2003).

Having reviewed the definitions of stroke and its subtypes, with a more detailed view of ICH, the following section reviews the epidemiology of stroke and ICH with attention to incidence, case fatality and demographic risk factors.

1.1.4 The Epidemiology of Stroke and ICH

Stroke: Incidence, Case Fatality and Demographic Risk Factors

Stroke is one of the leading causes of death in the world and yet it is a preventable disease, Feigin, Bennet, Barker-Collo and Parag (2009), undertook a review of 56 population based studies between 1970 and 2008 examining stroke incidence and case fatality in a variety of different countries. They found that in the years 1970-9, 1980-9, 1990-9 and 2000-8 stroke incident rates per 100,000 of the world population were 125-460, 156-466, 131-451 and 112-223, respectively. Over the four decades studied, the incidence of stroke in high-income countries has decreased by 42%, whereas low-income countries have experienced an increase in incidence of 100%. The disparity between high and low income countries has been attributed to the introduction of public health strategies in high-income countries, which target reducing the risk factors associated with stroke. Furthermore, in low to middle income countries, the mean case fatalities for stroke were 32.5%, 23.0% and 26.6% in the years 1980-9, 1990-9 and 2000-8, respectively. Fatalities in high-income countries in 1970-79, 1980-89, 1990-9 and 2000-8 were 35.9%, 21.5%, 22.2% and 19.8%, respectively. In the absence of significant interventions in lower income countries, the worldwide rate of death

caused by stroke is anticipated to increase by 1.3 million over the next twenty years (Strong, Mathers & Bonita, 2007).

In New Zealand, stroke is the third leading cause of death after cancer and heart disease, and more resources are spent on stroke than any other health problem (Scott & Scott, 1994). In 2001, it was estimated 5,200 people experienced a stroke in New Zealand, which is 1.3% of the population (Tobias, Cheung, Carter Anderson & Feigin, 2007). Between 1992-3 and 2002-3, the incidence of stroke in New Zealand decreased by 1% each year and the death rate decreased by 4%. However, as more people are surviving a stroke, it is has become the leading cause of disability in New Zealand (Tobias et al. 2007; Tobias, Cheung, McNaughton, 2002). Of the New Zealanders who experience a stroke, 75% will die or will be dependent on another person to assist them with their self-care in the year following their stroke (Gommans, Barber & McNaughton, 2003). The rate of stroke in New Zealand increases exponentially with age, and males have a 20% higher incidence rate than women at most ages (Tobias et al. 2007). However, men live almost a year longer than their female counterparts following a stroke (Tobias, et al. 2007). According to the findings of the Auckland Regional Community Stroke Study 2002-3, (ARCOS), (Feigin, Carter, Hackett, Barber, McNaught, Dyall, Chen & Anderson, 2006; Carter, Anderson, Hackett, Feigin, Barber, Broad, 2006), there are ethnic disparities between the average ages at which a stroke event occurs for Maori (61 years), Pacific Islanders (64 years) and Europeans (75 years). Whilst the risk of death does not differ significantly between ethnic groups, there is a trend for Maori to die more often following a stroke. In addition, non-European ethnic groups experience strokes of greater severity. For example, there is data suggesting that Maori are three times more likely to be dependent 12 months post stroke in comparison to Europeans (Feigin et al. 2006; Carter et al. 2006). However, this may be because stroke rehabilitation is only funded for those over 65 years of age within New Zealand; Maori frequently experience stroke before 65. Data from the Auckland Regional Community Stroke Study (ARCOS) from 1981-2 and 2002-3 indicates a reduction in stroke events by 19% in European

New Zealanders, no change in the rate of stroke events in Maori and a 66% increase in stroke events in Pacific peoples. However, this may be in part due to the increase in the number of Pacific people in New Zealand (Feigin et al. 2006; Carter et al. 2006). Fink (2006) suggests that the reduction in stroke events amongst Europeans (that is mirrored in high-income countries other than New Zealand) is due to improved care for cardiovascular disease and, in particular, better control over hypertension, cholesterol levels, and a reduction in cigarette smoking.

Intracerebral Haemorrhage: Incidence, Case Fatality and Demographic Risk Factors

Intracerebral haemorrhage is the most common form of haemorrhagic disorder stroke (Feigin, et al. 2009). It occurs more often in men and at an earlier age than ischemic strokes, (Squire, 2008). In a recent meta-analysis reviewing 36 studies, ranging from 1983-2006 the case fatality of ICH did not appear to have changed in the last thirty years (von Asch, Lutise, Rinkel, von der Tweel, Algra, & Klijn, 2010). This is in contrast to the findings for stroke in general (Fegin, et al. 2009). In addition to there being no change in the rates of ICH incidence, there was no difference in frequency of incidence between men and women. However, the incidence of ICH amongst those aged 45-50 and those aged over 85 has increased since 1980, whilst, incidence in those aged below 45 has decreased (von Asch, Lutise, Rinkel, von der Tweel, Algra & Klijn, 2010). In general, incidence rates are lower amongst people of African descent and Hispanic people in comparison to Caucasians but highest amongst Asian people (von Asch, et al 2010). In New Zealand (N.Z.) ICH accounts for about 10% of all strokes (Hangar, Wilkinson, Frayez-Iskander & Sainsbury, 2006). The rate of ICH in N.Z. Europeans is 11%, in Maori and Pacific Islanders, 17%, and amongst Asian people, 22%. Once adjusted for age, odds ratios indicate that Maori and Pacific people are 2.7 times more likely to have an ICH and Asian people are 2.3 time more likely to have an ICH than their European counterparts (Feign, et al. 2006). It is likely that this difference is due to the differing risk profiles amongst the different ethnic groups as Maori

and Pacific Islanders have higher rates of obesity, diabetes, and hypertension and have diets that contain higher levels of monounsaturated fats (Feign, et al. 2006; Fink, 2006). Asian people have very high rates of smoking in relation to their European counterparts (Feign, 2006; Fink, 2006).

Having briefly reviewed the definitions, aetiology and epidemiology of stroke and ICH the next section considers how outcomes for those who survive a stroke are conceptualised.

1.2 World Health Organisation Models of Health Outcomes

This section considers the way in which health conditions and outcomes of health conditions such as stroke have been conceptualised. As the primary models which informed this research have been developed by the World Health Organisation (WHO), these will be the focus of this discussion. The models are: the International Classification of Disease, which models health conditions and the International Classification of Impairment Disability and Handicap (ICIDH) (1980) and its subsequent development into the International Classification of Functioning (ICF) (2001). Also included is a discussion of the application of the ICF to research.

1.2.1. Models of Health Conditions and Health Outcomes

Historically, attempts to model the nature of health conditions have been based on the medical model (Wade, 1994). The main premise of this model is that all illness or injury may be traced to an organic process that occurs within the body. The presence of disease is established through observable signs and symptoms, which may limit the person's ability to go about their normal daily activities. Wade (1994) suggests that this model is limited in understanding the role of the person themselves and their environment in health outcomes. Another popular model of a health condition is the bio-psycho-social model. This model attempts to remedy the problems with the medical model by the inclusion of psychological and social welfare in addition to the biological bases of a health condition (Wade, 1994).

However, this model has been frequently criticised for lacking in specificity as the terms 'psycho' and 'social' have a variety of different meanings (Wade, 1994).

For much of the 20th century health outcomes were formulated in terms of the presence of a health condition (morbidity) or death (mortality) (Gray & Hendershot, 2000). The focus on those two outcomes is reflective of the concerns of medicine during the past century. In a time where acute diseases predominated, measuring outcomes was reasonably straightforward as the disease was either present or not, it ran its course and was cured or resulted in death (Gray & Hendershot, 2000). Subsequently, there was a far greater focus on the signs and symptoms of a health condition as classified by the International Classification of Disease (ICD), published by the WHO, which is currently in its 10th Edition (World Health Organisation, 2010). The ICD is the global standard for reporting and categorising diseases, health-related conditions and external causes of disease and injury and was first published in 1893. As the ability to intervene in health conditions became more successful (i.e. health conditions that would have lead to death are now managed chronically, the outcome delayed, or the symptoms improved); older concepts of outcomes are no longer adequate for describing the consequences of having a health condition (Gray & Hendershot, 2000). Thus, in the late 1970s the WHO recognised the need to develop a globally shared model to understand and classify the outcomes of health conditions, disease and injury, in a more comprehensive manner, that could account for the variety of outcomes of a health condition, that were the consequence of modern medical intervention.

1.2.2. The World Health Organisation's Models of Health Outcomes

The WHO has moved towards developing a model with which it is possible to classify the consequences of a health condition in a number of different domains. In 1984, the WHO published their first model of understanding health outcomes, called the International Classification of Impairment, Disability and Handicap (ICIDH), for trial purposes to generate

discussion and to begin the process of formulating a model (Gray & Hendershot, 2000). It was intended for use in conjunction with the International Classification of Disease (ICD). Together these two systems of classification would then allow for diagnosis of a health condition (ICD) and a comprehensive description of outcomes for the individual (ICIDH). The ICIDH structure suggested outcomes occurred across three dimensions: impairment, disability, and handicap. In this model, *impairment* was described as any loss or abnormality of psychological, physiological or anatomical structure or function, which was considered to occur at the level of organ or system function. Impairment was assessed through judging the mental and physical functioning of the body and its parts according to expected functioning and included difficulty with moving body parts (e.g. arms or legs), cognition, such as memory and attention, or disruption to physiological processes (WHO, 1984). In contrast, *disability* was described as: any restriction or lack of ability to perform an activity within the range considered normal for the individual. The list of possible areas of disability included activities that are important in daily life such as dressing, washing and cooking. Finally, *handicap* described a disadvantage experienced by an individual that limited or prevented the person's ability to fulfil a role that was expected, given his or her age, gender, social and cultural factors. The term '*handicap'* was meant to reflect the interaction between a person and their surroundings within the context of their social being, (i.e. their ability to fulfil roles within the family, social network or employment). To illustrate the ICIDH with an example, a person who has had an ICH may experience hemiplegia*, (impairment)* which affects their ability to drive their car *(disability)* which, in turn, may mean that they are not able to go to work and visit their friends *(handicap)*.

It is without doubt that when the ICIDH was first published it provided a powerful tool for conceptualising the impact of a health condition on the experience of the individual. It considered, in a specific way, the interrelation between the impact of the health condition on a person's body and functioning and the impact it had on their social roles (Australian Institute of Health and Work, 1994) and could be applied to both individuals and populations

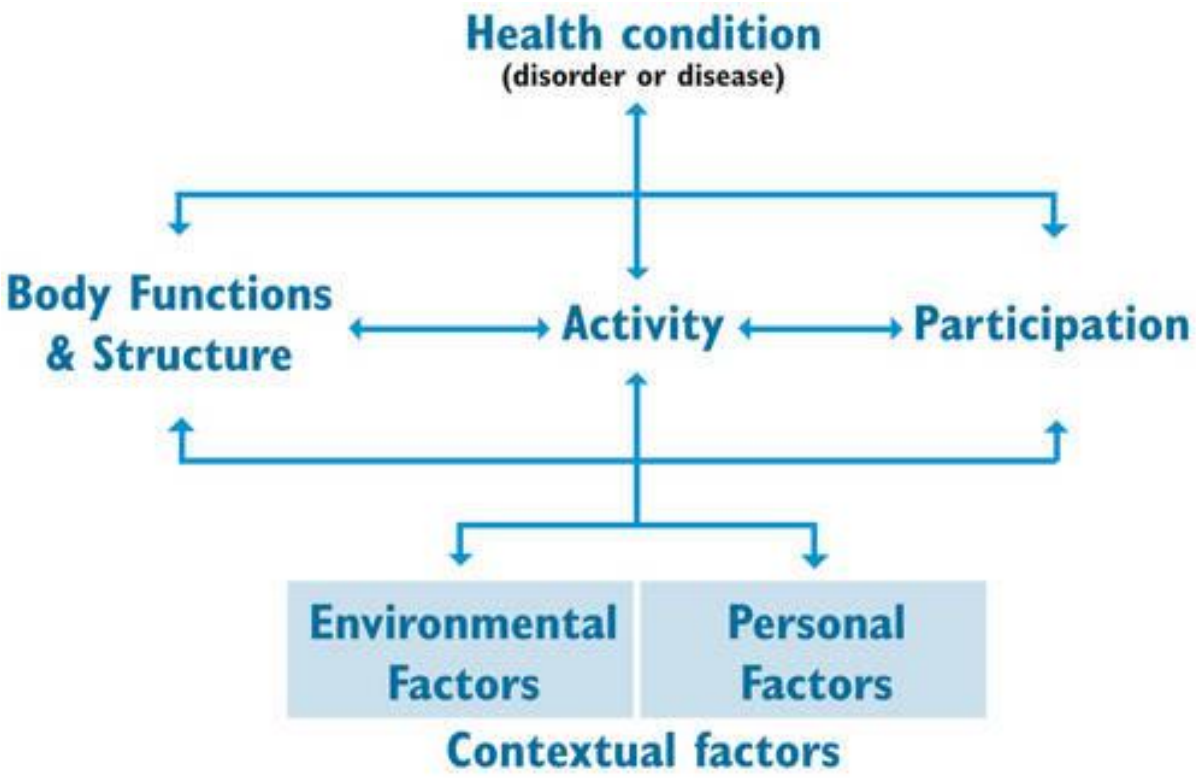
Badley (1993). Also, it could also be used in a number of different circumstances and settings such as: assessment and monitoring of health, rehabilitation, assessment of the success of an intervention, health records, service evaluation, conceptualisation of health in research, and comparing outcomes between countries (Badley, 1993).

However, in the years following its initial publication, the ICIDH has been subject to a number of criticisms. A meeting of The Australian Institute of Work and Health in 1994 summarised these points with the majority of concern centred on the idea that many of the outcomes identified within the dimension of handicap were, in fact, social constructs stemming from a western perspective of health. Therefore, this term was considered culturally loaded, and to be privileging of a westernised view of health and recovery. That is, the 'life' roles by which handicap outcomes were measured were westernised concepts. Reflective of this issue, was that the word 'handicap' could not be easily translated into non-western languages. Therefore, it was not considered possible to achieve comparisons in health outcomes between countries and across cultures whilst the handicap dimension was in place. Further, the dimension of handicap did not provide adequate recognition of the impact of the individual's environmental circumstances. For example, a person with mobility problems may be limited in their life roles because they do not have access to a wheelchair, as the country in which they live may not have the resources to provide them with one. Using the ICIHD criteria they would be labelled as 'handicapped' as they were not able to fulfil life roles: whereas, the problem actually lies within in their environment, which has limited access to wheelchairs. Further criticisms have included a lack of a clear boundary between the three dimensions and a lack of clarity concerning the causal and temporal relationships amongst the three dimensions (Gray & Hendershot, 2000).

In response to the criticisms of the ICIDH, the WHO developed a second model of health outcomes called the International Classification of Functioning Disability and Health (ICF), published in 2001. The aim of the ICF was to shift the focus from disability (what a person cannot do) to functioning (what they can do). In addition, there was an attempt to

move beyond the biological medical model of health and develop a model more reflective of a bio-psycho-social approach to understanding outcomes. This model was developed in conjunction with member countries of the WHO and thus so reflects a global, rather than a purely westernised, concept of health (Stucki, 2005). The aim was similar to that of the ICIDH in that it attempted to provide a unified, standardised and comprehensive language for describing and classifying health domains and states, and also a common framework for health outcome measurement. Figure 1 below presents an overview of the model.

Figure 1 The ICF Model



In the ICF, outcomes are viewed as a consequence of health conditions (e.g. ICH) and contextual factors. Contextual factors may refer to either *environmental factors* such as social policy law, societal attitudes, climate, landscape. While *personal factors* include

gender, age, education, coping styles, life experience and all other factors which influence how a person experiences health outcomes (WHO, 2002). The ICF describes outcomes as occurring at the level of *body functioning and structures, activities* and, *participation*. These are meant to be reflective of understanding outcomes at the level of body function, the person, and the person within his/her life context, respectively. *Body functions and structure* are conceptualised as being similar to impairment in the ICIDH, referring to the anatomical parts and functions of body systems. If there is significant loss or deviation in structure or function, this is called 'impairment'. *Activities* refers to the execution of a task by an individual such as, moving themselves, reading, getting dressed, or carrying out tasks around the home which frequently encompasses activities of daily living (ADLs) and is similar to the ICIDH category of '*disability'*. Difficulties in carrying out activities are described as *'limitations'. Participation* refers to behaviours involving a life situation such as social functioning, employment, and health related quality of life. Problems with participation are called '*restriction*s', (WHO, 2002). The WHO is clear in its advice that there is fluidity between the domains of activities and participation. Further, it is up to the user of the model to make the distinction between what is an activity and what is participation and whether it is necessary to make a distinction at all (WHO, 2002). To illustrate this model, a person who has an ICH (health condition) in the motor cortex would be considered to have an impairment in the *structure and functioning* of their brain due to the haemorrhage they had suffered and any resulting neurological deficits such as hemiplegia. This may cause limitation in *activities* such as difficulty moving their body, which may in turn prevent them from being able to drive a car. Not being able to drive a car may result in restrictions in *participation,* as they are unable to get to work or engage in social activities outside their home. The degree to which these outcomes would become negative would be somewhat moderated by the person's *environment*, such as the presence of social policies which allow provision of support workers to drive ICH survivors to social activities, and *personal* factors such as the person's interest in engaging in many social activities outside the home.

The ICF was considered to have overcome the criticisms of the earlier ICIDH and was endorsed by the World Health Assembly in 2001 and all member countries of the WHO have agreed to implement the model (WHO, 2001). The WHO has identified several areas in which the ICF could be used including; health outcome measurement, rehabilitation services, medical and multidisciplinary research, service provision, and policy in the arenas of health, education, labour and social development. Stucki (2005) maintains that the ICF represents a significant move away from a purely medical model of health that focuses largely on infection control and mortality prevention, and reframes outcomes as not purely consequences of disease, but also as a consequence of an individual's personality style and environment. Further, the ICF suggests that outcomes of health conditions be seen in relation to overall functioning and not as a unidirectional cause of difficulty stemming from disease (Stuck, 2005). However, a criticism of the ICF is that it is a huge classification system and a clinician/researcher is unlikely to have the time to filter through the entire system for each individual (Usten, Chatterji & Kostanjsek, 2004). In response to this, the WHO is developing 'core sets' which list the likely outcomes related to each particular health condition. This aims to allow the clinician/researcher to quickly reference the possible health outcomes a person may experience following a particular health condition, thereby ensuring comprehensive assessment. An initial 'core set' for stroke was recently released (Geyh et al. 2004). It includes five components relating to body structure (i.e. parts of the body that may be affected by stroke), 41 relating to function (i.e. working structures that may affected by stroke), 51 relating to activities and participation; the environmental dimension has 33 components. Unfortunately, Starrost et al. (2008) found this initial core set to have only poor to moderate inter-rater reliability. Further, Alguren, Lundgren-Nilsson and Sunnerhagen (2009) suggest that there needs to be a change in the items included in the stroke core set following an unsuccessful attempt to validate its use in a population three months post stroke. Currently, there are no separate core sets for stroke subtypes and a final core set for stroke more generally has yet to be agreed upon (Starrost et al. 2008).

The WHO has recommended that the ICF be employed as a method of classifying outcomes in research, but there is currently a challenge in so doing. The ICF is primarily a system of classification which describes only the presence of a health outcome (Starrost, et al., 2008). It does not easily allow for quantitative or qualitative measurement of health outcomes and experience, particularly concerning contextual factors which are, as yet, not clearly defined (Starrost et al. 2008). As the model is relatively new, measurement scales specifically designed to relate to its domains are small in number and have yet to be validated in stroke. Stuck, (2005) cautions that the core sets tell us what to measure, but not how to measure, or with which tools. This is particularly true of the contextual and environmental factors. A few attempts have been made to link existing scales used to measure health outcomes to the different ICF domains, however there is no accepted method for doing so (Stucki, 2005). Consequently, much of the current research into stroke uses scales available for determining stroke outcomes, which were in use prior to the development of the ICF, and then relating those pre-existing scales to the ICF domains. For example, existing scales of health-related quality of life, which have been validated in stroke populations, such as the SF-36, contain scales that assess changes in social functioning and ability to fulfil social roles depending on a health condition. These are used in the assessment of outcomes within the domain of participation. However, many of the scales available that measure activities and participation that are validated in stroke survivors overlap the ICF categories. For example, within the SF-36, which is primarily a measure of participation, the physical function scale is more a measure of activities.

The present study is a longitudinal follow-up of a 2002-3 population-based incidence study, for which planning began in 2000 during the time when the ICF was in the final stages of being developed and reviewed by the World Health Assembly. The measures selected during that first stage of the study related to the old ICIDH categories of impairment, disability and handicap. In order to make valid comparisons between outcomes at different time points, the same measures have been used in this study. Due to the relative similarity

of the ICIDH categories of outcomes to the ICF categories of body function and structures, activities and participation, it is possible to relate these measures to the ICF categories. Nonetheless, there is some overlap between the measures of activities and participation. However, as the WHO highlights the fluidity between these two domains this overlap does not present a problem for this research. As New Zealand has endorsed the ICF model, this thesis will use the ICF as a framework for examining outcomes of an ICH. For the reason that a method of comprehensively measuring contextual factors has yet to be developed, this thesis will consider outcome categories in terms of body structure and function, activities, and participation; it will also consider some personal factors such as; age, gender and education. Having reviewed the models of health outcomes most relevant to the present study, the remainder of this chapter will consider common the outcomes of stroke and ICH using the ICF framework.

1.3. Outcomes of Stroke and Intracerebral Haemorrhage

This study focuses on the long-term outcomes (five years) of ICH. Currently, there is a paucity of literature regarding the outcomes of ICH, so it has been necessary to draw on the wider stroke literature in order to provide an adequate background for the present study. Due to the large size of the body of wider stroke literature, this review focuses on studies most relevant to the present research, with preference given to population-based studies or studies with large cohorts and those that consider longer-term outcomes (i.e. of one year or more). This is justified in that the factors affecting long-term outcomes of stroke are often different to those affecting short-term outcomes (Woo, Kay, Yuen & Nicholls, 1992). However, in the absence of literature concerning long-term outcomes of ICH, studies considering outcomes at less than five years are also reviewed. In addition, the stroke literature is only considered if it contains participants who have had an ICH. The first outcome to be considered is mortality. Following this, outcomes of stroke and ICH survivors are reviewed using the domains of the ICF to provide structure. Relationships between areas of outcomes are discussed throughout the chapter.

1.3.1. Mortality

ICH, in comparison to other subtypes of stroke, is the least treatable and is far more likely to result in death. (Falk, 2007; Ciccone, Pozzi, Motto, Tiraboschi, & Sterzi, 2008). On average, rates of mortality at 30-days post ICH range between 50.6% and 52.55% (Fogleholm, Murros, Rissanen, & Avikainen, 2005; Christensen & Munro, 2008; Ronning, Sorteberg, Nakstad, Russel, & Helseth, 2008). This is in comparison to 13% in IS (Saposnil, Hill, O'Donnel, Fang, Hachinski, & Kapral, 2008) and 45% in SAH (Bedsen et al. 2009). The majority of deaths from ICH occur within the first two days of the haemorrhage occurring (Ronning, 2008). Mortality is particularly likely when associated with a Glasgow Coma Score (GCS) of less than eight at presentation, blood in the ventricles and a haematoma volume greater than 60ml (Broderick, Brott & Dundler, et al. 1993; Lisk, Pasteur & Rhoades, 1994; Mayer, Sacco, & Shi, 1994; Hemphill, Bonovich & Besmertis, 2001). Together, these factors predict a 30-day mortality rate of 90% (Broderic, Brott & Tomsick, 1993). It has also been shown that unconsciousness, lateral shift of cerebral midline structures, arterial pressure of ≥ 134mm systolic, hyperglycaemia, anticoagulant treatment, and ventricular extrasystoles, are associated with an increased likelihood of death at 28 days post-ICH (Fogleholm, Murros, Rissanen, & Avikainen, 2005). Mortality at 30 and 90 days post-ICH is also associated with hyperglycaemia in non-comatose diabetic patients, and hypertension (Passero, Ciacci, & Ulivelli, 2003; Tertri, Junda, Saloheimo, Pyhtinen, & Hullbom, 2009) and hydrocephalus (Diringer, Edwards, & Zazulia, 1998). Mortality also appears to vary according to the location of the haemorrhage. Flaherty et al. (2006) found that death rates at one year following lobar, cerebellar, and brain stem haemorrhages were 57%, 42%, and 65%, respectively. However, cortical location of the haemorrhage, mild neurological dysfunction, and low fibrinogen levels were associated with lower 30-day mortality rates (Castellanos, Leira, Tejada, Gill-Peralta, Davalos, & Castillo, 2005). Beyond the first few months, a Finnish population-based study found that those who survived the first 28-days have a 4.5 fold increased annual risk of dying in the first year post-ICH and a 2.2 fold increase of dying during the following two to six

years, in comparison to the rest of the population (Fogelholm, Murros, Rissanene, & Avikainene, 2005). The Oxfordshire Community Stroke Project (a population-based study) reports a 43% mortality rate in the first six months and 32-62% mortality at one year post-ICH (Bamford, Sandercock, & Dennis, 1990; Passero, Ciacci, & Ulivelli, 2003; Vermeer, Algra, & Franke, 2002; Daverat, Castel, & Dartigues, 1991; McGuire, Raikou, & Christensen, 2007).

There are also studies considering more long-term survival rates following ICH. In considering very long-term mortality, the previously mentioned Finnish population-based study reported a survival rate of 3.2% for men and 9.8% for women 16 years post-ICH (Fogleholm, Murros, Rissanen, & Avikainen, 2005). A cohort study in the U.K placed survival rates 11 years after an ICH at 24% (McGuire, Raikou, & Christensen, 2007).

Demographic factors are thought to impact mortality following an ICH. In a recent study of 474 ICH patients, males above the age of 75 were more likely to die than their female counterparts at 28-days and three years post-ICH (Zia, Engstrom, Svenson, Norrving, & Pessah-Rasmussen, 2009). Ethnicity is also thought to play a role in survival, though its role is unclear. A population-based study in the United States of America (U.S.A.), carried out during 1995-1998, found that African Americans were more likely to die from an ICH than their Caucasian counterparts (Ayala, Croft, & Greenlund, 2001). However, a population-based study in the U.K (The South London Stroke Register) found that although there was no difference between people of African descent and Caucasians in short-term survival (at 2, 7, and 28 days), after this time people of African descent were more likely to survive an ICH, and this was independent of the age at which the ICH occurred (Sarker et al. 2008). The same population-based study indicated that increased age is associated with a higher mortality rate for ICH (Sarker et al. 2008). A further predictor of mortality is recurrent ICH, which is thought to have a cumulative likelihood of 25-55% in the seven to eight years post-primary ICH, and 70% of those who experience a recurrent haemorrhage will die (Barinagarrementeria, 2005).

In summary, ICH is associated with high mortality rates in comparison to other stroke sub-types. Factors associated with increased mortality include location and size of haemorrhage, decreased consciousness, diabetes, hypertension, anticoagulant therapy, hydrocephalus, increased age, male gender, and recurrent haemorrhage. Although differences are evident in mortality rates relating to ethnicity, these findings are inconsistent.

1.3.2. Outcomes Relating to Body Structure and Function

This section will focus on the structural and functional outcomes relating to the neurological, neuropsychological, and on psychological/mood functioning following stroke and ICH; these are the areas of body structure and function most commonly affected by ICH (Geyh et al. 2004). The relationships between these different areas of outcome are also reviewed.

Neurological Outcomes

One of the most obvious outcomes of a stroke is the neurological impairment in body structures and functioning. A number of scales have been developed to measure neurological outcomes. One of the most commonly used measures is the National Institute of Health Stroke Scale (NIHSS) which aims to provide an overview of performance in areas of neurological functioning commonly affected by stroke such as limb movement and sensitivity, speech, and language disorders. Due to the diversity of locations in which an ICH can occur, there is diversity in the range of neurological deficits that can result. Wiebers, Feigin and Brown (2006) have broadly categorised the neurological outcomes associated with different possible locations of ICH, as summarised in Table 1. It is well documented that, in the early stages of recovery, ICH causes the impairment of a wide

Table 1 Neurological syndromes associated with ICH (Wiebers, Feigin & Brown, 2006)

Location	Possible Neurological Outcomes
Lobar *(bleeding into cortex or subcortical white matter)*	Coma, muscle weakness, delirium, sensory loss, hemianopia.
Supratentorial *(bleeding into basal ganglia and internal capsule)*	Coma, hemiparesis, sensory loss, hemianopia, respiration problems, dilated and fixed pupils, decerebrate posturing gaze palsy.
Thalamus	Coma, ocular motor abnormalities, contra lateral eye deviation, unilateral hemiplegia, hemiparesis, unusual sensory syndromes, (e.g. spontaneous pain).
Putaminal	Coma, deviation of gaze, hemiplegia, hemiparesis, global aphasia, hemineglect.
Caudate	Disorientation/confusion, gaze paresis, hemiparesis.
Basal ganglion	Muscle weakness, sensory changes, motor inertia.
Pons	Coma, quadriplegia, decerebrate rigidity, locked-in syndrome, hypernea, hyperhydrosis, hyperthermia.
Midbrain and medulla	Coma, quadriplegia, hemiplegia, ocular-motor paralysis.
Cerebellar	Coma, vertigo, inability to walk or stand, limb ataxia, facial palsy, nystagmus, decreased corneal reflex, gaze paresis, abducens palsy.

variety of physical functions. Lawrence et al. (2001) reporting in the South London Stroke Register (a population-based study), found at three months post-ICH there were numerous impairments experienced by ICH survivors in physical functioning, even after the data had been adjusted for age. Impairments included limb weakness (77%), urinary incontinence (70%), dysphagia (62%), dystharia (54%), dysphasia (29%), visual neglect (31%), gaze paresis (29%), sensory deficits (37%), and decreased level of consciousness (36%). In addition, other studies focusing on the outcomes of ICH have found oral apraxia to be present in 20% of survivors at six months (Maeshima, Turman, Smith, Dohi, Itakura, & Komai, 1997).

Though the focus of the present study is on the neuropsychological and functional outcomes of ICH (i.e. activities and participation), rather than neurological outcomes, measures of neurological outcome (i.e. National Institute of Health Stroke Scale) have been included in order to provide a boarder overview of ICH outcome.

Neuropsychological Outcomes

Within the ICF framework the domain of 'body structure and functions' are included consciousness, orientation, intellectual functioning, attention, memory, perception, higher-level cognition, mental functions of language, mental functioning and sequencing. These cognitive processes are typically measured by neuropsychological tests. In this section, the literature relating to neuropsychological outcomes of stroke are reviewed followed by a review of the available ICH literature.

There are a number of issues to be considered when reviewing the literature regarding the neuropsychological impact of a stroke and ICH, and the way in which cognitive function is recovered. The majority of studies examining the impact of stroke on cognition are not population-based, and those that are population-based often use only brief measures of cognition such as, the Mini Mental State Exam (MMSE) or, the Cambridge

Cognitive Examination for the Elderly (CAMCOG). These screening tests provide little information about the domains in which cognitive impairment occurs and are likely to under report cognitive deficits in stroke survivors. In fact, Nys, van Zandvoort, de Kort, Jansen, Kappelle, and de Haan (2005) compared the use of the MMSE with a neuropsychological battery and found that the accuracy of the MMSE in detecting cognitive impairment in stroke was no better than chance. Also, studies of cognition are often undertaken within the first months to one year following stroke and may therefore underestimate the level of recovery from cognitive impairment that is possible, as the brain can continue to recover and adaptively re-organise itself for many years post-stroke (de Haan, Nys, & Van Zandvoort, 2006). Of those studies that have used, a more complex neuropsychological battery of studies, most of which are not population-based and focus on hospitalised stroke survivors, or those admitted to inpatient rehabilitation and thus, skewing the sample (Fuh & Wang, 1995; Su, Chen, Kwan, Lin, & Guo, 2007). In order to gain an understanding of the long-term cognitive outcomes of stroke, studies using batteries of neuropsychological tests and those studies that include data pertaining to cognitive performance beyond 15 months post-stroke, are reviewed in the following section. Due to the dearth of population-based studies in which a comprehensive battery of tests was used, studies that are not population-based have been included here. Further, only stroke studies that include participants who have had an ICH are included in the current research. Details of these studies are provided in Table 2.

Stroke

As one can see in Table 2, cognitive impairments are present in both the acute and long-term stages of recovery. Some studies found an improvement in cognition over time (Hochstenbach, Otter & Mulder, 2003) while others found a decrease in cognitive performance leading to dementia (Serrano et al. 2007; Altieri et al. 2004; Ballard et al. 2003). Impairments were reported in all domains of neuropsychological functioning including:

Table 2 Neuropsychological Outcomes of Stroke beyond 15 months

Author/Study	Sample and Study Type	Testing time since stroke	Measures	Impairments
Serrano, Domingo Rodrigues-Garcia, Castro & Ser (2007).	n=327 Stroke survivors. Longitudinal.	3 and 24 mnths.	MMSE, SPMSQ, (hearing and simple/random visual reaction time), Bells Test, Verbal Fluency (category and phonetic), WAIS-R (PR, BD, Similarities), LM I II, BAB (verbal, picture), Token Test.	- 3 mnths: 26.9% cognitive impairment but no dementia. -24 mnths: 36.6% cognitive impairment but no dementia.
Altieri et al. (2004).	n= 191 IS and ICH. Longitudinal.	12 and 48 mnths.	AVLT, ROCF, Corsi Block-Tapping Test, SCWT, TMT, WCST, Coloured Progressive Matrices, COWA, (Animal Naming).	-incidence post-stroke dementia, 6.3% (12 mnths), 21.5% (48 mnths).
Ballard et al. (2003).	n=115 stroke >75years. Longitudinal.	3-15 mnths.	MMSE, CAMCOG, CDR (Simple Reaction Time, Digit Vigilance, Memory scanning and Spatial Memory), BNT, FAS.	Over time: - > 30 % ↓ cognition. -9% developed dementia (sig ↓ global cognition, memory, attention). -50% ↑ global cognition.
Hochstenbach, Otter, & Mulder (2003).	n= 57 IS, n=8 Haemorrhages, n=33 Controls, Cohort home-based.	Mean = 2.3 & 27.7 mnths.	AVLT (Dutch version), RBMT (Recounting a story), TMT, WAIS-III (DS, DSy, Letter Cancellation, Similarities, BD), BIT (copy and photograph scanning), Bobertag (structural clock test), CDT, BIT, Money's road map test, Dutch Aphasia Society Test (word comprehension	-Significant ↑ in all cognitive domains. -Largest improvement in attention & language. -Least improvement for memory.

			sentence comprehension) sentence comprehension, naming, and verbal fluency (animals), Aspects of handling money (recognizing, counting, and arithmetic).	
Desmond, Moroney, Sano, & Stren (2002).	n= 334 stroke, n=24 control. Longitudinal.	Mean = 21.1 mnths.	MMSE (orientation), SRT, BVRT (multiple-choice recognition), BNT, BDAE, RDT, BVRT, WAIS-R Similarities, MDRC (identities, oddities), Cancellation Tasks.	- increased incidence of dementia in Stroke=8.49 cases/100; Controls=1.37 cases/100. -RR of dementia post-stroke=3.83 (95% CI, 2.14-6.84).
Srikanth, Quinn, Donnan, Saling, & Thrift (2006).	n=99 stroke; n=99 controls. Mean = 69.9years. Population-based.	Mean = 2.14 yrs.	WAIS-R, (Information, DS, Similarities, Arithmetic, PC, BD, DSy), K-SNAP, Gestalt Closure (number recall, 4-letter words), S-MMSE, RAVLT, RBMT, ROCF, CDT, COWA, IQCODE.	Recurrent stroke ↑ risk of dementia. -37% with ↓ cognition developed dementia -↓ spatial ability, memory, attention/speed, executive functioning. orientation/knowledge, compared to controls. - 10.6% no cognitive impairment post-stroke.
Engstad, Almkvist, Viitanen, & Arnesen (2003).	n=199 IS & ICH. 24= Controls. Cross-sectional.	Mean = 8.9 years.	MMSE, ROCF, COWA, DS, TMT, TAPDOM, TAPDON, ANS.	-Stroke=cognitively impaired, ↓motor speed, visuospatial, episodic memory, and verbal fluency.
Rasquin, Lodder, & Verhey (2005).	n=156 strokes. ≥ 40 yrs. Prospective.	24 mnths.	CAMCOG, AVLT, CST, Stroop (Colour, Word), GIT (Calculation and Mental Rotation).	-↓: memory, mental speed, executive functioning, orientation, attention, language, praxis, visuospatial abilities and calculation. -Most impaired= speed (44.2%); executive functioning (25.2%). - Least impairment= orientation (7.2%).

del Ser et al. (2005).	n=193 stroke. X=66.8 yrs. Longitudinal.	24 mnths.	SPMSQ, SS-IQCODE, MMSE, Visual and Hearing reaction time, Bell Test, Verbal Fluency, WAIS-R -(Picture Recognition, Word Learning, LM I and II, BD, Similarities), BAB (verbal and picture), Token Test, Lowton-Brody Scale.	-Cognitive status stable=78.2%. -Cognition ↓=14%. -Cognition ↑ =7.8% (↑ language).
Rasquin, Lodder, Ponds, Winkens, Jolles, & Verhey, (2004).	n=159 stroke survivors. Longitudinal.	1-mnth, 6-mnths and 1 year post stroke.	CAMCOG, AVLT, Concept-Shifting Task, Stroop, GIT (Calculation and Mental Rotation).	Trend for improvement on performance of cognitive tasks for sample. 30 participants cognitive performance declined but they were older had lower overall MMSE scores, and decline was not related to gender, education, or stroke variables.

ANS= Aachener Naming Subtest; AVLT=Auditory Verbal Learning Test; BAB=Boston Aphasia Battery; BD=Block Design; BDAE=Boston Diagnostic Aphasia Examination; BIT= Behavioural Inattention Task; BNT= Boston Naming Test; BVRT=Benton Visual Retention Test; CAMCOG= Cambridge Examination for Mental Disorders of the Elderly; CBTT=Corsi Block-Tapping Task; CDR= Cognitive Drug Research; CDT= Clock Drawing Test; CIND= Cognitive Impairment No Dementia; CFST= Colour Form Sorting Test; CST=Concept Shifting Test; COWAT=Controlled Oral Word Association Test; CST=Concept shifting Test; DS= Digit Span; DSy= Digit Symbol; GIT= Groninger Intelligence Test; ICH= Intracerebral Haemorrhage; IS=Ischemic Stroke; JOLO=Judgement of Line Orientation; K-SNAP= Kaufman Short Neuropsychological Assessment; LM=Logical Memory; X= Mean, NCI= No cognitive Impairment; MDRT= Mattis Dementia Rating Scale; MMSE=Mini Mental State Examination; mnths=months; n= number pf participants; PC=Picture Completion; PR=Picture Recognition; PS=Post-stroke; RAPM=, Raven Advanced Progressive Matrices; RAVLT= Rey Auditory Verbal Learning Test; RBMT= Rivermead Behavioural Memory Test; RCFT= Rey Complex Figure Test; RDT= Rosen Drawing Test; SCWT=Stroop Colour Word Test; SDMT=Symbol Digit Modalities Test; SF=Short Form; S-MMSE= Standardised MMSE; SPMSQ=Short Portable Mental Status Questionnaire; SRT= Selective Reminding Test; SS-IQCODE= Short Spanish version-Informant Questionnaire on Cognitive Decline in the Elderly; TAPNOM= Finger -Tapping Performance of Non- Dominant Hand; TAPDOM= Finger -Tapping Performance of Dominant Hand; TFP=Test of Facial Perception; TIA-Transient Ischemic Attack; TMT=Trail Making Test; VaD= Vascular Dementia; vaMCI= Vascular Mild cognitive impairment;

VR= Visual Reproduction; WAB=Western Aphasia Battery; WAIS-R=Wechsler Adult Intelligence Scale-Revised; WAIS-III= Wechsler Adult Intelligence Scale-III; WCST= Wisconsin Card Sorting Test; WL=Word Learning; WMS-R=Wechsler Memory Scale-Revised.

memory, language, attention, visuospatial ability, speed of processing, executive functioning, verbal fluency, orientation in time and place, and overall cognitive performance. One of the most frequently reported impairments was in memory, which was closely followed by impairments in executive functioning, spatial ability, and attention. One of the least reported areas of deficit was in language. However, stroke survivors with language deficits were often excluded from the reported studies, as they could not undertake the neuropsychological tests.

One of the areas that was found to be least associated with cognitive recovery was memory. However, attention and language were the areas where recovery was frequently observed. The recovery of cognitive function is a process that occurs over time and for the majority of stroke survivors (Ballard, Rowan, Stephens, Kalaria, & Kenny, 2003; Hochstenbach, Otter, & Mulder, 2003; Srikanth, Quinn, Donnan, Saling, & Thrift, 2006). However, for a lesser proportion there is a definite decline in cognitive functioning following the stroke, which can eventually lead to a diagnosis of dementia (Ballard, Rowan, Stephens, Kalaria, & Kenny, 2003; Altieri, et al. 2006; Srikanth, Quinn, Donnan, Saling, & Thrift, 2006; Serrano, Domingo, Rodriguez-Garcia, Castro, & der Sel, 2007; Desmond, Moroney, & Sano, 1996). Various factors appear to influence the course of cognitive recovery; those with a lower GCS on arrival at hospital usually have poorer outcomes in terms of their recovery of cognitive function (Hochstenbach, Den Otter, & Mulder, 2003). In addition, those with left-hemisphere strokes appear to recover less well than those who have right-hemisphere strokes (Hochstenbach, Den Otter, & Mulder, 2003). Also, those who do not show a global improvement on cognition following stroke tend to be of an older age (Rasquin, Lodder, & Verhay, 2005) have poor cognitive abilities prior to the stroke, have a history of frequent drug use, and are less well educated (del Ser et al. 2005).

There are methodological problems with the studies summarised in Table 2. Many of the studies that were controlled comparisons did not have equal numbers of stroke and control participants. Neither were the controls matched by age, gender, ethnicity, and

education to the stroke survivors (Desmond et al. 2002; Srikanth et al. 2006; Engstad et al. 2003), this is despite these factors being well known to influence performance on neuropsychological tests (Lezak, 2004). In addition, in spite of extensive batteries of neuropsychological tests being used frequently, the comprehensive results of these tests were not fully reported, making it difficult to make comparisons about the nature of cognitive performance across domains (Serrano et al. 2007). Further, studies excluded people due to advanced age, those who had a serious medical condition, and/or those who were significantly impaired in their ability to speak, hear, or see (Altieri et al. 2004; Srikanth et al. 2006); this may have resulted in difficulties with cognition being under reported. In addition, the time lapse between test points was inconsistent across longitudinal studies.

ICH

Given the dearth of current literature available, trying to understand the nature of the cognitive impact of an ICH poses problems. There are few investigations into the cognitive outcomes of ICH, and almost none of those available consider the long-term outcomes. Table 3 below summarises the relevant studies. There are a variety of different cognitive impairments associated with an ICH, which is unsurprising given that an ICH can affect any area within the brain and, collectively, the studies reported impairment in many domains of cognitive functioning. This is similar to the findings reported for stroke in the previous section. The most common finding was aphasia (this is dissimilar to the findings from the stroke literature); this was a common finding in those who had experienced a haemorrhage in the basal ganglion. This was closely following by problems in verbal fluency. Other areas that were identified as impaired were visuospatial ability, memory, executive functioning, and attention. In one study, correlations existed between impairments in executive functioning and attention; and between memory and language (Su, Chen, Kwan, Lin, & Guo, 2007). There was evidence of improvement over time for those who had aphasia in the earlier stages (Ibayashi, Tanaka, Joanette, & Lecours, 1992). Those with a larger haematoma

Table 3 Neuropsychological outcomes of ICH

Authors	Sample and Study Type	Haemorrhage Location	Time since Haemorrhage	Measures	Impairments Reported
Ibayashi, Tanaka, Joanette, & Lecours (1992).	n=23 survivors. Longitudinal.	Thalamus.	5 – 28 days.	Standard Language Test of Aphasia, WAIS-R, RCPM, MMT, BVRT.	- Left 34% had a category naming impairment, - Left posterior had poorest VIQ, - Right posterior associated with a poorer IQ and PIQ.
			5 years.		-No improvement in performance on the WAIS, MMT or BVRT for left or right thalamus. -Survivors who had aphasia, which lasted longer than one month, still had problems finding words.
		Putamen.	3 months.		Aphasia problems largely resolved.
		Basal ganglia.	3 months.		Apraxia of speech common.
Liang et al. (2001).	n=140. Prospective.	Basal ganglia.	5 days – 3 months.	Aphasia scale of the Scandinavian Stroke Scale.	-Larger haematoma and initial poor score associated with poorer outcome at 3 months.
Su, Chen, Kwan, Lin, & Guo (2007).	n=30 survivors excluding those with significant aphasia and	Basal ganglia.	1 to 6 months.	Attention; *digit span.* Visual Memory Span; *subtests of the WMS-R, serial 7 subtractions task from MMSE.* Visuospatial function;	-Right sided strokes caused more deficits than left. -Most significant deficits compared to controls observed in visuospatial function and memory. -Deficit in language, attention and

	neglect. n=37 non-matched healthy controls. Control comparison.			*block design, hopper visual organisation test, and Test of Visual Perceptual Skills.* Memory; *MMSE, BVRT, Verbal Memory Scale.* Language; *Expressive and Receptive scales of the Luria Nebraska Neuropsychological Battery.* Executive function; WCST.	executive function in comparison to controls. -Deficits in attention were highly correlated with deficits in executive function. -Deficits in memory were highly correlated with deficits in language.
Fuh & Wang (1995).	n=6 ICH, 6 non-matched controls. Control comparison.	Caudate head.	2 weeks.	MMSE, BNT, WAIS-R, Digit Span Modified Comprehension, Proteus Maze Like Maze Test, Delayed Picture Recognition Span, Paired Word Learning, Word sentence reading, Simple Calculation, Pattern Matching, Verbal Fluency, Simple Figure Copy.	-ICH survivors had significant deficits in short- and long-term memory and verbal fluency in comparison to controls.

BVRT =Benton Visual Retention Test; BNT = Boston Naming Test; MMT=Miyake's Memory Test; MMSE=Mini Mental State Exam; RCPM =Ravens Coloured Progressive Matrices; WAIS-R=Wechsler Adult Intelligence Scale-Revised; WCST= Wisconsin Card Sorting Test; WMS-R=Wechsler Memory Scale-Revised

were less likely to experience improvement in aphasia over time in comparison to those with smaller hematomas (Liang, et al. 2001).

Whilst the studies presented do identify that cognitive impairment is associated with an ICH, the nature of these cognitive impairments, how they change over time and their relationship to lesion location is still difficult to interpret. All of the studies individually identify an area of impairment, but there is no collective body of literature that confirms these findings as common. Further, there was only one study that examined outcomes any later than six months post-ICH, and that was only for a proportion of the sample taken. In addition, methodological problems with the existing studies must be considered. Ibayashi, Tanaka, Joanette, and Lecours (1992) examined a larger sample of ICH survivors with thalamus, putamen and basal ganglion lesions. While they reported trends in cognitive impairments, there was no control with which to compare performance, therefore, it is not possible to know whether, or not, these trends were significant. In addition, reporting of the time periods in which participants were tested was inconsistent. All of these variables have been linked to performance on neuropsychological tests (Lezak, 2004). In the controlled comparison studies carried out by Su et al. (2007) and Fuh and Wang (1995), the controls were not matched for age, gender, education, and ethnicity so the data variations could be due to demographic variables. Furthermore, both of these studies examined cognition in the early stages of recovery when recovery, and the associated cognitive impairments, are in a state of flux, again making it difficult to draw conclusions about the long-term outcomes of cognitive recovery from an ICH.

To summarise, it is without doubt that deficits in cognition are a common outcome of stroke and ICH, and further, they occur within a variety of different domains including memory, language, attention, visuospatial ability, speed of processing, executive functioning, verbal fluency, orientation in time and place and overall cognitive performance. Recovery can occur, although for older and less educated individuals it is possible that cognitive functioning will continue to decline and develop into post-stroke dementia. From the ICH literature, it appears that different deficits are associated with lesion location. This is similar

to findings in the wider stroke literature, but it also appears that there is no effect of age, gender, or ethnicity on those outcomes according to (Su, Chen, Kwan, Lin, and Guo, 2007). At present there is little understanding of the long-term cognitive outcomes of an ICH, not only due to a paucity of literature, but also because the studies that are available on cognition post-ICH have not used neither fully matched controls for comparison nor sourced population-based samples.

Mood

Problems with mood, particularly depression and anxiety, are common in the aftermath of the survival of a stroke (Barker-Collo, 2007). The presence of a mood disorder can negatively affect mortality rates and rehabilitation outcomes (Whyte & Mulsant, 2002). The most commonly reported post-stroke mood disorder is post-stroke depression (PSD) which can be experienced as low mood, anhedonia, feelings of worthlessness, diminished concentration, psychomotor agitation, fatigue and insomnia (American Psychiatric Association, 2000). The prevalence of PSD is estimated to be between 14% and 62% (Bhopal, Teasell, Foley, & Speechley 2004; De Haan, Limburg, van der Meulen, Jacobs, & Aaronson 1995; Eriksson et al. 2004; Fuh, Liu, Wang, Liu & Wang, 1997; Hermann, Black, Lawrence, Szekely, & Szalai 1998; Steffens, Krishnan, Crump, & Burke 2002; Tang, Ungvari, Chui, Sze, Woo, & Kay, 2002). In a recent systematic review of 51 studies between the years 1977-2002, the prevalence rates of PSD were found to vary, but on average 33% of stroke survivors had PSD at some point in their recovery (Hackett, Yapa, Parag, & Anderson, 2005). PSD has been identified as being present in stroke survivors at three months (Barker-Collo, 2007), at two years (Schultz, Castillo, Kosier, & Robinson, 1997), at three years (Astrom, Adolfsson, & Asplund, 1993), and at 10-years (Morris, Robinson, Andrzejewski, Samuels, & Price, 1993). All of these studies found that the prevalence rates of PSD amongst stroke survivors were higher than would be found in the general population. PSD has been found to occur in survivors of an ICH at three months (Christensen, Mayer, Ferran, & Kissela 2009). A further study in the acute stages of recovery from ICH found the

prevalence rate of PSD was 48% (Massada, Makebe, Kunisshio, & Matsumoto, 2007). At 18-months, 58% of ICH survivors, based in China, in a sample of patients who had received surgical intervention for a hypertensive basal ganglion haemorrhage, suffered from depression (Hai, Zhang, Wang, Jue-Feng, & Pan, 2010). In a recent population-based study in the French West Indies, over a quarter of all stroke survivors suffered from depression five years post stroke (Chausson, Olindo, Cabre, Saint-Vil, & Smadja, 2010), unfortunately the rates of depression were not reported by stroke sub-type. In a Finnish population-based study, PSD was associated with an increased risk of suicide; this particularly manifested itself two years after the stroke. This risk of suicide increased in those who also suffered depression before the stroke (Forsstrom, Hakko, Nordstrom, Rasanen, & Mainio, 2009). Depression in the acute stages of recovery (i.e. the first weeks to three months) is also associated with a higher mortality rate 10-years post-stroke (Morris, Robinson, Andrzejewski, Samuels, & Price, 1993).

There are a variety of predictors of PSD, although many of these were identified from samples, including a variety of stroke subtypes, and thus this information may not be generalizable to depression post-ICH. In the acute stages of stroke recovery infarcts in the left hemisphere are thought to be predicative of depression (Astrom, Adolfsson, & Asplund, 1993; Bhogal, Teasell, Foley, & Speechley, 2004; Hosking, Marsh, & Friedman, 1990). However, no such association is found at six months or three years (Thomas & Lincoln, 2008; Astrom, Adolfsson, & Asplund, 1993). In a recent study at three months post stroke, factors such as being married, living in a nuclear family, and having greater restrictions in ADLs were associated with higher levels of depression (Srivastava, Taly, Gupta, & Murali, 2010). In the acute stages of recovery, ICH survivors who suffer depression are more likely to have reduced cerebral blood flow to the frontal lobes in comparison to ICH survivors who do not have depression, but there appears to be no correlation between severity of haemorrhage and a previous history of depression (Massada, Makebe, Kunisshio, & Matsumoto, 2007).

There is controversy over whether the occurrence of PSD relates to gender. Women have been found to have a higher prevalence of depression at one month, six months, one year, and three years post-stroke (Morrison, Pollard, Johnston, & MacWalter, 2005). According to Paradiso and Robinson (1998), women are twice as likely to be diagnosed with PSD as men are, are more likely to have left hemisphere infarcts, and are more likely to have had psychiatric complaints and cognitive impairments prior to the stroke. However, depression is more prevalent in women amongst the general population, but the prevalence rates of PSD in women are greater amongst stroke survivors than in the general population (Morrison, Pollard, Johnston, & MacWalter 2005; Paradiso & Robinson, 1998). In contrast, Srivastava, Taly, Gupta, and Murali, (2010), found men were more likely to be diagnosed with depression. Men who have PSD are more often restricted in their social functioning and ADLs in comparison to other men recovering from a stroke (Paradiso & Robinson, 1998). However, others have found no correlation between gender and PSD at one month, six months and three years (Astrom, Adolfsson, & Asplund, 1993; Kolita, Numminen, Waltimo, & Kaste, 1998; Thomas & Lincoln, 2008). In ICH survivors, depressed mood is more prevalent in women at three months (Christensen, Mayer, Ferran, & Kissela, 2009).

There is varying evidence relating to the role of age in PSD. A large number of studies have found no correlation between the two (Anderson, Vestergaard, Riis, & Lauritzen, 1994; Chemerinski, Robinson, & Kosier, 2001; Herrmann, 1999; Lipsey, 1983; Morris, Robinson, Andrzejewski, & Samuels, 1993; Starkstein, Robinson, Berthier, Parikh, & Price, 1988; van de Weg, Kuik, & Lankhorst, 1999). However, there is also evidence to suggest that increased age is more likely to be associated with PSD (Fruehwald, Loffler, Eher, Saletu, & Baumhackl, 2001, Giaquinto, Buzzelli, Francesco, Lottarini, Montenero, & Tonin, 1999). Although Schultz, Castillo, Kosier, and Robinson, (1997) have found that younger stroke survivors are more likely to experience depression.

Neurological deficits have also been associated with increased rates of depression post-stroke. Dysphasic and aphasic survivors, and those with difficulty in communicating, are more likely to be depressed than stroke survivors who do not have difficulty with

communication (Astrom, Adolfsson, & Asplund, 1993; Damecour & Caplan, 1991; Thomas & Lincoln, 2008). Further, those who experience restrictions in the functioning of a leg or arm are more likely to experience depression (van de Port, Kwakkel, Bruin, & Linderman, 2007). For those who have an ICH there is a correlation between depression and moderate to severe neurological impairment at three months (Christensen, Mayer, Ferran, & Kissela, 2009).

Deficits in cognition have also been associated with depression. However, whether depression causes the deficits or vice versa is unclear (Morris, Robinson, & Raphael, 1990; Paradiiso & Robinson, 1998). When depression is treated, cognitive deficits are alleviated (Naurishima, Chan, Kosier, & Robinson, 2003). However, Naurishima et al. (2003) used the MMSE to assess cognition, which, as a screening instrument, is problematic in gaining an accurate picture of cognition following stroke. Depression, when co-morbid with cognitive deficits, has been linked more closely to left-hemisphere strokes than to right-hemisphere strokes in the acute stages (House, Dennis, & Moridge, 1991; Murata, Kimura & Robinson 2000). PSD at three months has been associated with deficits in attention but not in memory or verbal fluency (Hosking, Marsh, & Friedman, 2000). Severity of depression also appears to play a role in cognitive performance. For example, Nys (2005) reported that those with severe PSD were more likely to exhibit deficits in memory, language and visual perception and construction than those with mild PSD. At one year post-stroke, the cognitive deficits most commonly associated with depression are in memory, problem solving, attention and psychomotor speed (Rasquin, Lodder, & Ponds, 2004; Kauhanen et al.1999).

As stated earlier, beyond three months the likelihood of the occurrence of depression is linked to the long-term loss of social and leisure activities, and the difficulty in completing ADLs (van de Port, Kwakkel, Bruin, & Linderman, 2007; Clark & Smith,1999; Angeleri, Angelrei, Foschi, & Nolfe, 1993; Feibel & Spreinger, 1982). Further, dependence on others in ADLs has also been found to be a strong indicator for depression (Astrom, Adolfsson, & Asplund, 1993). Some studies have reported depression in stroke survivors as being more strongly correlated with poor social functioning than with limitations in ADLs (Clark & Smith,

1998). In ICH, depressed mood has been associated with impairment in ADLs and poor health related quality of life (HRQoL) at 3-months (Christensen, Mayer, Ferran, & Kissela, 2009).

PSD is frequently co-morbid with anxiety disorders, in particular, with generalised anxiety disorder; excessive worry, restlessness, irritability, muscle tension, insomnia, fatigue difficulty in concentrating (American Psychiatric Association, 2000). In the acute stages, Astrom (1996) found a prevalence rate of 28% of post-stroke anxiety (PSA) and this did not change over the following two years. However, other studies have identified a prevalence rate of only 4% (House, Dennis, & Moridge, 1991). Schultz, Castillo, Kosier, Robert and Robinson (1997) found that in a cohort of 142 stroke survivors of those who met the criteria of generalised anxiety disorder, 74% also met the criteria for dysthymia or depression. At three months, post-stroke Barker-Collo (2007), found that moderate PSA was co-morbid with moderate PSD in 6.8% of the sample and that severe PSA was co-morbid with severe PSD in 5.5% of the sample. PSA has been associated with right-hemisphere infarcts and a history of alcohol abuse (Castillo, Starkstein, Fedoroff et al, 1993; Astrom, 1996; Starkstein, Robinson, & Price, 1988; Starkstein, Cohen, Fedoroff et al, 1990). The literature regarding the predictors of (PSA) is similar to the literature regarding PSD in that there is evidence, both supportive, and unsupportive, of demographics such as gender and age playing a predictive role. Women and those below the age of 59 years have been found to be more vulnerable to anxiety (Schultz, Castillo, Kosier, & Robinson, 1997; Morrison, Johnston, & Walter, 2000). However, others have found no association between gender, age, and PSA (Dennis, O'Rourke, Lewis, Sharpe, & Warlow, 2000). PSA has not been found to correlate significantly with deficits in cognition or impairment in neurological functioning or social functioning (Starkstein, Cohen, Fedoroff et al, 1990; Castillo, Starkstein, Fedoroff et al, 1993; Castillo, Schultz, & Robinson, 1995). There is however, a correlation between PSA and restriction in ADLs in both the acute stage following a stroke, and at three years post-stroke (Schultz, Castillo, Kosier, & Robinson, 1997).

To summarise, amongst stroke survivors depression and anxiety are experienced at rates much higher than in the general population. There are various factors that may predict PSD and PSA including, lesion location, gender, age, and neurological impairment. In addition, relationships exist between cognitive ability and limitations and restrictions in activities such as ADLs. However, there is controversy over the exact nature of these relationships and, due to the paucity of the literature regarding PSD and PSA by stroke sub-type, it is unclear if these relationships hold true for ICH.

1.3.3. Outcomes Relating to Activities and Participation

The stroke literature traditionally focuses on functional outcomes as aspects of activities described as 'activities of daily living' (ADLs) which include activities such as washing, dressing, preparing meals, lifting or carrying objects. Another area that is the focus of much research in the stroke outcomes literature is 'health related quality of life' (HRQoL) which is often related to the domain of participation within the ICF.

The section below reviews the relevant literature in these areas.

Activities

It is clear from the population-based studies that many survivors of stroke continue to experience problems in ADLs in the years after the stroke. The Sydney Stroke Study (2009) found that over the course of a year, 24.8% of stroke survivors enjoyed an improvement in their ADLs and reached a good level of functional recovery, however, 75.2 % still experienced impairments in their ADLs. Factors associated with poor recovery were increased age, lower pre-morbid intelligence, apathy about their recovery, and a further cerebrovascular event in the intervening year. There was no effect found for gender, education, marital status, stroke severity, location or volume of infarct (Withall, Brodaty, Altendorf, & Sachdev, 2009). A population-based study in Auckland during 1991-1992 found that at 3-years post-stroke over half of stroke survivors still experienced restrictions in ADLs and over a third required assistance in at least one ADL. In contrast to The Sydney Stroke

Study, males were more likely than females to make a complete recovery (Bonita, Solomon, & Broad, 1997). Chausson et al. (2010) found that 25% of stroke survivors were dependent on caregivers for carrying out basic ADLs 5-years post-stroke. In the Perth Community Stroke Study (2002), of the 55% of stroke participants who were still alive at 5-years post-first ever stroke, 36% were described as being disabled and 14% required 24-hour nursing care (Hankey, Jamrozik, Broadhurst, Forbes, & Anderson, 2002). In the population-based South London Stroke Study (Patel, 2001), of the 61% of stroke survivors still alive at 3-months 9% were severely impaired in their functioning and 15% were moderately impaired. At one year, 35% were still alive, of whom 11% had a moderate or severe disability. Thus, it is clear that for stroke in general, limitations in activities are common and often long-term outcomes.

The proportion of people who have survived an ICH who are functionally independent ranges from 12% at 1-year in a population-based study from Estonia (Vibo, Korv, & Roose, 2007), to 39% (mean follow up period of 50 months) in Italy amongst a population of young adults (Marini, Totaro, De Santis, Ciancarelli, Baldassarre, & Carolie, 2001). Nuutila and Vuorela (1992), in a population-based study of ICH survivors found that at the end of a median of 32 months follow up 35% of the original population was still alive; of whom, 51% were considered to have no difficulties in their ADLs, while 45% were dependent in their ADLs, and 4% were in need of constant care. The only identified predictor of poor functional outcomes was being over 70 years of age. There was no association found between functional outcomes and hematoma size or location. In contrast, Rost et al. (2008) examined 629 ICH survivors and found that those who were independent in their ADLs at 90-days post-ICH had smaller hematomas, were younger, had a lobar haemorrhage had a higher GCS at admission, and did not have a cognitive impairment prior to the ICH. In addition, neurological impairment such as motor problems has been found to limit ADLs in ICH survivors in the acute stages (Mercier, Audet, Herbert, Rochette, & Dubois, 2001).

Several studies have shown that cognitive impairment predicts impairment in ADLs (Patel, et al, 2002; Paolucci, Antonucci, & Gialloreti, 1996; Saxena, Ng, Koh, Yong, & Fong,

2007; Claessona, Lindéna, Skoogb, & Blomstranda, 2005). It has been found that in stroke survivors, impairment in memory, visuospatial functioning, language, and problem solving are associated with increased limitations in ADLs (Mercier, Audet, Herbert, Rochette, & Dubois, 2001). Stephens et al. (2005) found that the most severe limitations in ADLs were associated with impairments in global cognition and attention. Somewhat less severe limitations in ADLs were more commonly associated with impairment in executive functioning and memory. However, in contrast Cederfeldtac, Gosman-Hedströmac, Sävborgb, and Tarkowskibd (2009) found that there was no effect of impairments in cognition on a stroke survivor's ability to perform more personal aspects of ADLs such as washing and dressing. While there is varying evidence for the role of neuropsychological functioning in ADLs, none of the studies are population-based or focus on sub-types or ICH or long-term outcomes, or whether the participants had depression.

The most commonly associated mood disorder in relation to ADLs is depression. Depression has been documented as being associated with limitations in ADLs at both three and six months post-stroke (Chemerinski, Robinson, & Kosier, 2001). In a 2-year follow up study stroke survivors who had a diagnosis of depression in the first month after their stroke were more likely to experience problems in ADLs 2-years later, irrespective of whether the depression had remitted or not (Parikh, Robinson, Lipsey, Starkstein, Fedoroff, & Price, 1990). However, in a double-blind randomised treatment study (where an anti-depressent was the treatement) stroke survivors whose depression remitted had siginificantly better recovery in their ADLs than those who continued to be depressed. This was independent of demographic varaibles, lesion characteristics, and neurological signs and symptoms (Chemerinski, Robinson, Arndt, & Kosier, 2001). Unfortunately the link between depression and ADLs in ICH has not yet been explored.

Participation

Participation in the ICF model is most commonly discussed in reference to health related quality of life (HRQoL). Whilst there is no universally accepted definition of HRQoL

the WHO defines it as: ‘An individual’s perception of their position in their life in the context of their culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns’ (WHO, 1997, pg 1). HRQoL is becoming an increasingly important area for stroke outcomes research as it can provide a measurement of efficacy of rehabilitative programmes beyond that of function focused measurements (Kuroda, Kanda, & Sakai, 2006). As an indicator of broader functional outcome, HRQoL can highlight disparities in outcomes, poor adjustment to illness, and lowered psychosocial functioning (Buck, Jacoby, Massey, & Ford, 1993). Stroke survivors have significantly lower HRQoL in comparison to people with hypertension (Baune & Aljeesh, 2006). In recent studies, male survivors of stroke have been found to have a higher HRQoL than females (Sturm, Donnan, & Dewey, 2004; Wyller, Sveen, Sodring, Pettersen, & Bautz-Holter, 1997; Angeleri, et al. 1993). Patel, McKevitt, Lawrence, Rudd, and Wolfe (2007) examined the factors that determined HRQoL at one and three years post-stroke. Using a population register of first ever strokes they found that predictors of a poor physical health summary score on the SF-36 in the first year after stroke were female gender, being a manual worker, having diabetes, having a right-hemispheric infarct, urinary incontinence, and cognitive impairment. Predictors of a poor score on the mental health summary score of the SF-36 were being Asian, having ischemic heart disease, and cognitive impairment. Overall, participants who were over the age of 65 had better mental health summary scores that those who were below the age of 65. At three years’ post-stroke, independent predictors of physical summary score were hypertension, urinary incontinence, and cognitive impairment. In the North East Melbourne Stroke Incidence Study (NEMESIS) (Sturm, Donnan, & Dewey, 2004) HRQoL was assessed at two years post-stroke. They found that predictors of poor HRQoL post-stroke were physical impairment, limitations in activities, depression, anxiety, institutionalisation (i.e. permanently cared for in a setting outside their home), dementia and increased age. Factors found to predict poor quality of life that were present at the onset of stroke were female gender, hemi-neglect, significant impairment in body function and low socioeconomic status.

There has very recently been a large study on the HRQoL three months after ICH, which found that at three months the majority of ICH survivors (87%) had a similar HRQoL as the general population. However, amongst those for whom HRQoL was reduced, predictive factors for lower HRQoL were; advanced age, neurological impairment, high systolic blood pressure, larger haematoma volume, and a deep location (as opposed to lobar) of the haemorrhage. (Christensen, Mayer, & Ferran, 2009). In addition, those who were experiencing depressed mood (20%) had lower scores for HRQoL (Christensen, Mayer, Ferran, & Kissela, 2009). The role of cognition in HRQoL in ICH has yet to be explored.

Higher HRQoL scores have been associated with higher scores on measures of ADLs (Kuroda, Kanda, & Sakai, 2006), being married, and having a system of social support (Kim, Warren, Madill, & Hadley, 1998). Poor HRQoL scores have been associated with mood disorders such as anxiety and depression (Kuroda, Kanda, & Sakai, 2006). Cognitive impairment present at seven months post stroke has been associated with poor HRQoL, in particular, in tasks involving spatial-temporal skills and sequencing (Hochsteinbach, Anderson, van Limbeek, & Mulder, 2001). Factors such as subtype of stroke or lesion location appear unrelated to HRQoL (de Haan, Limburg, Van de Meulen, Jacobs, & Aronson, 1995). Hackett, Duncan, Anderson, Broad, and Bonita (1999) assessed HRQoL of a population of 639 stroke survivors (Auckland Stroke Study) 6-years post their first stroke and compared their scores to a healthy control group. Overall, they found the HRQoL post-stroke was generally good, and there was no difference between perceived mental health of the stroke survivors and the controls. The factor that made the biggest difference to HRQoL amongst survivors and controls was physical functioning. Amongst the stroke survivors, females, those over the age of 75, those living in institutions, and those requiring help with ADLs had lower scores for physical quality of life.

To summarise, in stroke survivors various factors have been associated with higher rates of limitations in activities such as age, lower pre-morbid intelligence, attitude towards stroke recovery, and being female. In ICH survivors, limitations in activities have been

associated with increased age. Factors that are apparently protective are smaller haematomas, lobar haemorrhage, higher GCS at admission, and no cognitive impairment prior to admission. Impairments in neurological functioning and cognition appear to be correlated with impairments in ADLs and reduced HRQoL. HRQoL appears to be reduced in stroke survivors, particularly those who are females, have a mood disorder, have cognitive impairment, are at an older age, were institutionalised, and were of low socio-economic status. Factors found to be protective were being independent in ALDs, being married and having a good system of social support. However, HRQoL in ICH survivors at 3-months was largely similar to the general population.

1.3.4 Summary of Outcomes

Both stroke and ICH survivors experience impairments in neurological and neuropsychological functioning and mood. They also experience limitations in ADLs and in some cases a lower HRQoL, but lower HRQoL is not so often found in ICH survivors. It has also been documented that there are relationships between each of these dimensions; however, the exact nature of the relationships and the factors that influence them often vary when the collective evidence is reviewed. Most of the research reviewed here considers outcomes within the first 2-years post-stroke, only a few studies examine the longer-term outcomes (i.e., greater than 2 years). As recovery from stroke continues to occur for many years, an understanding of the outcomes when stroke survivors stabilise has yet to be developed. This is particularly true for ICH where the available literature is limited especially for long-term outcomes and on the relationships between areas of outcomes.

1.4. Aims of This Study

The main aim of this study was to examine the long-term (five-year) outcomes of an ICH. This study examined each of these areas of outcome denoted by the ICF, including body structure and function (i.e. neurological, neuropsychological functioning and mood outcomes), activities (i.e. independence in ADLs as assessed by measures of disability) and

participation (i.e. involvement in meaningful life situations assessed by measures of HRQoL and handicap). The sample used is drawn from a population-based incidence study conducted in 2002-3 (the Auckland Regional Community Stroke Study [ARCOS]). Data for the current study participants obtained during the ARCOS study at; baseline, one month and six months post ICH regarding activities, participation and mood were made available for analysis. To gain a better picture of ICH outcomes a control group was recruited from the general adult population each of whom was selected according to; age, gender, ethnicity and education and then matched to an ICH participant. The specific aims of the study were to explore outcomes in ICH survivors in neurological and neuropsychological functioning, mood, ADLs and HRQoL in comparison to the matched health controls. In addition, to explore whether there is evidence of recovery in mood, ADLs, and HRQoL in the ICH group over time, and whether there are relationships between the different outcomes, and whether demographic variables such as age, gender and education play a role in outcomes of an ICH.

Chapter 2: Methodology

This chapter outlines the methodology used in the present study. First, the participants are described; this is followed by a description of all tests used in the study. Next to be outlined is the procedure used for the collection of participant data, data management and the preparation for the preliminary analyses.

2.1. Participants

The participants in this study consisted of two groups: an intracerebral haemorrhage (ICH) group and a matched control group. The ICH group was drawn from a population-based study carried out in Auckland in 2002-3 (Auckland Regional Community Stroke Study [ARCOS]). During ARCOS, individuals living in the Auckland region who had been reported as having suffered a stroke between March 1st 2002 and 28th February 2003 were identified and asked to participate in a study examining outcomes over the 6-month period following their stroke. 1938 potential participants were asked of which 1292 agreed to take part. Of the 1292 who had agreed to take part, at the six-month follow up, 1026 (88%) agreed to be contacted in the future for further study. Of the group who agreed to be contacted, 77 had suffered an ICH and formed the basis from which the ICH group in this study was identified. When contact with the 77 ICH survivors was attempted in 2007-8, it was found that, during the 5 year interval, 12 (15%) had died. Of those remaining 14 (18%) did not wish to take part in further study, 26 (34%) were lost to follow up, 1 (1%) was too hearing impaired to undertake neuropsychological testing (unrelated to the stroke), and 5 (7%) did not speak English well enough to undertake the neuropsychological tests. Those who did not speak English well enough to undertake neuropsychological testing were excluded due to the issues associated with neuropsychologically assessing the bi-lingual brain. This left an ICH group of 19, 25% of the original sample. Of the 19 participants, four had had a recurrent ICH in the intervening five years. No other neurological events were reported by the participants. A control sample matched for age *(+/- 1 year*) gender, ethnicity and education (*+/- 1 year*)

was recruited from the general adult population. These variables were selected for matching criteria because of their contribution to variance in neuropsychological performance (Lezak, 2004). Further inclusion criteria were; that they did not have a current diagnosis of depression, a previous diagnosis of psychosis, a personality disorder, head injury, had not participated in substance abuse neither did they have any other neurological or neuropsychological problems, and were not suffering from a chronic health problem. Matched participants could be found for all but one of the ICH group participants. It proved impossible to find a 68-year-old Pacific Island male who was also able to speak English to the level required to undertake the neuropsychological testing and was willing to take part in the study. This meant the ICH group consisted of 19 participants, while the matched control group consisted of 18 participants. Tables 4 and 5 below summarise the demographic characteristics of the two groups. As can be seen in Tables 4 and 5, there is little difference between the two groups on the matching criteria of age, gender, ethnicity and education. Marital status is largely similar between the two groups; however, a greater number of the ICH group appeared to be living in rest homes. In addition, 100% of the ICH group described themselves as retired whilst of the control group, 27% were still working.

Table 4 Age and years of education of ICH and matched control groups

	ICH Group n=19		Matched Control n=18	
Demographic	Mean	(SD)	Mean	(SD)
Age	66.7	16.59	66.1	16.59
Years of Education	15.4	2.5	14.8	1.3

n = total number in group; (SD) = standard deviation.

Table 5 Demographics of ICH and matched control groups

		ICH Group n=19	Matched Control n=18
Demographic		%	%
Gender	Females	56.0	56.0
	Males	54.0	54.0
Ethnicity	Maori	5.0	5.0

	Pacific Islander	5.0	5.0
	European	90.0	90.0
Marital Status	Married	80.0	73.0
	Separated	10.0	16.0
	Single	10.0	11.0
Dwelling	Own home	63.0	73.0
	Friends/family home	0.0	5.0
	Retirement Village/Home	11.0.	17.0
	Rented Home	11.0	5.0
	Rest Home	15.0	0.0
Occupation	Retired	100.0	73.0
	Employed	0.0	27.0

n=total number in group.

2.2. Measures

2.2.1. Measures of Body Structure and Function

According to the ICF, the areas of body structure and functioning broadly affected by stroke include neurological and neuropsychological functioning, and mood (Geyh, et al. 2004). In this study, the neurological outcomes of ICH were measured using the The National Institute of Health Stroke Scale (NIHSS), which has been specifically developed to measure the neurological outcomes of stroke. Neuropsychological functioning was measured using a battery of tests which assessed the domains of information processing speed, executive functioning, verbal and visual memory, language, and visuoperception. The neuropsychological tests described below are presented in the order in which they were administered to the participants. Mood was assessed using the General Health Questionnaire-28 (GHQ-28) and GDS-SF. Examples of the measures of body structure and function (excluding neuropsychological tests) are found in Appendix A. Below is a review of each of the measures selected.

Measure of Neurological Functioning

National Institute of Health Stroke Scale (Lyden, Lu, Jackson, Marler, Kothari & Brot, 1999)

The National Institute of Health Stroke Scale (NIHSS) is a 15-item impairment scale intended to evaluate neurologic outcome and degree of recovery for patients with stroke.

The scale assesses level of consciousness, extraocular movements, visual fields, facial muscle function, extremity strength, sensory function, coordination (ataxia), language (aphasia), speech (dysarthria), and hemi-inattention (neglect). The possible score for each of these neurologic outcomes varies from 0, indicating no impairment, to a maximum of 2, 3, or 4 (depending on the item), indicating total impairment. For example, in measuring facial palsy 0 = normal symmetric movements, 1= minor paralysis (e.g., asymmetry on smiling) 2 = partial paralysis and 3 = no movement of the face. The total score for the NIHSS ranges from 0-42, the higher the value, the greater the impairment. Certification is required to administer the NIHSS and the researcher for this study was trained and received certification to use the scale. The NIHSS has established reliability and validity for use in prospective clinical research and predictive validity for long term stoke outcome (Adams, Davis, Leira, Chang, Bendixen, Clarke, et al. 1999; Lyden, et al. 1999).

Measures of Neuropsychological Functioning

Bell Cancellation Test (Gauthier, DeHaut, & Joanette, 1989)

Bell Cancellation Test (Bells) is a test of visual inattention. Initially the participant is presented with a practice sheet on which a single bell is presented in the centre, surrounded by 14 distracters (e.g., bird, key, apple, mushroom, car, etc). The participant is asked to name each distracter item after which, he/she is asked to name the target item (the bell). The examiner then presents the test sheet and asks the participant to circle all the bells he/she can find. The test sheet is an A4 printed sheet divided into seven equal columns, each containing five targets (bells) and 35 distracter figures. All figures are presented as solid black silhouettes. If the participant says they have finished before all the bells have been circled they are asked (only once) to check their work. No time limit is set for the task.

Scoring for this test is based on the total number of bells identified. Gauthier et al. (1989) recommends scoring the errors separately in the three right columns, the three left, and the centre column, in order to gauge attention deficits. Omission of three or more bells on either the left or right side is thought to indicate a lateralised inattention deficit. The

test/re-test reliability of the Bells test is marginal (*r*=.69), but as hemi-neglect is a fluctuating deficit it may be unreasonable to expect highly comparable performance (Vanier, Gauthier, Lambert, Pepin, Roillard & Dubouloz, 1990). In terms of concurrent validity, comparison with Albert's Line Crossing Test, line bisection test, letter cancellation test, and star cancellation test, indicates that the Bells test can identify a higher proportion of patients with neglect (Vanier et al. 1990). Further, the use of distracter items appears to allow for the detection of both mild and moderate deficits (Marsh & Kersel, 1993; Weintraub & Mesulam, 1985), possibly since it is more demanding of selective attention (Ferber & Karnath, 2002).

Trail Making Test (Partington & Leiter, 1949; Reitan, 1955)

The Trail Making Test (TMT) is used to assess mental flexibility, speed of processing, and shifting attention. The test has two parts: Trails A, which requires the participant, using a pencil, to connect 25 encircled numbers in numeric order as quickly as possible, and Trails B, which requires the participant to connect 25 encircled numbers and letters in alternating order (i.e. A – 1 – B – 2, etc.). If a participant makes an error, he/she is immediately corrected by the examiner and told to keep going from the point at which they made the mistake. There are practice tasks for each trial and performance; these can assist the examiner in deciding whether to administer both parts of the test, A and B. Administration of the test is not recommended (Strauss, Sherman, & Spreen 2006) if the participant is unable to perform the practice task for either A or B within 30 seconds. Performance for each trial is measured as the time in seconds to complete the task; the raw scores thus obtained are then converted into z-scores.

Test-retest reliability has varied across studies (Strauss, Sherman, & Spreen 2006). However, Dikmen et al. (1999) found that in neurologically stable and unstable adults aged 15-83, that coefficients were adequate for Trails A (*r*=.79) and high for Trials B (*r*=.89) (Levine et al. 2002). Trails B correlate moderately well with other tests measuring attention and speed of processing (i.e. Symbol Digit Modality Test and a variation of the Paced Auditory Serial Attention Task [PASAT]) (Royan, Tombaugh, Rees, & Francis, 2004). The

TMT is sensitive to a variety of disorders including heterogeneous neurological damage, alcoholism, polysubstance abuse, and lead exposure, and it has been used widely as a measure of attention and executive function in stroke (Grant, Adams & Reed, 1984; McCaffery, Krahula, Heimberg, & Keller, 1988; Stewart, Schwartz, Simon, Bola, Todd, & Links, 1999; Reitan & Wolfson, 1995; Royan et al. 2004).

Stroop: Victoria Version (Regard, 1981).

The Stroop Test (Victoria Version) is a measure of the ease and speed with which an individual can quickly shift perceptual set to conform to changing task demands and the ability to suppress a habitual response in favour of an unusual response. The task is administered in three parts with the presentation of three white cards each depicting different stimuli. The first card consists of 24 dots (in six rows of four) occurring in equal ratios of green, blue, yellow, or red ink in random order. As quickly as he/she is able, the participant must read out the colour of each of the 24 dots printed on the card. The stimuli on the second card consist of 24 four letter words (e.g. 'when', 'hard', and 'over') each printed in green, blue, yellow, or red ink, in random order. When presented with the second card, the participant must state the colour of ink in which each word is printed. The final card (also known as the interference trial) is the same as the second card, but the words presented are the names of the colours of the ink used to print the words (i.e. red, yellow, blue, or green). The coloured ink in which the words are printed is always incongruent with the colour word. Performance is measured as the number of mistakes made for each card in correctly identifying the colour of the stimuli (spontaneous corrections are scored as correct) and the time taken (measured in seconds) to complete each card. Raw scores are compared to age appropriate normative data, and then converted into z-scores. It is also possible to calculate an interference ratio by dividing the time taken to complete the first 'dot' trial by the time taken to complete the third 'colour-words' trial, and this ratio is thought to provide an index of speed of processing.

Test-retest reliability has been reported as ranging from .83 to .91 across the three portions of the test (Strauss, Sherman, & Spreen 2006). The interference task correlates reasonably well with measures of attention such as the PASAT (MacLeod & Prior, 1996) and with tasks of response inhibition such as the stop-signal task (May & Hasher, 1998). It has also been found to be sensitive to executive disturbance in psychosis (Haynes, Smith, & Pantelis, 1996; Moritz & Kloss, 2002), Parkinson's Disease (Haynes et al.1996), Huntington's Disease (Haynes Smith, & Pantelis, 1996; Snowden Crawford, Griffiths, Thompson, & Neary 2001), HIV infection,(Castellon, Hinkin, & Myers, 2000), ADHD (Homack & Riccio, 2004; Reeve & Schandler, 2001), alcoholism (Dao-Castellana et al. 1998), stroke (Strauss, Sherman, & Spreen, 2006), and age associated memory impairment (Hanninen , Hallikainen, Koivisto, Partanen, Laakso, Reikkinen, et al.1997).

Matrix Reasoning, Wechsler Adult Intelligence Scale-III (WAIS-III) (Wechsler, 1997)

Matrix Reasoning (MR) is a measure of non-verbal abstract and spatial reasoning. It includes four types of nonverbal task: pattern completion, classification, analogy, and serial reasoning. The test includes three practice items and 26 test items. On each item, the participant is presented with a matrix. The matrix is a pattern with a missing part, and the participant must choose a pattern from five options that will complete the matrix. There is no time limit on this task. Each correct answer receives a score of one, with a maximum score of 26. The test begins at item 4, if the respondent scores a zero on items 4 or 5; items 1-3 are administered in reverse sequence until perfect scores are obtained on two consecutive items. Full credit is given for preceding items that were not administered. The task is discontinued if the participant receives four consecutive scores of zero or four scores of zero on five consecutive items. The score is converted into a standard score using available age related norms in the test manual (Wechsler, 1997) and then z-scores are generated. Average reliability coefficients are high and range from .84 -.94 across age groups. Further, MR correlates significantly with the Comprehensive Test of Nonverbal Intelligence (Dugbartey, Sanchez, & Rosenbaum, 1999).

Rey-Osterrieth Complex Figure (Meyers & Meyers, 1995).

The Rey-Osterrieth Complex Figure (ROCF) is a test of visuospatial constructional ability and visual memory. It is also considered to have an executive functioning component. Participants are initially presented with a detailed geometric figure and allowed to study it for a period of five minutes. They are then asked to copy the figure onto a blank sheet of paper to the best of their ability. This copy trial is used to assess their visuospatial constructional ability. An immediate recall trial is carried out 3 minutes later and a delayed recall trial, 30 minutes later. In both sets of conditions, participants are asked to reproduce the figure onto a blank piece paper from memory. In scoring each of these trials the figure is divided up into 18 scoring units, each of which receives a maximum of two points (one for accuracy and one for placement), with the highest score possible being 36. The 30-minute recall trial is followed by a recognition trial in which the participant is presented with 24 different figures some of which were part of the original figure and some of which were not. The participant is asked to circle figures that were part of the original design. Each correct response (either correctly circling or not circling) receives 1 point, with a maximum score of 24 points possible. Scores are then compared to age group norms to calculate z-scores.

Split-half and coefficient alpha reliabilities were found to be above .60 for the copy trial and .80 for the recognition trial (Berry, Allen & Schmitt, 1991; Fastenau, 1996). Myers and Myers (1995) evaluated test-retest reliability and found correlations of r=.76 for immediate recall, r=.89 for delayed recall, and r=.87 for recognition total correct for an interval of about 6-months. They also found significant correlations between the immediate recall, delayed recall, and the recognition trial and other tasks involving constructional ability and memory (i.e. Benton Visual Retention Test [total correct], Form Discrimination, Trials B and the Token Test) in a sample of patients with neurological disorders. The ROCF has been found to be sensitive to impairment in individuals with a wide variety of neurological issues including; head injury, medial temporal lobe damage, seizure disorders, Alzheimer's disease, Parkinson's disease, ischemic vascular dementia, Korsakoff's syndrome, anterior

communicating artery aneurysm, Huntingdons disease, cocaine, polydrug abuse, and stroke (Strauss, Sherman & Spreen, 2006).

Controlled Oral Word Association (Benton, Hamsher, & Sivan 1994)

The Controlled Oral Word Association (COWA) assesses fluency of speech under restricted search conditions and is considered a measure of language ability, though it is also thought to measure processing speed and executive function. The participant is given one minute in which to produce as many words as possible beginning with the letters F, then A, then S, and then one minute in which to name as many animals as possible. All responses are written down verbatim and a point is scored for each word produced, excluding non-words, proper names, and repetitions. Age appropriate normative data (Strauss, Sherman, & Spreen, 2006) is then used to convert raw scores to z-scores for the FAS totla and animals total scores.

The internal consistency between F, A and S is high *(r*=.83) (Tombaugh Kozak, & Rees, 1999). Test-retest reliability is also high *r*=.70 for both letter and semantic fluency for long (5-years) and short (1-week) intervals (Basso, Bornstein, & Lang, 1999; Dikmen et al. 1999; Harrison, Buxton, Husain, & Wise, 2000; Levine et al. 2004; Ross, 2003). Correlations between F, A, S and other fluency tasks involving letters such as C, L, and F and B, H, and R are high, ranging from r=.83 to r=.95 (Strauss, Sherman & Spreen, 2004). Between semantic categories (i.e. animals, clothes and food) correlations are moderately high *r*=.66 to .71 (Delis et al. 2001). The COWA also correlates with Verbal IQ from the WAIS-III (Henry & Crawford, 2004). The COWA has been identified as being sensitive to a wide range of neurological problems in particular aphasia, dementia, head injury, mood disorders, and stroke (Strauss, Sherman, & Spreen, 2006).

California Verbal Learning Test-II (Delis, Kramer, Kaplan & Ober, 2000)

The California Verbal Learning Test-II *(*CVLT-II) provides an assessment of verbal learning and memory. It includes learning trials as well as free recall, cued recall, and

recognition conditions. The CVLT-II assesses both recognition and recall of two 16-word lists (A and B). The CVLT-II begins with the oral presentation of the 16 words from list A. Immediately after presentation, the participant is asked to recall the list of items; their responses are written down verbatim. This immediate learning is repeated over five trials. Learning trials are followed by a single presentation of a 16-item interference list (List B), which participants are asked to recall immediately following presentation of the list. Both lists A and B can be divided into four separate semantic categories (e.g. vegetables or furniture) that consist of four different words (e.g. cabbage or lamp). List A and B have two categories that are the same (i.e. vegetables and animals) but the words that make up those categories are different. Words from the same category are never presented consecutively. Following free recall of list B, participants are asked to recall items from list A; no repetition of the list having been given (short delay free recall). They are then asked to remember the words associated with each of the semantic categories used in List A (i.e. “Tell me how many animals, were on the list) (short delay cued recall). After a 20-minute delay, free and category-cued recall trials are repeated. This is followed by a recognition trial in which the participant must recognise the 16 items pertaining to list A from a larger list of 44 items. Data from the following trials were used in this study: Short-Delay Free Recall, Short-Delay Cued Recall, Long-Delay Free Recall, Long-Delay Cued Recall, Recognition Hits, and False Positives. Responses for each trial are categorised into items correct (i.e. words that were on the list), repetitions (i.e. the participant has already named this item during the trial), and intrusions (i.e. the item does not appear on the list being tested). In order to generate z-scores, scoring is carried out by totalling the number of correct items for each trial and then comparing those to age appropriate norms.

Developing an estimate of internal consistency in recall tasks poses problems since, due to difficulties in memory and learning capacity, the recall of any one word on the trial decreases the likelihood that other words will be recalled. In addition, if a participant recalls one word on a trial they are more likely to recall that word on the following trial. However,

split-half reliability (across trials 1+3 vs. trials 2+4, and trials 2+4 vs. 3+5) is high for normal samples *(r*=.94) and a mixed clinical sample (*r*= .96) (Delis et al 2000). Coefficient alphas indicate that the CVLT-II has a high level of internal consistency (Delis et al. 2000). The authors of the test also examined test-retest reliability and practice effects over 9 to 49 days with a median of 21 days. The reliability coefficients for learning trials 1-5, Short and Long-Delay free recall and total Recognition Discrimination, were high *(r*=.80 to .89). In terms of its validity, Delis et al. (2000) found that the CVLT-II correlated well with the original CVLT and that most of the variables measured by the CVLT-II were found to have coefficients ranging adequate to high (Strauss, Sherman, & Spreen, 2006).

In clinical populations, the effects of mood and lesions within the brain on CVLT-II performance have been examined. O'Jile, Schrimsher, and O'Bryant (2005) found that self reported anxiety and depression in patients under psychiatric care only had a small effect on performance. In stroke, the CVLT-II has been found to be sensitive to deficits in verbal memory (Chand, 2005).

Visual Paired Associates, Wechsler Memory Scale-Revised (WMS-R) (Wechsler, 1987)

Visual Paired Associates (VPA) is a measure of visual memory that requires no physical response; this is important in a study of stroke where hemiplegia is a frequent outcome. Initially, the participant is shown six abstract line drawings; each drawing is quite different and is paired with a different colour presented in the shape of a square. As the participant looks at the figures, he/she is instructed to remember the colour that goes with each figure. They are then shown the figures in a different order, without their colours, and are asked to indicate the colour, from a separate card displaying all six colours, that is associated with each figure. If they answer incorrectly, the examiner points to the correct colour. If the participant answers all six items correctly on or before the third trial, the test is discontinued after three trials. If the participant does not achieve six correct answers on or before the third trial, if necessary, fourth, fifth and sixth trials are administered. The examiner

continues to correct any incorrect responses. The test is discontinued when the examinee answers all six items correctly on any subsequent trials, or after the sixth (and final) set, whichever comes first. For each correct response one point is scored. The immediate recall score is obtained by summing the number of correct responses across the first three trials, with a maximum score of 18. A delayed recall trial is administered approximately 30 minutes later in which the participant is shown each of the six figures and asked to indicate which colour goes with which figure. For each correct response, one point is scored, and no corrective feedback is given during the delayed recall trial. The total score for delayed recall is the total number of items correctly recalled with a maximum score of six. Immediate and delayed recall raw scores are converted to z-scores using the means and standard deviations presented by age group in the WMS-R manual (Wechsler, 1987).

In terms of the reliability of the immediate recall trial, it has an internal consistency and a test-retest reliability of above *r*=.90 (Strauss, Sherman, & Spreen, 2004). The delayed recall trial internal consistency is high (*r*=.80 to .89) (Strauss, Sherman, & Spreen, 2004), with a test-retest reliability of *r*=.70 to .79 (Strauss, Sherman, & Spreen, 2004). There is a moderate correlation between the VPA and other memory subtests such as Logical Memory (Strauss, Sherman, & Spreen, 2004).

Logical Memory Wechsler Memory Scale-III (WMS-III) (Wechsler, 1997)

Logical Memory (LM) is used to examine auditory immediate and delayed memory and is thought to be a good indicator of memory in everyday conversations (Lezak, 2004). It consists of two orally presented short prose passages, each of which contains 25 items or pieces of information. Each passage concerns a different character and the events that happen to them. Participants are awarded points for recalling units of specific information (i.e., time, day, name, location), with a maximum of 25 points for each story, and units of thematic information (e.g. gender of main character), which can reach a maximum of eight points for the first story and seven for the second story. Administration of the immediate

recall condition of the subtest involves the examiner reading the first passage aloud and then asking the participant to recall as much of the passage as possible, followed by the same procedure for the second passage. The second passage is then administered a second time. The immediate recall total score is calculated by summing the number of correctly recalled units of information from the reading of each passage with a maximum total of 75. The delayed recall condition involves asking the participant to retell each passage and is administered approximately 30 minutes after the administration of the immediate recall condition. A measure of learning can also be calculated from the scores on the first and second presentations of the second story on the immediate recall condition. The total raw scores for immediate and delayed memory are converted to scaled scores using age-standardised norms available in the WMS-III manual (Wechsler, 1997), and then to z-scores to allow for ease of comparison to other measures. Reliability estimates for internal consistency are high for LM immediate recall (*r*=.80 to.89) and adequate for LM delayed recall *(r*=.70 to.79). For test-retest reliability LM was found to be adequate (*r*=.70 to.79) (Strauss, Sherman, & Spreen, 2004). As mentioned above, LM has been found to correlate with VPA.

Boston Naming Test (Kaplan, Goodglass, & Weintraub, 2001)

The Boston Naming Test (BNT) is an assessment of the participants' ability to verbally identify pictures of black and white drawings of common objects of increasing difficulty (e.g. starting with 'bed' and ending with 'abacus') and is commonly used as a test of anomia. The subject is presented with up to 60 drawings and is asked to name each object represented. If the participant is not able to name a picture spontaneously within 20 seconds (i.e. if an incorrect response is made or if no response is made) a stimulus cue is provided (e.g. [item=beaver] 'it is an animal'). If provision of a stimulus cue does not result in a correct answer, a phonemic cue is provided (e.g. 'it starts with 'be'...'). Participants receive a score of one if a correct response is made spontaneously or following a stimulus cue. A score of zero is given if the answer is incorrect or if a phonemic cue was given. Item

administration begins at item 30, and full credit is given (29 points) for items 1 – 29 if correct answers are provided on items 30-38. If an incorrect response is made before item 38 then the administrator returns to item 29 and works backwards until there are eight correct consecutive responses. The test is discontinued if there is a failure to correctly name objects on six consecutive trials. The total score may range up to a maximum of 60, and these raw scores are converted to z-scores using available age related normative data (Ivnik, Malec, Smith, Tangalos, & Petersen, 1996)

Internal consistency has been found to range between *r*=.78 to .96 (Graves, Bezeau, Fogarty, & Blair, 2004; Fastenau Denburg, & Mauer, 1998; Franzen Haut, Rankin, & Keefover, 1995; Saxton Ratcliff, Munro, Coffey, Becker, & Kuler, 2000, Tombaugh & Hubley, 1997; Storms Saerens, & de Deyn, 2004, Williams, Mack, & Henderson ,1989). Test-retest reliability is also high *(r*=.91) (Flanagan & Jackson, 1997). In terms of its validity, the BNT is highly correlated (*r*=.76-.86) with the Visual Naming Test of the Multilingual Aphasia Examination (Axelrod, Ricker, & Cherry, 1994; Schefft, Testa, Dulay, Privitera, & Yeh, 2003). The BNT has been shown to be sensitive in neurological conditions such as left hemisphere strokes, anomia, multiple sclerosis, Parkinson's disease, Alzheimer's disease and small white matter infarcts in the brain stem (Strauss, Sherman, & Spreen, 2004).

Block Design, Wechsler Adult Intelligence Scale-III (WAIS-III) (Wechsler, 1997)

Block Design (BD) is a subtest of the WAIS-III and is thought to measure visuospatial construction and executive function (WAIS-III), as a timed test, speed of response impacts upon it. In this test, each participant is presented with a series of trials where he/she is asked to replicate a two dimensional geometric red and white design using plastic blocks. Each block has two red sides, two white sides, and two sides that are half white and half red. The designs progress in difficulty, requiring an increasing number of blocks to replicate them. There are 14 trials in total. For items 1-5 the administrator demonstrates how to replicate the pattern using the blocks, and the participant has two chances to replicate the pattern, each lasting 30 seconds. A score of two is received if the pattern is replicated on

the first trial and a score of one is received if the pattern is replicated on the second trail. A score of zero is given if the pattern is not replicated on either trial within the time allowed. Administration begins at item 5, and if the participant scores a 0 or 1 on items 5 or 6 then items 1-4 are administered in reverse sequence until the participant obtains perfect scores (2 points) on 2 consecutive items. For item 6, the procedure for administration and scoring is the same but a booklet showing a two dimensional image of the design to be produced is presented. If the participant obtains perfect scores for items five and six, full credit is given for items 1-4. For trials 6 to 14, the participant is required to reproduce a design from a picture in the booklet. The task is time limited with 60 seconds allowed to complete designs requiring four blocks and 120 seconds to complete designs requiring nine blocks. Participants receive a score of zero if they do not complete the task within the time allowed, otherwise they receive a score ranging from four to seven, with higher scores being associated with the quicker completion of each design. Administration is discontinued if a participant obtains a score of zero on three consecutive designs. A maximum raw score of 68 may be obtained. Participants' scores are then compared to age relate normative data in the WAIS-III manual (Wechsler, 1997) and then z-scores. Internal consistency and test-retest reliability is high (*r*=.80-.89), validity for block design is not reported (Strauss, Sherman, & Spreen, 2004).

Integrated Visual and Auditory Continuous Performance Test (Sandford & Turner, 2004)

The Integrated Visual and Auditory Continuous Performance Test (IVA-CPT) is a computerised visual and auditory continuous performance test. It uses a counterbalanced approach to measure both visual and auditory inattention and response inhibition. It also provides an objective measure of fine motor regulation and speed. This is a very simple, 13-minute test, that is fully computerised. Test instructions are presented visually on the screen, and spoken in a clear female voice. This test requires the examinee to click the mouse when they see or hear number "1'' (target) and not to click when they see or hear the number "2''

(foil). Initially, a one and a half minute warm-up session for both visual and auditory targets is given, providing the opportunity for the examinee to learn to click the mouse correctly. In the warm-up session only “1”s are presented, first visually and then, orally. Following this session there is a 32-item practice session teaching the participant (with the examiner’s help) how to respond when both targets, the “1” and foils, “2” are presented. The computer provides corrective feedback (i.e. “opps”) to the examinee if he/she makes an error. This practice session may be stopped if the participant is experiencing problems. The practice period gives the examiner the opportunity to determine whether the participant understands the test, maximises performance and, minimises practice effects. The test itself involves responding or inhibiting a response over five sets of 100 trials (a total of 500) with each lasting 1.5 seconds. The visual “1”s and “2”s are presented for 167 milliseconds, and the verbal “1”s and “2”s are presented for 500 milliseconds. The main test measures impulsivity by creating a response set of ‘not responding’. In this response set, out of the first 50 ‘frequent’ block of trials 42 stimuli are “1”s intermixed with 8 “2”s, and the participant must inhibit his or her response to the “2”s. During the second ‘rare’ block of 50 trials, many “2”s (84% of stimuli) are presented and few “1”s; the participant must wait to make his or her responses every six to nine seconds when a “1” is heard or seen. This second block of trials “pulls” for inattention and creates a response set of non-responding. An equal number of auditory and visual stimuli are presented in a fixed pattern in each block, with the patterns of “1”s and “2”s; during the presentation, both the frequent and the rare blocks are mirror images of one another. The computer automatically saves the performance scores for later analysis.

All IVA-CPT raw scores are compared to age and gender norms and then converted to quotients scores. Quotient scores, having a mean of 100 and a standard deviation of 10, can therefore easily be converted into z-scores. The higher the quotient score, the better the performance. Quotients for the following areas were produced:

1) Full Scale Attention: A measure of ability to respond to both auditory and visual stimuli.

2) Auditory Attention: A measure of vigilance speed and ability to focus in the auditory domain.
3) Visual Attention: A measure of ability to focus in the visual domain.
4) Auditory impulsivity: A measure of impulsivity and response inhibition in the auditory domain.
5) Visual impulsivity: A measure of impulsivity and response inhibition in the visual domain.

Seckler, et al. (1995) conducted a test-retest reliability study, with tests being completed at intervals of one to four weeks. All the composite quotient scores demonstrated significant and moderate to very strong correlations (ranging from .37 to .75) for test-retest relationships. Overall, this test was found to be a significantly stable measure of performance with very small practice effects (Stanford & Turner, 2004). It has also been found to be sensitive to deficits in attention in stroke survivors (Barker-Collo, Feigin, Lawes, Parag, Senior, & Rodgers, 2009).

Measures of Mood

The General Health Questionnaire-28 (Goldberg & Hillier, 1979)

The General Health Questionnaire-28 (GHQ-28) is a 28 item self-administered questionnaire used for the detection of psychological distress related to general medical illness. The original version of the GHQ had 60 items and the three shorter versions have 30, 28, and 12 items. The GHQ-28 was used with the ICH participants in the ARCOS study so was selected again for this study to allow comparison between time points. The GHQ-28 yields four subscales including somatisation, anxiety, social dysfunction, and depression. It is important to note that the social dysfunction scale of the GHQ-28 may be better understood as an outcome that falls within the domains of activities and participation and will be used as such in this study. Each of the four subscales is derived from seven items on the questionnaire. It is a self-administered questionnaire where participants base their

responses on the state of their health over the previous two weeks. Participants are asked a question such as: 'Have you lost much sleep over worry?', and have the option of four answers such as: 'Not at all', 'No more than usual', Rather more than usual', and 'Much more than usual'. The first two answers indicate little or no change but the third and forth answers indicate a change in distress levels. The test authors, Goldberg and Hillier (1979), advocate the use of the GHQ scoring method (0-0-1-1), where 0 is given for the 'little or no change' symptom severity options and 1 for the 'definite change' symptom severity options. Over 50 publications have attested to the reliability of the GHQ in both stroke and other clinical populations (Nagyova, Boudien, Szilasovia, Stewart, van Dijk, & van de Heuvel, 2000). It has been validated in New Zealand women (Romans-Clarkson, Walton, Herbison, & Mullen, 1989) and used in other population studies of stroke, such as the Perth Community Stroke Study, where it was found (when used in conjunction with the GDS-SF) to be a valid measure of mood in stroke survivors (Johnson, Burvill, Andersen, Jamrozik, Stewart-Wynne, & Chakera, 1995).

Geriatric Depression Scale – Short Form (Yesavage, Brink, Rose, Lum, Huang, Adey & Leirer, 1983)

The Geriatric Depression Scale (Short Form) (GDS-SF) was designed specifically for rating depression in older adults but can be used from the age of 17 years (Lezak, 2004). It has been designed to omit items contained in other depression scales that may relate to a medical condition and uses a yes/no format, which makes it less confusing. The Short Form (GDS-SF) is a derivative of the 30-item Long Form (GDS-LF) which consists of 15-items that describe the characteristics of a depressed and non-depressed mood. The response options to each item are dichotomous being 'yes' or 'no'. Agreement with an item associated with depression (e.g. Do you feel that your life is empty?) scores 1 point. Disagreement with a non-depressed item (e.g., Are you happy most of the time?) also scores 1 point. Thus, a total score of 15 is possible and a score ≥5 indicates the presence of depression with a specificity rate of 84% (Brink et al. 1982) to 95% (Yesavage et al, 1983). The GDS-SF can

be self administered or read out to the participant if help is required. The GDS-SF was developed primarily for brevity and, in particular, for use in populations such as the medically ill or those with dementia, where the longer form might be burdensome. It correlates highly with the Beck's Depression Inventory (*r*=.84) (Ferraro & Chleminski, 1996; Zalsman, Weizman, Carel, & Aizenburg, 2001) and the Zung Self-Rating Depression Scale (Iglesias, 2004). In community dwelling older adults, internal consistency ranges from *r=.71 tp.84* (Iglesias, 2004; Jang, Small, Haley, 2001; Knight McMahonon, Green, & Skeaf, 2004; Mui & Shibusawa, 2003; Stiner Raube, Stuck, Aronow, Draper, Rubenstein, et al. 1996) and has a split half reliability of α= .73. Agrell and Dehlin (1989), compared six depression-rating scales in geriatric stroke survivors; they found the GDS-SF scale to have the highest sensitivity and predictive values and as having good internal consistency.

2.2.2. Measures of Activities and Participation.

The three scales presented here (the Modified Rankin Scale, Barthel Index and the Frenchay Activities Index) are commonly used to measure a wide variety of activities. They were selected for use in this study because of the broad scope of activities they measure, and as they had been used previously in the ARCOS study. Another area explored in this study of ICH survivor experience is, participation. Commonly, HRQoL falls within the domain of participation and as such, the SF-36, which is a well-known measure of HRQoL and was previously used in the ARCOS study, was included. Additionally, the London Handicap Scale was used; this was also used in the ARCOS study and covers areas relevant to participation. All measures of activities and participation can be found in Appendix B.

Modified Rankin Scale (Lindley Waddell, Livingstone, Sandercock, Dennis, & Slattery, 1994).

The Modified Rankin Scale (MRS) (Lindley et al.1994) is a clinician-rated measure of global disability that is widely used in evaluating stroke patient outcomes and as an end point in randomized clinical trials (Bank & Marotta, 2007). The MRS is concerned with instrumental activities of daily living (IADLs) (e.g. meal preparation, shopping, and handling

money) and the basic activities of daily living (e.g. walking, dressing, and grooming). The MRS is a seven point scale, from zero to six, with zero corresponding to 'no symptoms', five corresponding to 'severe disability' (bed ridden, incontinent and requiring constant nursing care and attention) and six, corresponding to 'death'. The test-retest reliability for one to two weeks ranges from *r*=.81 to .95 (Banks & Marotta, 2007). Convergent reliability is strong between the MRS and BI, *r*=.89 and between the American Heart Association Stroke Outcomes Classification, Stroke Impact Scale, and SF-36 (Banks & Marotta, 2007).

Barthel Index (Mahoney, & Barthel, 1965)

The Barthel Index (BI) is a widely used measure of independence in ADLs. (i.e. the freedom from help be it physical, verbal, or in any other minor way from another person) (Sainsbury, Seebass, Bansal, & Young, 2005). Through 10 questions the following areas are assessed: the presence of faecal or urinary incontinence; whether the person is independent in toileting, grooming, feeding, mobility, dressing, climbing the stairs, taking a bath, and transfers (i.e. from a chair to a bed). Each question has a range of two to four response options, each option has a numeric value assigned ranging from zero, indicating they are unable to do the activity to 5, 10, or 15, indicating that they are completely independent in this activity. The scores for each item are summed; there is a maximum possible score of 100. The lower the score, the greater the limitation in ADLs. In a recent review of reliability studies, the BI was found to have excellent reliability in older clinical populations (Sainsbury, Seebass, Bansal, & Young, 2005) and in stroke survivors (Murdock, 1992).

Frenchay Activities Index (Hollbrook & Skilbeck, 1983).

The Frenchay Activities Index (FAI) was developed to measure IADLs in stroke survivors. In measures activities of daily living such as preparing meals, washing clothes, housework, and going shopping. The activities are measured by how frequently they have been undertaken in the past three months, there are four options of frequency for each activity (i.e. for preparing meals there were the options of: never, under once a week, 1-2

times a week, and most days). Each of the four options has a weighted value, which can range from 0-4. The total is then calculated by summing the scores for each option. The higher the score, the less the restriction in activities. The FAI has been found to have good internal consistency in a stroke population with α =0.78 to 0.87 (Schuling, de Hann, Limburg, & Groenier, 1993). It also has been found to be an excellent measure to use with the BI, as when analysed together they were found to load onto different orthogonal factors suggesting minimal content overlap (Pederson, Jorgensen, Nakyama, & Olsen, 1999).

Short Form-36 (Ware, Snow, Kosinski, & Gandek, 1993)

The Short Form-36 (SF-36) is a generic measure of health and well-being and is used to examine the effect on quality of life of a wide variety of health issues ranging from arthritis to surgical procedures. The SF-36 is a 36-item questionnaire that consists of eight scales and two overall summary measures for physical and mental health derived from the scale scores. The eight scales derived from the 36 items include physical functioning (PF), role limitations due to physical health problems (RP), bodily pain (BP), social functioning (SF), mental health functioning (MH), role limitations due to emotional problems (RE), vitality energy and fatigue (VT), and general health perceptions (GH). Some of the dimensions measure health status as the absence of disability (e.g. PF, RP, and RE). Other scales (e.g. GH, VT, and MH) measure both positive and negative states of health. The two summary scores; the Mental Component Summary (MCS) and Physical Component Summary (PCS), draw on scores from SF, VT, RE and MH, and PF, BP, RP and GH respectively.

Most of the 36-items consider functioning over the past month. There are a variety of response formats ranging from a two category yes/no response to a six-category response. For example, a six-category response can be found on item 23, which asks 'How much of the time during the past four weeks did you feel full of energy', with the choice from one indicating 'none of the time', to six indicating 'all of the time'. An interviewer can administer the SF-36 by computer, telephone, or through self-administration in five to ten minutes to

anyone over the age of fourteen (Ware, 1993). Standardised norms are available for New Zealand (Scott, Tobias, Sarfa, & Haslett, 1999).

It has been used in populations, and to compare health related quality of life between diseased, and treatment and control groups (Ware, 2008). It has been validated in stroke populations (Anderson et al. 1996) and been used in over 50 stroke publications (Ware, 2008). In most studies, reliability of the eight scales has reached the minimum standard of 0.7 (Tsai, Bayliss, & Ware, 1997) and in most cases, exceeds r=.80 (McHorney, Haley, & Ware, 1997). Reliability of the PCS and MCS has been estimated to be above r=.90 (Ware, Kosinski, & Keller, 1994). These coefficients have been replicated in over 24 different patient groups with different diagnoses and social demographics (McHorney et al. 1997; Ware et al. 1994).

The SF-36 has shown a high level of validity in its high and low scores (Ware et al. 1993; Ware et al. 1994). For mental health, the MH, RE, SF, and MCS have been shown to be the most valid in both longitudinal and cross-cultural studies (Turner-Bowker, 2008). For physical health, the PF, RP and BP scales, and have been shown to be the most valid (Turner-Bowker, 2008). In addition, the SF-36 scales and summary scores have been found to be valid in predicting utilisation of health care services (Ware et al. 1994), the course of depression in the elderly (Wells, Burnham, Rogers, Hays, & Camp, 1992; Beusterien, Steinwald & Ware, 1996), the loss of employment within 1-year (Ware et al. 1994), 180 day survival following cardiac surgery (Rumsfield, MaWhinney, McCarthy, Shroyer, Villa Neuva, O'Brien, Moritz, Henderson, Grover, Sethi & Hammerstien, 1999), and five year survival following a health event (Ware et al. 1994).

London Handicap Scale (Harward, Rogers Dickinson, & Ebrahim, 1994)

The London Handicap Scale (LHS) is a self-rating scale measuring participation, which can be used at any age. It asks six questions covering the domains identified by the WHO as areas in which restrictions in participation can occur (i.e. mobility, physical independence, occupation, social integration, orientation, and economic self-sufficiency).

There is some overlap with activities in the items regarding mobility and physical independence. Participants have a six-point scale from which to choose their answer for each item, ranging from no restriction, to being completely restricted. Each of the points along the scale has a numeric weighting which can be positive or negative depending on whether handicap is present or absent (e.g. when measuring mobility, no impairment has a weighting of .071 and complete impairment has a weighting of -.108). The final score on the scale is achieved by summing the scores across all six dimensions. The scale has a minimum value of zero (indicating total handicap) and maximum value of one (indicating no handicap). The scale has been validated in stroke survivors and has a reliability coefficient of .91 (Harwood, Gompertz Pound, & Ebrahim, 1997).

2.3 Procedure

Ethical approval for the ICH group was obtained from the Multi Regional Ethics Committee as the ICH group was part of a larger population-based follow up study (Auckland Stroke Outcomes Study [ASTRO]). Approval to collect data for the matched control group was obtained from the University of Auckland Human Participants Ethics Committee. The procedure for the ICH group will be first described, followed by the procedure for the control group.

ICH Group

The recruitment of ICH participants involved contacting individuals from the ARCOS study in 2002-3 who had previously agreed to take part in future research; this consisted of 77 potential participants. Where no contact details were available, or where contact details were out of date, attempts were made to trace the ICH survivors via telephone directories, electoral rolls, General Practitioners' (G.P.) surgeries, and by contacting the relatives listed in ARCOS data files. If this was unsuccessful, checks of vital status were made through the New Zealand Health Information Service to identify those people who had died since last

contacted. As stated earlier, 12 potential participants had died and 26 could not be found. Contact with potential participants was initially made via a letter which included a covering letter of introduction, a participant information sheet (PIS), consent form (see Appendix C), and the LHS, and GHQ-28 questionnaires. This was followed up by a telephone call to determine willingness to participate. 14 of the 39 people contacted did not wish to take part. After gaining verbal consent from the remaining 19, the SF-36, BI, FAI, and GDS-SF were administered over the telephone if the participant was able to do this over the phone. At the end of this telephone contact, an appointment was made for a face-to-face assessment to be conducted at the participant's place of residence. During this assessment, the participant signed the consent form (see Appendix C) and the NIHSS, neuropsychological tests and MRS were administered. At the start of the face-to-face assessment, time was taken to establish a good rapport with the participant, as Lezak (2004) suggests, this is essential to minimise the effect of anxiety on test performance. Also, as testing was carried out in the participant's home, all steps were taken to ensure an optimum testing environment by reducing distractions such as noise and the presence of other people in the room. Participants were asked to unplug the telephone during the assessment and to use glasses or hearing aids if they needed to. For those who were not able to carry out the measures by telephone, the LHS, BI, FAI, GHQ-28, SF-36, and GDS-SF were administered face-to-face during this appointment. Any mood disorder highlighted by the GDS-SF was reported to the study supervisor, and the participant was advised to go to their G.P and provided with information on resources for depression. Breaks were taken during the interview when required by the participant and both their fatigue and anxiety levels were monitored throughout the procedure. If the assessment was noted as being too fatiguing, then a follow-up appointment was made in order to complete the assessment at a later date. On occasions when only the neuropsychological tests and MRS were administered, on average, the face-to-face assessments took about three hours each. However, nearly a third of the participants (n=6) required the assessment to be carried out over two appointments due to

fatigue. All assessments were carried out within five to five and a half years post primary ICH.

All measures and neuropsychological assessments were administered and scored according to standard procedures. Neuropsychological assessments requiring verbal output (e.g., CVLT-II, LM, BNT, and COWA) were omitted for patients with expressive aphasia. If the aphasia was quite mild the BNT, which is designed to quantify mild expressive aphasia, was attempted subject to participant willingness and level of frustration experienced. It is noteworthy that dysphasia does not necessarily mean presence of alexia or agraphia; therefore, many dysphasic subjects could still complete written tests. Where receptive aphasia or other impairment was suspected, standard administration protocols were used, which for all assessments except the ROCF and COWA, involves presentation of practice items. Thus, an individual's ability to participate was determined by his/her ability to perform on practice items. If it became apparent that he/she did not understand the nature of a task, it was discontinued, as data collected would not necessarily have been a valid indication of ability level. Similarly, those tasks requiring physical responses (i.e. BD, ROCF, and Trails A/B) were omitted if hemiplegia was likely to impact performance.

During the interview, information was also gathered on general medical status, (e.g. further stroke current mood disorder or cognitive decline or presence of dementia) which was likely to impact performance of the participant. None of the 19 ICH participants were excluded for this reason. Demographic information regarding marital status and living situation was also obtained (see Appendix D).

Matched Control Group

Control participants were recruited by advertising using the participant information sheet (PIS) (see Appendix C) within Auckland University, the Waitemata and Counties Manukau District Health Boards, and Retirement Villages located in the Auckland region. 23 potential participants who were contacted following the sighting of the PIS were initially

assessed by telephone to see if they met the eligibility criteria. Five were rejected on the grounds that after questioning three had experienced a head injury, and one had experienced TIAs, and one did not meet the age matching criteria. Those who met the criteria were sent a consent form and questionnaire consisting of the LHS, SF-36, GDS-SF, BI, FAI, GHQ-28, and questions regarding their demographic and medical history. They were then contacted by telephone and an appointment was made for the face-to face assessment and administration of the MRS. As with the ICH group, the assessment was carried out in the participant's primary place of residence. The assessment took two hours on average for the control participants and none of the control group participants required a follow up appointment.

Data Management and Preparation of the Data for Preliminary Analyses

All data was entered into a computer file called PSAW Statistics 18 for analysis. Total scores and summary scores for measures related to body function and structure, activities, and participation were calculated according to standard procedure. The raw scores for neuropsychological measures were converted into z-scores using norms from Strauss, Sherman, and Spreen (2006) and Ivnik, Malec, Smith, Tangalos, and Petersen (1996) WAIS-III (1997) for LM, BD, and MR and the WMS-R (1993) for the VPA. New Zealand norms were used for the CVLT-II (Barker- Collo, 2001; Barker-Collo, Clarkson, Cribb, & Grogan, 2002). The z-scores from the neuropsychological measures were used both to compare performance between the two groups on all of the measures, and to develop summary scores for neuropsychological domains. The summary scores were used in the correlation analysis only. Summary scores for domains of neuropsychological functioning have previously been used in the literature (Desmond, Moroney, and Sano, 1996; Sachdev et al., 2004) and are often utilised if a study has a large number of data points from neuropsychological tests. If all of the neuropsychological test data has been used when exploring the relationships between areas of neuropsychological function and for

example measures of activities, there is a risk of Type 1 errors, due to the large number of comparisons. The summary scores were calculated by averaging the z-scores on selected neuropsychological measures relevant to a particular domain using a method developed by Desmond, Moroney, and Sano (1996). Using this methodology, summary scores for six domains were developed by averaging a participant's z-scores on selected measures. The z-scores from the following measures were used to develop the following summary scores:

1) Verbal Memory summary score: CVLT-II and LM long delay free recall
2) Visual memory summary score: VPA and ROCF delayed recall
3) Language summary score: BNT and COWA total
4) Visuoperception summary score: BD and MR
5) Executive functioning summary score: IVA-CPT Full scale attention
6) Information processing speed summary score: Trails A, and Stroop Dots

In addition, a summary score for overall impairment was developed for each participant. Overall, neuropsychological impairment was calculated by summing the number of z-scores from the above neuropsychological tests that were below -2. Also counted was whether they missed more than three bells on the Bells test.

Chapter 3: Results

In this chapter, the findings of the research are presented in four different sections. The first section describes how the data was prepared for analysis including: inspection of the data set for accuracy of input, management of missing data, and the outcomes of preliminary analyses performed on the data; this involved testing the statistical assumptions of normality, linearity, and homogeneity. The section also includes the results of a sensitivity analysis carried out in order to determine the generalizability of the present sample to the initial ARCOS sample of 77 ICH survivors and to the 40 ICH survivors who were either not contactable or who did not wish to take part. The second section presents descriptive and frequency statistics for the matched control and ICH groups and the findings of a one-way ANOVA comparing the performance of control and ICH participants on the measures of body structure and function, activities, and participation, in this analysis the neuropsychological test data was used. In addition, the effects of age, gender, and education on the five-year outcomes of the ICH group are examined using a one-way ANOVA. The third section focuses on reporting the findings of within subject comparisons concerning change over time using the data available for measures taken at baseline, 1-month, six months, and five years post-ICH. The effects of age, gender, and education, on the measures taken at different time points are also considered. Through the generation of correlations, section four examines the relationships for the ICH between measures of outcomes at five years post-ICH, in this section this section the neuropsychological summary scores were used.

3.1. Preparation of Data for Analyses and Preliminary Analyses

Management of Missing Data

The data for the ICH and matched control group was examined for accuracy of input and missing data by generating the means, maximum, and minimum, values for each variable, and eyeballing the data. One mistake regarding accuracy of input was found and

corrected. There was a very small amount of data missing from the matched control group. One Pacific Island participant (5%) did not complete the CVLT, LM, COWA, and BNT, as English was not his first language. Unfortunately, a proportion of the data from the IVA-CPT was lost (22%) due to a virus on the computer used to administer the test, this resulted in the data being lost. This data was recorded as missing can came from the control group. For the ICH group, the proportion of missing data for each test is presented in Table 6. Where relevant, tests are reported according to the different time point at which they were used (i.e. at one month, or at six months) if they were used more than once with the ICH group. The proportion of data missing is largely due to participants experiencing impairment such as aphasia (n=3, 16%), hemiplegia (n=1, 5%) and blindness (n=1, 5%), which precluded them from completing neuropsychological tests. The IVA-CPT was particularly affected by invalid performances due to random responses to the stimuli (25%) of cases; this is also reflective of significant impairment. Two of the participants spoke English as a second language (*n=2, 11%)* so did not complete the language tests as this was expected to impact performance. The data in these instances was left as missing. As noted in the procedure section, the GHQ-28 and LHS at five years were collected via a questionnaire that was posted to each participant. All of those who returned the questionnaire completed the measures. The proportion missing, shown in Table 6, is reflective of the low response rate of 31%. There was one value missing from the SF-36 in two cases, carried out at five years' post-ICH. There are a variety of methods to manage missing values recommended by Tabachnick and Fidell (2007). In this instance, the mean of the case's individual values on the SF-36 subscale, from which the value was missing, was substituted for the missing value. When the whole measure was missing for a case, it was excluded from the analysis using the 'exclude cases pair wise' option in SPSS.

Table 6 Measures with cases missing from the ICH group

ICF Domain	Proportion of Missing Values	
Body Structure and Function	**N**	**%**
Neuropsychological		
TMT A/B	4	21
MR	1	5
CVLT-II	3	16
ROCF	5	26
VPA	4	21
COWA	5	26
LM I	5	26
BNT	2	11
BD	4	21
IVA-CPT	9	47
Stroop	4	21
Mood		
GHQ-28 baseline	4	21
GHQ-28 6-months	2	11
GHQ-28 5-years	6	31
Activities and Participation		
Activities		
FAI 6-months	1	5
SF-36 6-months	2	11
LHS 5-years	6	31

BD= Block Design; BNT=Boston Naming Test; CVLT II=California Verbal Learning Test (2nd Edition); COWA=Controlled Oral Word Association; FAI=Frenchay Activity Scale; GHQ-28=General Health Questionnaire-28; IVA-CPT=Integrated Visual and Auditory Continuous Performance Test; LM I=Logical Memory (trial 1); LHS= London Handicap Scale; MR=Matrix Reasoning; ROCF=Rey Osterreith Complex Figure; SF-36=Short Form-36; TMT A/B=Trail Making Test; VPA=Visual Paired Associates.

Testing Assumptions of Normality, Homogeneity of Variance and Linearity.

Normality is the assumption that the data collected for a variable is normally distributed (i.e. the three measures of central tendency, mean, median and mode have the same or reasonably similar values) (Clegg, 1990). It is preferable that data is normally distributed if it is to undergo multivariate analysis (Tabachnick & Fidell, 2007). In this instance, as there are less than 50 cases in each group, the Shairo-Wilk test was used to explore normality. A significance value of $p \geq .05$ indicates that the data collected for the variable significantly deviates from a normal distribution. The normality for all neuropsychological summary scores, measures (and their individual trials) were explored including Bells, TMT A/B, Stroop, MR, CVLT-II, ROCF, COWA, VPA, LM, BNT, BD, and IVA-CPT. The normality for measures taken at baseline, one month, six months, and five years

(and their sub-scales) were also explored including; NIHSS, GDS-SF, MRS, BI, FAI, LHS, GHQ-28, and the SF-36. The normality for the ICH and control groups was examined separately. Table 7 below shows the variables that were not normally distributed.

Table 7 Measures violating the assumption of normality across the ICH and matched control groups

ICH	Control
ICF Domain: Body Structure and Function	
Neuropsychological Measures	
IVA-CPT*(Full Scale Attention, Visual Attention, Visual Prudence)*	IVA-CPT *(Full Scale Attention, Auditory Prudence)*
TMT A/B	TMT B
Stroop *(Words, Names)*	LM I
CVLT II *(False Positive)*	CVLT II *(Recognition, False Positive)*
ROCF *(Copy)*	VPA II
VPA II	
BNT	
COWA *(F, A, S)*	
Neuropsychological Summary Scores	
Overall Impairment	Overall Impairment
Executive Functioning	
Mood	
GHQ-28 1-month *(Somatic, Anxiety, Depression)*	GHQ-28 *(Depression, Somatic, Anxiety, Social Functioning)*
GHQ-28 6-months *(Somatic, Anxiety, Social Functioning, Depression)*	GDS-SF
GHQ-28 5-years *(Somatic, Anxiety, Depression, Social Functioning)*	
GDS-SF	
ICF Domains: Activities and Participation	
Activities	
MRS 1-month	MRS
BI 1-month	
BI 5-years	
Participation	
SF-36 6-months (*PF, PR, ER, BP, MHC)*	SF-36 *(PF, RP,RE,MH, SF, BP, PHC, MHC)*
SF-36 5-years *(RP, RE, MH, SF, BP, MHC)*	LHS

BI=Barthel Index; BNT=Boston Naming Test; BP=Body Pain; CVLT II=California Verbal Learning Test-II; COWA=Controlled Oral Word Association; GDS-SF= Geriatric Depression Scale; GHQ-28=General Health Questionnaire-28; IVA-CPT=Integrated Visual and Auditory Continuous Performance Test; LHS= London Handicap Scale; LM=Logical Memory; MH= Mental Health; MHC=Mental Health Component; MRS= Modified Rankin Scale; PF=Physical Role; PHC=Physical Health Component; ROCF=Rey Osterreith Complex Figure; RE= Role Emotional; RP=Role Physical; SF=Social Functioning; SF-36=Short Form-36; TMT (A and B)=Trail Making Test ; VPA=Visual Paired Associates.

According to Tabachnick and Fidell (2007), it is possible to address the issue of non-normal distributions by undertaking the square root, logarithmic, and inverse transformations of the data. These transformations were conducted for each of the variables listed in Table 7, but this did not improve the normality for any of the variables. However, Tabachnick and Fidell

(2007) do not consider this a problem as the analyses used later (i.e. one-way and repeated measures ANOVA and correlations) are fairly robust to violations of normality when the groups are of relatively equal size (Tabachnick & Fidell, 2007).

The second assumption to be tested was linearity. Linearity refers to the relationship between two variables and assumes a straight line relationship when variables are plotted on bivariate scatter plots (Tabachnick & Fidell, 2007). Scatter plots were examined for all bivariate combinations of functional and neuropsychological measures and there was no evidence that the assumption had been violated for any of the relationships examined.

The third assumption to be tested was homogeneity of variance. This refers to the assumption that the variance of the populations in each group is equal (Tabachnick & Fidell, 2007). Levene's test of equality of variance was used to identify if there was a significant difference between the variances of the two groups across the measures used in this study. A significance level of $p \leq .05$ indicates that there is not homogeneity of variance. Table 8 shows the variables where the variances of the ICH and Control group were not equal.

Table 8 Measures violating the assumption of homogeneity of variance between the ICH and matched control groups

ICF Domain
Body Structures and Function
Neuropsychological Measures
IVA-CPT (Full Scale Attention, Auditory Attention, Visual Attention, Visual Prudence)
Stroop (Dots, Words)
CVLT-II (Recognition)
ROCF (Copy, Short Delay)
BNT
Neuropsychological Summary Scores
Impairment
Information Processing
Mood
GDS-SF
GHQ-28 (Anxiety)
Activities and Participation
Activities
MRS
FAI
Participation
SF-36 (PF, MH)

BNT=Boston Naming Test; CVLT II=California Verbal Learning Test (2nd Edition); FAI=Frenchay Activity Index; GDS= Geriatric Depression Scale; GHQ-28=General Health Questionnaire-28; IVA-CPT=Integrated Visual and Auditory Continuous Performance Test; MH= Mental Health; MRS=

Modified Rankin Scale; PF=Physical Role; ROCF=Rey Osterreith Complex Figure; SF-36=Short Form-36.

Although the above variables do not have homogeneity of variance between groups, Tabachnick & Fidell (2007), do not consider this a problem when using ANOVAs and correlations when the groups are of a comparable size as they are in this instance.

Sensitivity Analyses

Parametric (t-tests) and non parametric (X^2) sensitivity analyses were carried out to determine if the 19 ICH participants differed significantly from the initial incidence sample (n=77) from which they were drawn in terms of gender, ethnicity, severity of index stroke (Barthel Index) and age at stroke. The present sample was found to differ significantly from the original sample in age ($p \leq .001$) with the present sample being significantly younger at the time of ICH (mean ages 66.7 years and 76.9 years respectively. None of the other comparisons were significant ($p \leq .05$). A second set of sensitivity analyses were then performed to compare those included in the present study to those who were alive but were not contactable or unwilling to take part in the study (n=40). These two groups did not differ on any of the variables ($p \leq .05$).

3.2. Comparison of ICH and Matched Control Groups Across Measures Five Years post-ICH.

Following the preliminary analyses, the ICH group's performance on neuropsychological measures was examined in terms of the proportion of the group whose performance fell into varying commonly used z-score ranges (Strauss, Sherman, & Spreen, 2006). This information along with means and standard deviations is presented in Table 9 below. Overall, the ICH group displayed a negative skew on all of the neuropsychological tests and summary scores. None of the participants performed above the 'above average' range on any of the measures.

Table 9 ICH performance across neuropsychological measures as mean performance and percentage of z-scores falling within particular z-score ranges

Neuropsychological Measures	No. of participants out of 19 excluded as too impaired to do test	Mean z-score	SD	% participants < - 3 Very Impaired	% participants <-2 & ≥ -3 Impaired	% participants <-1 & ≥ -2 Below Average	% participants <1 & ≥ -1 Average	% participants <2 & ≥ 1 Above Average
Executive Function								
Executive Summary Score	6	-2.46	(3.70)	30.00	-	20.00	40.00	10.00
IVA-CPT - Full Attention	6	-2.46	(3.70)	30.00	-	20.00	40.00	10.00
Auditory Attention	6	-2.50	(3.81)	30.00	10.00	10.00	40.00	10.00
Visual Attention	6	-1.72	(2.66)	20.00	-	20.00	60.00	-
Auditory Impulsivity	6	-.18	(1.20)	-	10.00	10.00	60.00	20.00
Visual impulsivity	6	-.63	(3.52)	10.00	10.00	-	40.00	40.00
Trails B	3	-1.08	(1.86)	13.33	-	26.66	53.33	6.67
Stroop Test - Words	4	-1.56	(2.48)	20.;00	6.67	20.00	53.33	-
Colour Names	4	-.91	(1.86)	6.67	13.33	20.00	53.33	6.67
Information Processing								
Information Processing Summary Score	4	-1.54	(1.83)	28.57	7.14	7.14	50.00	7.14
Stroop Dot Trial	4	-2.19	(2.47)	33.33	6.67	13.33	40.00	6.67
Trails A	2	-1.58	(2.51)	12.50	6.25	31.25	50.00	-
Verbal Memory								
Verbal Memory Summary Score	2	-.02	(.53)	-	12.50	18.75	50.00	18.75
Logical Memory I	2	-.12	(.97)	-	-	12.5	75.00	12.50
II	2	.19	(.92)	-	-	6.25	87.50	6.25
CVLT-II Short Delay Free	1	-.59	(1.28)	-	25.00	6.25	62.50	6.25
Short Delay Cued	1	-.78	(1.00)	-	12.50	25.00	62.50	-
Long Delay Free	1	-.26	(.90)	-	5.88	23.53	70.59	-
Long Delay Cued	1	-.53	(1.06)	-	11.76	5.88	82.35	-
Recognition	1	-.32	(1.07)	-	5.88	17.65	76.47	-
False Positives	1	-.12	(.96)	-	-	-	88.24	11.76
Visual Memory								
Visual Memory Summary Score	4	-.47	(.67)	-	-	25.00	75.00	-
ROCF Copy	4	-4.17	(3.79)	50.00	14.29	28.57	7.14	-

	3-minute recall	4	-1.12	(.86)	7.14	-	57.14	35.71	-
	Delayed recall	4	-1.50	(1.10)	14.28	14.28	42.86	25.00	-
	Recognition	4	-2.05	(1.89)	31.25	18.75	18.75	31.25	-
VPA I		3	.28	(.98)	-	-	13.33	66.67	20.00
II		3	.45	(.66)	-	-	6.67	73.33	20.00
Visuoperception									
Visuoperceptual Summary Score		3	-.31	(1.21)	-	13.33	13.33	60.00	13.33
Block Design		2	-.64	(1.28)	-	13.33	26.67	60.00	-
Matrix reasoning		1	-.07	(1.22)	-	5.56	16.67	55.56	22.26
Language									
Language Summary Score		3	.03	(1.02)	-	-	8.33	83.33	8.33
COWA	FAS	2	-.44	(1.54)	7.14	7.14	28.57	57.14	-
	Animals	2	-1.05	(1.62)	7.14	7.14	28.57	57.14	-
Boston Naming Test		1	-.79	(2.61)	18.75	-	6.25	62.50	12.50

COWA=Controlled Oral Word Association; CVLT II=California Verbal Learning Test (2nd Edition); IVA-CPT=Integrated Visual and Auditory Continuous Performance; ROCF=Rey Osterreith Complex Figure; VPA=Visual Paired Associates

All of the tests had some participants excluded due to being too impaired to undertake the test. When considering the proportion of participants excluded due to impairment, the executive functioning and information processing tests had the highest proportions of participants excluded. In addition, the information processing and executive functioning domains have smaller percentages of participant's performance falling within the average range in comparison with the domain scores for verbal and visual memory, visuoperception, and language tests. Tests that include an executive component, but which are included in other neuropsychological domains, such as the ROCF copy (visual memory) and COWA (language) when compared to other visual memory and language tests that do not contain an executive component, also display a smaller percentage of participants falling within the average range. Interestingly, the verbal memory tests (excluding CVLT-II recognition and false positive tests), verbal memory summary score and visuoperception tests and domain score do not have any participants with a performance level below -3. However, performance below -3 is a feature of executive function information processing, indicating that there are participants who have more extreme impairments within those domains. In comparison to the other domains, verbal memory tests have the highest proportion of participants falling within the average range.

Comparison of ICH and matched control groups on measures of body structure and function

A one-way ANOVA was carried out to determine whether the differences between the groups on measures of body structure and function were significant. The means and SD of the two groups on each measure and the results of comparisons are presented in Table 10. Also presented are the effect sizes which ranged from small $d \leq .2$ to large $d \leq .8$. As would be expected, there was a significant difference was recorded between the two groups in neurological functioning, with the ICH group having poorer physical functioning as measured by the NHISS. With regard to neuropsychological performance, the ICH group had a significantly poorer performance on the neuropsychological summary scores for executive

Table 10 Comparison of ICH and matched control groups on measures of body structure and function at five years post-ICH

Measure	**ICH**		**Control**		**F value**	**p value**	**Choen's *d***
	Mean	(SD)	Mean	(SD)			
Neurological							
NIHSS (Raw Score)	4.95	(3.95)	.17	(.51)	F(1,36) = 25.90	.001**	1.51
Neuropsychological (z-scores)							
Executive Function							
Executive Function Summary Score	-2.46	(3.70)	.36	(.85)	F(1,23) = 7.67	.011*	1.05
IVA-CPT - Full Attention	-2.46	(3.70)	.36	(.85)	F(1,23) = 7.67	.011*	1.05
Auditory Attention	-2.50	(3.81)	.25	(.71)	F(1,22) = 6.58	.018*	1.82
Visual Attention	-1.72	(2.66)	.34	(.97)	F(1,23) = 7.20	.014*	1.03
Auditory Impulsivity	-.18	(1.20)	1.19	(.38)	F(1,23) = 16.4	.001**	1.54
Visual impulsivity	-.63	(3.52)	.97	(.71)	F(1,23) = 2.74	.109	.63
Trails B	-1.08	(1.86)	.15	(.93)	F(1,32) = 6.12	.019*	.84
Stroop - Words	-1.56	(2.48)	.01	(1.02)	F(1,32) = 6.01	.020*	.83
Colour Names	-.91	(1.86)	.47	(.67)	F(1,32) = 8.60	.006**	.99
Interference Ratio (Raw Score)	3.11	(5.41)	1.15	(3.24)	F(1,32) = 1.65	.206	.44
Information Processing							
Information Processing Summary Score	-1.54	(1.83)	.09	(.60)	F(1,31) = 12.62	.001**	1.18
Stroop - Dots	-2.19	(2.47)	-.03	(.70)	F(1,32) = 3.03	.002**	1.19
Trails A	-1.58	(2.51)	.21	(.64)	F(1,33) = 8.55	.006**	.98
Verbal Memory							
Verbal Memory Summary Score	.16	(.53)	.82	(.73)	F(1,32) = 13.13	.001**	1.03
Logical Memory I	-.12	(.97)	.41	(1.19)	F(1,33) = 1.34	.256	.49
II	.19	(.92)	.94	(1.11)	F(1,33) = 4.50	.042*	.74
CVLT-II Short Delay Free	-.59	(1.28)	.65	(1.07)	F(1,32) = 9.15	.005**	1.05
Short Delay Cued	-.78	(1.00)	.47	(.80)	F(1,32) = 15.88	.001**	1.38
Long Delay Free	-.26	(.90)	.71	(.87)	F(1,33) = 10.21	.003**	1.11
Long Delay Cued	-.53	(1.07)	.32	(.79)	F(1,33) = 7.02	.012**	.90
Recognition Hits	-.32	(1.07)	.41	(.48)	F(1,33) = 6.66	.015**	.88
False Positive	-.12	(.96)	.62	(1.34)	F(1,33) = 3.38	.075	.63

Visual Memory							
Visual Memory Summary Score	-.47	(.67)	.67	(.83)	F(1,28) = 14.80	.001**	1.5
ROCF - Copy	-4.17	(3.79)	-.08	(.70)	F(1,31) = 20.23	.001**	1.5
3-minute recall	-1.12	(.86)	.68	(1.48)	F(1,30) = 16.47	.001**	1.49
Delayed recall	-1.5	(1.10)	.72	(1.49)	F(1,31) = 21.90	.001**	1.7
Recognition	-2.05	(1.89)	-.73	(1.44)	F(1,32) = 5.17	.030*	0.79
VPA - I	.28	(.98)	.46	(1.01)	F(1,31) = 1.57	.219	0.19
II	.45	(.66)	.61	(.55)	F(1,31) = .50	.483	0.26
Visuoperception							
Visuoperceptual Summary Score	-.31	(1.21)	.70	(.85)	F(1,32) = 7.84	.009**	.97
Block Design	-.64	(1.28)	.44	(.88)	F(1,32) = 8.33	.007**	.98
Matrix Reasoning	-.07	(1.22)	.95	(1.27)	F(1,35) = 6.04	.019*	.82
Bells (Raw Score)	33.35	(2.23)	34.79	(.43)	F(1,34) = 7.06	.012*	.74
Language							
Language Summary Score	-.32	(.64)	.72	(.71)	F(1,28) = 16.34	.001**	1.57
COWA – F,A,S	-1.03	(1.20)	.23	(.84)	F(1,30) = 11.69	.002**	1.22
Animals	-1.05	(1.62)	.88	(1.06)	F(1,31) = 15.97	.001**	1.41
Boston Naming Test	-.79	(2.61)	1.21	(.83)	F(1,32) = 9.05	.005**	1.02
Overall Impairment Summary Score	-2.42	(-2.71)	.11	(.32)	F(1,36) = 12.84	.001**	1.31
Mood (Raw Scores)							
GDS-SF	4.05	(3.96)	1.28	(.46)	F(1,36) = 8.69	.006**	.98
GHQ –28							
Somatic Symptoms	1.00	(1.63)	.61	(1.24)	F(1,30) = .57	.457	.24
Anxiety	.50	(.94)	.06	(.24)	F(1,31) = 3.75	.620	.08
Depression	.14	(.36)	.06	(.24)	F(1,31) = .68	.417	.15

*p<.05

**p<.01

COWA=Controlled Oral Word Association; CVLT II=California Verbal Learning Test (2nd Edition); GDS-SF= Geriatric Depression Scale; GHQ-28=General Health Questionnaire-28; IVA-CPT=Integrated Visual and Auditory Continuous Performance; NIHSS= National Institute of Health Stroke Scale; ROCF=Rey Osterreith Complex Figure; VPA=Visual Paired Associates.

functioning information processing, verbal and visual memory, visuopercpetion, language and overall impairment. On the IVA-CPT, there was a significant difference between the two groups performance on all indices apart from the visual impulsivity index. There was no significant difference between the groups in the ability to inhibit impulsive responses to visual stimuli. The two group's performance on Trails B and Stroop trials was also significantly different. Within the information processing domain, performances of the ICH group on Stroop dots and Trails A were both significantly weaker in comparison to the control group. Neuropsychological tests relating to verbal memory also revealed significant differences between the two groups. There was a significant difference between the two groups on the CVLT-II short delay free, short delay cued, and long delay free recall trials, and long delay cued recall. There was also a significant difference in performance on the long delay trial of logical memory. On both tests the ICH group's performance was worse. Within the visual memory domain, there were significant differences between the two groups on all of the trials of the ROCF but not the VPA. Within the visuoperception domain there was a significant difference between the groups on BD, MR, and Bell's test. Within the language domain, the performance levels of the ICH group on the COWA (F, A, S and Animals) and BNT were significantly weaker than those of the matched control group.

When considering outcomes relating to mood there was a significant difference between the two groups on the GDS-SF, with the ICH group having significantly more symptoms of depression and the mean score on the GDS-SF for the ICH group was only just below the cut off point for depression (≥5). However, there was no significant difference between the two groups on any of the GHQ-28 sub-scales.

Comparison of ICH and Matched Control Group on Measures of Activities and Participation

Table 11 below shows the means, standard deviations and significant differences generated by a one-way ANOVA used to compare the ICH and matched control groups across the measures of activities and participation. Also presented are the effect sizes which ranged

Table 11 Comparison of ICH and matched control groups on measures of activities and participation

Measure	**ICH**		**Control**		**F value**	**p value**	**Choen's *d***
Activities	Mean	(SD)	Mean	(SD)			
MRS	2.37	(1.34)	.06	(.24)	F(1,36)= 51.87	.000**	2.40
BI	86.32	(25.60)	100	(.00)	F(1,36) = 5.14	.030*	.76
FAI	30.89	(15.65)	45.61	(6.28)	F(1,36) = 13.80	.001**	1.23
Participation							
LHS	.24	(.22)	.42	(.12)	F(1.29) = 8.29	.008**	1.02
SF-36 - Physical Functioning(PF)	50.79	(34.89)	78.33	(20.94)	F(1,36) = 8.34	.007**	.98
Role Physical (RP)	75.0	(40.82)	76.39	(37.84)	F(1,36) = 17.83	.915	.04
Body Pain (BP)	79.6	(24.13)	77.92	(22.45)	F(1,36) = .05	.827	.07
Vitality (VT)	53.95	(22.58)	64.44	(17.4)	F(1,36) = 2.49	.124	.07
General Health (GH)	63.16	(22.80)	63.33	(23.26)	F (1,36) = .00	.982	.52
Social Functioning (SF)	90.13	(18.90)	90.97	(16.5)	F(1,36) = .02	.886	.01
Role Emotional (RE)	82.46	(37.46)	85.19	(30.73)	F(1,36) = .06	.811	.05
Mental Health (MH)	75.37	(19.79)	82.0	(12.37)	F(1,36) = 1.48	.233	.40
Mental Component Score (MCS)	72.88	(18.17)	78.95	(15.17)	F (1,36) = 1.21	.279	.36
Physical Component Score(PCS)	61.09	(22.10)	88.17	(23.42)	F(1,36) = 13.10	.001**	1.19
GHQ –28 Social Functioning	1.07	(1.73)	.61	(1.65)	F(1,31) = .59	.449	.27

*p<.05
**p<.01
BI=Barthel Index; FAI=Frenchay Activity Index; GHQ –28=General Health Questionnaire-28; LHS=London Handicap Scale; MRS=Modified Rankin Scale; SF-36=Short Form-36.

from small $d \leq .2$ to large $d \leq .8$. As can be seen in Table 11, there was a significant difference between the ICH and the control groups on the BI, FAI and the MRS measures of activity. There was also a significant difference between the two groups on measures of participation including the LHS, SF-36 PCS and the SF-36 PF subscales. *The Effect of*

Demographic Factors on 5-year Outcomes

One-way ANOVAs were carried out to examine the effects of gender, age, and education on each of the measures of body structure and function, activities and participation for the ICH group. The ICH group was divided into two groups for each of the demographic variables (i.e. male verses female, >65 versus ≤65, tertiary level education/ versus secondary level education). Unfortunately, within the sample, there were too few people of varying ethnicity to examine its effect on outcomes. (See Table 5 in the Methodology Chapter). Age and gender had no significant effect on any of the measures of outcomes in the ICH group. When the effect of education was examined, on the neuropsychological summary scores, significant differences were found between those who had tertiary education in comparison to those educated to a secondary level. Specifically participants who were educated to a tertiary level had a better visuoperception summary score in comparison to those educated to a secondary level (F [1,14] = 14.06, p=.002, tertiary x= .19, SD = .90, secondary x= -1.71, SD =.75) and had a lower overall impairment domain score than those educated to a secondary level (F[1,18] = 10.72, p= .004, tertiary x= 1.18, SD=1.32, secondary x= 4.13, SD= 3.27).

3.3. Change over Time in the ICH Group

In this section the measures of mood, activity and participation which were administered at baseline during the ARCOS study at one month, six months and at five years post- ICH,) are examined for trends over time using repeated measures ANOVAs for the purposes of this study. In addition, demographic characteristics such as age, gender, and level of education are considered in terms of their impact on the outcomes measures at each time point.

Table 12 Comparison of measures of mood, activities, and participation taken at different time points during recovery post-ICH

Measure	Time point									
	Baseline		1-month		6-months		5-years			
	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	F value	p value
BI	-	-	34.21	(35.72)	-	-	86.32	(25.60)	F(1,19) = 117.22	.001**
FAI	39.61	(7.8)	-	-	25.28	(12.47)	30.89	(15.65)	F(2,16) = 14.17	.001**
MRS	-	-	2.58	(.37)	-	-	2.37	(.31)	F(1,18) = .79	.385
GHQ-28 - Somatic	-	-	1.33	(1.58)	1.24	(1.84)	1.00	(1.63)	F(2,8) = .46	.649
- Anxiety	-	-	.73	(.1.35)	.56	(.82)	.50	(.94)	F(2,9) = .52	.609
- Social Function	-	-	2.2	(1.93)	1.29	(1.16)	1.07	(1.73)	F(2,8) = 1.88	.215
- Depression	-	-	.18	(.60)	.00	(.00)	.14	(.36)	F(1,10) = 1.00	.341
SF-36 - *Physical Functioning (PF)*	-	-	-	-	60.59	(32.92)	50.79	(34.89)	F(1,16) = 3.99	.063
Role Physical (RP)	-	-	-	-	51.56	(42.3)	75.00	(40.82)	F(1,16) = 5.42	.034*
Body Pain (BP)	-	-	-	-	77.65	(21.19)	79.60	(24.13)	F(1,16) = .36	.558
Vitality (VT)	-	-	-	-	61.47	(21.99)	53.95	(22.58)	F(1,16) = 3.97	.064
General Health (GH)	-	-	-	-	67.35	(15.01)	63.16	(22.80)	F(1,16) = .16	.696
Social Functioning (SF)	-	-	-	-	82.35	(25.02)	90.13	(18.90)	F(1,16) =2.04	.173
Role Emotional (RE)	-	-	-	-	84.31	(35.59)	82.46	(37.46)	F(1,16) = 1.15	.299
Mental Health (MH)	-	-	-	-	85.65	(12.81)	75.37	(19.79)	F(1,16) = 8.04	.012**
Mental Component Score (MCS)	-	-	-	-	77.98	(17.18)	72.88	(18.17)	F(1,16) = .01	.945
Physical Component Score(PCS)	-	-	-	-	60.83	(23.79)	61.09	(22.10)	F(1,16) = .35	.561

*p<.05
**p<.01
BI=Barthel Index; FAI=Frenchay Activity Index; GHQ-28= General Health Questionnaire-28; MRS=Modified Rankin Scale; SF-36=Short Form-36.

Table 12 presents the means, standard deviations, and significance of each of the comparisons at the various time points. Several measures indicated change in performance over time. Performance on the BI was significantly poorer when assessed at one month post-ICH as opposed to five years post-ICH, indicating a good level of recovery. The FAI indicated a significant change over time, with post hoc analyses revealing a significant decrease in engagement in activities at six months post-ICH, in comparison to reports obtained at baseline about retrospective functioning prior to the stroke. However, there was no significant difference between the level of engagement in activities at baseline and five years post-ICH. The SF-36 highlighted changes overtime. There was a significant improvement in the ability to engage in roles which were dependent on physical functioning. There was also a significant decrease in the mental health of ICH survivors five years post - ICH.

Demographic Effects on Change over Time

One-way ANOVAs were conducted on outcomes over time to explore the effect of age (above 65 v below 65), gender (male/ female) and education level (secondary v tertiary).There were no significant differences due to age, gender or education found on the BI, MRS, FAI, GHQ-28 or SF-36 taken at the different time points.

3 .4. Investigating the Relationships between Body Structure and Function, Activities and Participation Five Years Post-ICH

To investigate the degree and direction relationships between measures of body structure and function, activities and participation in the ICH group Pearson-product moment correlations were generated. Initial correlations consider the relationships amongst measures within each of the ICF domains. Then, correlations considering the relationships between measures from the different ICF domains are explored.

Correlations between Measures of Body Structure and Function

First, correlations between the measures of body structure and function, namely the measures of neurological and neuropsychological functioning and mood, amongst the ICH group at five years post-ICH were generated. This included the NIHSS, neuropsychological domain scores for executive function, information processing, verbal and visual memory visuoperception, language and overall impairment, the GDS-SF score, and the GHQ-28 depression, anxiety and somatic scales. The correlations are presented in Table 13. The NIHSS was significantly negatively correlated with all of the neuropsychological summary scores. Suggesting that reduced neurological functioning is associated with decreased cognitive function. The NHISS positively correlated with the summary score for overall neuropsychological impairment, meaning that the greater the neurological impairment there was, the greater the overall cognitive impairment. Overall impairment was negatively correlated with executive functioning, information processing, verbal memory and visuopercpetion. This suggests that impairment in these areas are associated with reduced cognitive functioning overall.

There were a number of correlations between the neuropsychological summary scores. Executive functioning was positively correlated with verbal memory suggesting that those with better executive functioning have a better memory for verbal information. Information processing is positively correlated with visual memory and visuoperception. Suggesting that better information processing speed is associated with increased ability in the domains of verbal memory and visuopercpetion. Also verbal memory was positively correlated with visual memory and visuoperception. This indicates that better verbal memory is associated with better visual memory and visuopercpetion.

Mood also appeared to influence cognition. The GDS-SF was negatively correlated with vsiouperception, and positively correlated with overall impairment. This indicates that reduced visuoperception and increased overall impairment are associated with increased symptoms of depression.

Table 13 Correlations between measures of body structure and function

	NIHSS	Ex.Func	Info. Process	Verbal Mem	Visual Mem	Visuo-perception	Language	Overall Impairment	GDS-SF	GHQ-28 Depression	GHQ-28 Anxiety
NIHSS											
Ex. Func	-.581**										
Info. Process	-.756**	.410									
Verbal Mem	-.387*	.468*	.285								
Visual Mem	-.583**	.425	.430*	.433*							
Visuopercpetion	-.628**	.211	.542**	.554*	.651**						
Language	-.430*	.261	.353	.123	.199	.220					
Overall Impairment	.756**	-.814**	-.611**	-.367*	-.443	-.632**	-.320				
GDS-SF	.263	-.337	-.066	-.214	-.534**	-.326	-.140	.391*			
GHQ-28 Depression	-.172	.012	.229	-.002	.084	.108	-.266	-.017	.679**		
GHQ-28 Anxiety	-.007	-.045	.069	-.265	-.182	-.114	-.320	.153	.814**	.689**	
GHQ-28 Somatic	-.152	-.067	.243	-.060	.060	-.020	-.039	-.046	.260	.477*	.271

*=p<.05
** =p<.01
GDS-SF= Geriatric Depression Scale – Short Form.; GHQ-28= General Health Questionnaire-28; NIHSS= National Institute of Health Stroke Scale .

Positive correlations were also found between the GDS-SF and GHQ-28 anxiety and GHQ-28 depression scales. This indicates that ICH survivors who experienced depression as measured by the GDS-SF were also more likely to experience symptoms of anxiety and depression, as measured by the GHQ-28. The correlation between the GDS-SF and GHQ-28 depression scale is expected given that they are measuring similar aspects of mood. There were positive correlations between the GHQ-28 scales of depression and anxiety and somatisation. This suggests that those with higher rates of depressive symptoms also have greater rates of anxiety and somatisation.

Correlations between Measures of Activities and Participation

Table 14 presents the correlations amongst the measures of activities and participation. Variables included in this analysis were the BI, FAI, MRS, LHS and the SF-36 subscales and component scores. Correlations between the SF-36 MCS and PCS and the subscales of the SF-36 that compose the component scores (MRS; SF, VT, RE, and MH; PCS: PF, BP,RP and GH) are not reported in the text (but are shown in the table) as these correlations are expected. The BI was negatively correlated with the MRS and positively correlated with the FAI, LHS, and SF-36 PF, GH, MH and PCS. This suggests that those who have difficulty engaging in ADLs also have greater global disability and more difficulty engaging in IADLs, and are more restricted in their life roles. Further those who are able to be independent in ADLs are more likely to have better general and mental health and overall physical health related quality of life The FAI was negatively correlated with the MRS. This suggests that those who have difficulty engaging in IADLs are also more likely to experience greater global disability . The FAI was also correlated with a number of measures of participation. Namely the LHS, the SF-36 PF, VT, MH, MCS and PCS. This suggests that difficulty engaging in IADLs is also associated with mobility and participation as measured by the LHS. According to the correlations between the FAI and SF-36 those who are better

Table 14 Correlations between measures of activities and participation

	BI	FAI	MRS	LHS	GHQ-28 Social	SF-36 PF	SF-36 RP	SF-36 RE	SF- 36 BP	SF-36 VT	SF- 36 GH	SF- 36 SF	SF-36 MH	SF -36 MCS
FAI	.752**													
MRS	-.550*	-.744**												
LHS	.735**	.743**	-.758**											
GHQ- 28 Social Func.	-.003	-.229	.082	-.313										
SF-36 PF	.642**	.791**	-.762**	.847**	-.159									
SF-36 RP	-.068	.089	-.050	.284	-.547**	.175								
SF-36 RE	-.099	.119	.025	.037	-.380*	.030	.696*							
SF-36 BP	.430	.256	-.148	.126	-.288	.361	.560**	.320						
SF-36 VT	.308	.421**	-.378*	.404*	-.609**	.434**	.564**	.235	.564**					
SF-36 GH	.508*	.202	-.157	.448*	-.303	.220	.391*	.220	.588*	.507**				
SF-36 SF	-.003	.193	-.055	.193	-.307	.191	.596**	.625*	.657*	.394*	.341*			
SF-36 MH	.690**	.456**	-.284	.377*	-.326	.367	.459**	.416*	.713*	.544*	.572**	.606*		
SF-36 MCS	.343	.389*	-.231	.349	-.585**	.324	.770*	.765*	.685*	.618*	.729*	.784*	.838*	
SF-36 PCS	.628**	-.708**	-.703**	.765*	-.411*	.850**	.390*	.390*	.607**	.676**	.638*	.463**	.656*	.658*

*=p<.05
** =p<.01

BI=Barthel Index; FAI=Frenchay Activity Index; LHS=London Handicap Scale; MRS=Modified Rankin Scale; SF-36=Short Form-36; RP= Role Physical; RE=Role Emotional; BP=Body Pain; VT=Vitality; GH=General Health; GHQ-28 Social Func.= General Health Questionnaire-28 (Social Functioning); PF-Physical Function; SF=Social Function; MCS=Mental Component Score; PCS=Physical Component Score

able to engage with IADLs are less likely to have problems with physical function and mental health and are likely to feel more vital in their lives. The MRS was negatively correlated with the LHS and SF-36 PF and PCS. This suggests that those with greater global disability are more likely to have impairment in physical function and restrictions in participation. The LHS which is a measure of both activities and participation was positively correlated with the SF-36 PF, VT, GH, MH, MCS and PCS. The GHQ-28 social scale was negatively correlated with the SF-36 RE, RP, VT, MH, MCS and PCS This suggests that those who are more social are less likely to have difficulty with fulfilling roles related to their physical or mental well being, they are less likely to have mental health problems and are more likely to feel vital in their lives. The SF-36 PF was positively correlated with the SF-36 VT indicating that those who not are limited in their better mental health, general health, social functioning, feel more vital in their lives and have less body pain. The SF-36 BP was positively correlated with the SF-36 VT and GH. This suggests that those with less body pain had better general health and greater vitality. The SF-36 VT is positively correlated with the SF-36 GH, SF and MH. This indicates that those with greater vitality are more likely to experience better general and mental health, and social functioning. The SF-36 GH was positively correlated with the SF-36 SF and MH suggesting that those with greater general health were more likely to experience greater social functioning and mental health. The SF-36 SF was positively correlated with the SF-36 MH indicating those with better social functioning had better mental health. Finally the SF-36 MCS was correlated with the SF-36 PCS indicating that the better the quality of overall mental well being the better the overall quality of physical well being.

Correlations between Measures of Body Structure and Function and Activities and Participation

Correlations were generated between each of the measures of body structure nad functioning and activities and participation (i.e. NIHSS, neurological summary scores GDS-SF, and GHQ-28) and the BI, FAI, MRS, LHS, SF-36, and GHQ-28 Social Functioning) and

are presented below in Table 15. No significant correlations existed between the NIHSS and any of the measures of activities or participation (i.e. BI, FAI, MRS, LHS, and SF-36; $p > .05$). Similarly, no significant correlations existed between neuropsychological summary scores for executive functioning, information processing speed, visual and verbal memory, visuopercpetion, or language and the measures of activities (BI, FAI, and MRS; $p > .05$). However, there were a number of significant correlations between information processing and executive functioning summary scores and the LHS and sub-scales of the SF-36. Both the information processing and executive functioning summary scores were negatively correlated with the LHS. This suggests that reduced engagement in life roles and situations is associated with decreased processing speed and executive functioning. Information processing speed was also negatively correlated with the SF-PF and SF-PCS. This suggests that poorer information processing speed is associated with poorer physical functioning. In addition the executive functioning summary score was positively correlated with the SF-36 scales of role physical (RP), role emotional (RE), social function (SF), and the mental component score (MCS). This suggests that increased executive functioning is associated with increased social functioning, and a better mental health component score. It also suggests that limitations in expected roles due to emotional problems and reduced physical functioning are associated with decreased executive functioning. Table 15, below, shows which measures of mood correlated significantly with measures of activities and participation. The GDS-SF correlated negatively with the BI, FAI, LHS and SF-36 PF and BP. This suggests that an increase in symptoms of depression is associated with a decrease in physical functioning, reduced independence in ADLs a decrease in the engagement in IADLs, greater restrictions in life roles and an increase in body pain. The GDS-SF was also negatively correlated with the following SF-36 sub-scales; general health, mental health, and overall physical and summary scores. This indicates that increased symptoms of depression are associated with worse general and mental health and poorer mental and physical health related quality of life. The BI also correlated negatively with the

Table 15 Correlations between measures of body structure and function, activities and participation.

	BI	FAI	MRS	LHS	GHQ-28 Social	SF-36 PF	SF-36 RP	SF-36 RE	SF- 36 BP	SF-36 VT	SF- 36 GH	SF- 36 SF	SF-36 MH	SF-36 PCS	SF -36 MCS
NHISS	.164	.066	-.324	.479	-.314	.256	.129	-.044	.092	.236	.150	-.100	-.054	.284	.028
Executive Functioning	-.191	-.034	.280	-.919**	.422	-.265	.924**	.924**	.632	.520	.495	.972**	.507	.350	.840**
Information Processing	-.457	-.474	.510	-.894**	.251	-.673*	.115	.176	-.176	-.290	-.307	.246	-.117	-.568*	-.035
Visuo-perception.	.160	.197	.236	-.017	-.474	-.099	.098	-.014	.017	.126	-.035	.099	.253	-.083	.132
Verbal Memory	.285	.215	.064	.086	-.474	-.033	.309	.119	.017	.447	-.035	.110	.263	.085	.315
Visual Memory	.467	.302	-.290	.170	.104	.370	.109	.113	.530	.164	.175	.379	.557	.444	.315
Language	.171	-.243	.047	.128	.347	-.139	-.003	.314	-.281	-.488	.150	.135	.213	-.097	.021
Overall Impairment	.071	-.160	-.228	.009	-.224	.117	-.063	-.360	.071	.003	-.153	-.212	-.268	.035	-.294
GDS-SF	-.782**	-.711**	.435	-.685*	.092	-.508*	-.172	-.367	-.566*	-.325	-.647**	-.234	-.821**	-.661**	-.632**
GHQ-28 Depression	-.680**	-.518	.335	-.577*	.227	-.361	-.213	-.679**	-.229	-.128	-.582*	.001	-.705**	-.468	-.684**
GHQ-28 Anxiety	-.758**	-.553	.367	-.626*	.118	-.352	-.029	-.459	-.221	-.158	-.693**	.106	-.688**	-.122	-.553*
GHQ-28 Somatic	-.293	-.202	.680	-.626*	.806**	-.101	-.140	.184	-.117	-.782**	-.517	.298	-.228	-.232	-.389

*=p<.05
** =p<.01
BI=Barthel Index; FAI=Frenchay Activity Index; GHQ-28= General Health Questionnaire-28; GHQ-28 Social Func.= General Health Questionnaire-28 (Social Functioning); LHS=London Handicap Scale; MRS=Modified Rankin Scale; NIHSS= National Institute of Health Stroke Scale; SF-36=Short Form-36; RP= Role

Physical; RE=Role Emotional; BP=Body Pain; VT=Vitality; GH=General Health; PF-Physical Function; SF=Social Function; MCS=Mental Component Score; PCS=Physical Component Score.

GHQ-28 depression scale suggesting that decreased independence in ADLs is associated with increased symptoms of depression. The GHQ-28 depression scale is correlated negatively with the LHS, SF-S6 MH, MCS and GH. This indicates that increased symptoms of depression in ICH survivors are associated with restriction of in life roles and poorer general and mental health and overall mental health relating to quality of life. The GHQ-anxiety scale is negatively correlated with the BI, indicating that increased anxiety is associated with decreased independence in ADLs. The GHQ-28 anxiety is negatively correlated with the SF-36 GH, MH and MCS and the LHS. This suggests that ICH survivors with increased anxiety have poorer general and mental health and greater restriction in engaging in life roles. The GHQ-28 somatic scale correlated negatively with the LHS and SF-36 vitality subscale. This suggests that those with increased rates of somatic symptoms feel less vital in their lives and have greater restriction in life roles.

Chapter 4: Discussion

This study examined the long-term outcomes (five years) of a primary ICH. The specific aims of this research were to explore outcomes in ICH survivors in neurological and neuropsychological functioning, mood, ADLs and HRQoL in comparison to matched healthy controls. Further, to explore, over a period of time, whether there has been, evidence of recovery in mood, ADLs, and HRQoL in the ICH group, whether there are relationships between the different outcomes, and whether outcomes are impacted by demographic variables such as age, gender and education. These aims were explored by comparing the performance of ICH survivors to a healthy control group matched for age, gender, ethnicity and education. Data collected from the ICH survivors from an earlier population-based study (ARCOS) at baseline (at the time of ICH), and at one month and six months post-ICH were used to explore changes in outcomes for members of the ICH group over time. This discussion examines the findings in relation to each of these aims in turn, with reference to the relevant literature. This is followed by a discussion of the clinical implications of the findings as well as of the strengths and limitations of the study, with a view towards future research.

4.1 Comparison of the ICH Group with Matched Controls at Five Years post-ICH.

Although performance of ICH participants across the neuropsychological measures was variable, overall, the ICH group experienced greater impairments in neurological and neuropsychological functioning than did the matched control group. ICH survivors also reported higher rates of depressive symptoms and had poorer functional outcomes; they experienced greater global disability and were more likely to be dependent in their ADLs and less likely to engage in IADLs. However, there was relatively little difference in HRQoL between the two groups, in spite of the health condition of the ICH survivors. Each of these areas is discussed in relation to the literature below.

Neurological Functioning

The ICH group had significantly poorer neurological functioning as measured by the NHISS. The areas most affected in this study included; facial paresis (84.2%); limb mobility (46.2 %); sensory deficits (42.1%); dystharia (36.8%) and visual field deficit (10.5%). This is consistent with the findings of other studies, especially in regard to the outcomes of neurological impairment and the sensory deficits of both stroke and ICH (Wiebers, Feigin, & Brown, 2006; Lawrence, et al. 2001; Liang, et al. 2001; Maeshima, Turman, Smith, Dohi, Itakura, & Komai, 1997). This suggests that ICH survivors experience residual problems in neurological functioning five years post-ICH. There was no effect on neurological outcomes of age, gender or education.

Neuropsychological Functioning

The ICH group performed significantly worse than the matched controls in all areas of neuropsychological functioning that were assessed and had a poorer overall neuropsychological impairment summary score. Significant differences between the groups in the area of executive functioning were observed on the executive functioning summary score, the IVA-CPT measure of full attention, auditory attention, visual attention, auditory impulsivity ; the Stroop words and colour names and on Trails B. This suggests that there were participants with significant difficulties with attention and executive function amongst the ICH group in comparison to the matched controls. This finding has not been reported in any previous ICH studies (Su, Chen, Kwan, Lin, & Guo, 2007; Liang, et al. 2001; Fuh & Wang, 1995; Ibayashi, Tanaka, Joanette, & Lecours, 1992). Although there were no differences found on any of the other measures of executive functioning, it is likely that the extent of executive functioning problems amongst the ICH group is understated in this data set as a large majority of the ICH group could not complete the IVA-CPT due to impairment (25%). In addition, on the Trails B 16% of the ICH had to be excluded as they could not complete the practice item, and were too impaired to undertake the test, which suggests that there may be difficulty with attention and mental flexibility. Problems in executive functioning

are consistent with the wider stroke literature; there was one study in the ICH literature which reported deficits in executive function in the ICH survivors using the Wisconsin Card Sorting Task (Ballard, Rowan, Stepehens, Kalaria, & Kenny, 2003; Srikanth, Quinn, Donnan, Saling, & Thrift, 2006; Su, Chen, Kwan, Lin, & Guo, 2007; Rasquin, Lodder, & Verhay, 2005).

In comparison to the matched control group, the ICH group also had significantly reduced speed of information processing across all neuropsychological measures, and the information processing summary score. In addition, the ICH group's performance in comparison to the normative mean was also poor. Difficulties with information processing in stroke are consistent with the findings of Srikanth, Quinn, Donnan, Saling, and Thrift, (2006) and Rasquin, Lodder, and Verhay, (2005), who found deficits in this area at two years post stroke; however, neither of these studies were population-based. Information processing difficulties had not, until now, been reported amongst ICH survivors. This may be a function of information processing speed in ICH survivors not having been explored until now, as at the time of writing no literature on this topic could be found.

The ICH group exhibited poorer performance on the verbal memory summary score, the CVLT and LM II Findings from the CVLT-II revealed significantly poorer performance amongst the ICH group in retrieving information in free and cued recall trials with a short and long time delay, and free recall in the long delay trial. The ICH group also had a poorer performance on the LM II. LM is thought to be a measure of memory for everyday conversations (Strauss, Sherman, & Spreen, 2006) so this finding suggests that long delayed recall of conversations may present difficulties for ICH survivors. Difficulties with verbal memory are recorded in both the stroke and ICH literature (Su, Chen, Kwan, Lin, & Guo, 2007; Srikanth, Quinn, Donnan, Saling, & Thrift, 2006; Engstad, Almkvist, Viitanen, & Arnesen, 2003; Fuh & Wang, 1995; Ibayashi, Tanaka, Joanette, & Lecours, 1992)

Visual memory was an area that demonstrated a variation in performance across measures. The ICH group members had a significantly poorer visual memory summary score than the control group members, and their performance on the ROCF 3-minute recall and delayed recall and recognition trials were significantly worse than those of their matched

controls. Due to the element of executive functioning in the ROCF, and because the ICH participants produced particularly poor performances on the copy trial, it is possible that the poorer performance on this task was also due in part to problems in executive functioning as well as in visual memory. There was also no difference between the two groups on the VPA. A reason for this is that the ROCF, in comparison to the VPA, places a greater demand on visual memory due to its greater complexity and also requires good fine motor skills. In the ROCF, participants must free recall (drawn from memory) a complex image they have only seen once, where as in the VPA the participant has a number of exposures to the stimuli and is provided with both the pattern and the possible choice of colours during the trial which act as cues. In addition the VPA is more easily verbalised that the ROCF. During testing many participants developed verbal mnemonics such as 'blue-robot', where the pattern was related to an object with semantic meaning and the colour associated with it. Difficulties in visual memory have been a consistent finding throughout much of the stroke and ICH literature (Ballard, Rowan, Stepehns, Kalaria, & Kenny, 2003; Hochstenbach, Otter, & Mulder, 2003; Srikanth, Quinn, Donnan, Saling, & Thrift, 2006; Engstad, Almkvist, Viitanen, & Arnesen, 2003; Rasquin, Lodder, & Ponds, 2004; Su, Chen, Kwan, Lin, & Guo, 2007; Fuh & Wang, 1995). However, the two studies within the ICH literature that reported memory deficits did not use matched controls and tested participants at two weeks (Fuh & Wang, 1995) and between one and six months post-ICH (Su, Chen, Kwan, Lin, & Guo, 2007), and the samples for the two studies were not population-based so their findings may not be generalizable to wider populations of long-term ICH survivors. This study confirms that, five years post-ICH, visual memory performance is poor when compared with the results for a matched control group.

Visuoperception was also an area that revealed a significantly poorer performance amongst the ICH group than controls on BD, MR and Bells and the overall summary score. Deficits in visuopercpetion than the MR and deficits in visuoperception are common findings in the stroke literature (Srikanth, Quinn, Donnan, Saling, & Thrift, 2006; Engstad, Almkvist, Viitanen, & Arnesen, 2003; Rasquin, Lodder, & Verhay, 2005) and in one study in the ICH

literature (Su, Chen, Kwan, Lin, & Guo, 2007). However, the ICH study was not population based, excluded those with significant aphasia and tested participants at varying times between one and six months.

Language is also an area where the ICH group performed significantly worse in comparison to the matched controls on all of the measures and the summary score. Although, in the ICH group only the scores for the COWA fell below the normative mean. The ICH group had reduced verbal fluency (which also has an executive component and a processing speed component) in comparison to their matched controls. They also greater difficulty in word finding during a naming task than did the matched participants. These findings are consistent with the stroke literature and ICH literature (Hochstenbach, Otter, & Mulder, 2003; Engstad, Almkvist, Viitanen, & Arnesen, 2003; Rasquin, Lodder, & Verhay, 2005 and ICH literature (Ibayashi, Tanaka, Joanette, & Lecours, 1992; Liang, et al., 2001; Fuh & Wang, 1995).

When considering the effect of demographics in the ICH group, there were no effects of age or gender on any of the measures of neuropsychological functioning. However, those with a tertiary level of education had a better visuoperception summary score and had a higher overall impairment summary score in comparison to those with a secondary level of education. Education has frequently been identified as a protective factor for cognition following brain injury (Lezak, 2004), which is consistent with the finding from this study. It is possible that the better scores in visuoperception are a function of the education and occupation type of the participants it was qualitatively noted that one third of the ICH survivors who had been educated to a tertiary level had been engineers. This kind of occupation may indicate a particular strength for some of the participants in this study. This relatively higher score in visuoperception may reflect an area of pre-morbid strength rather than an area less affected by an ICH. The finding that, at five years post-ICH, there is some effect of education suggests that, in the long-term, education does offer some protection from cognitive impairment. A similar finding regarding gender was reported by Rasquin, Lodder, and Verhay, (2005), who found that cognitive decline across the year following a

stroke was unrelated to gender. Literature regarding the role of gender in ICH outcomes could not be located.

Alternate reasons for differences in cognitive ability between the two groups could be that, for the ICH participants, a degenerative process was currently occurring such as dementia. However, when asked, none of the participants reported any neurological events that were unrelated to an ICH, nor had they been to see a Doctor or other Health Professional regarding problems with cognition. None of the participants scored below the cut-off level for possible dementia on the Hodgkinson Mental Test which was used as an initial screen for inclusion in the neuropsychological test battery as part of the larger ASTRO study (HMT cut-off is <6).

Mood

In considering mood amongst the ICH and matched control group, the ICH group experienced more symptoms of depression according to the GDS-SF. In comparison to the general population, a higher rate of depressed mood, post-stroke, is a common phenomena reported in the stroke and ICH literature (Bhopal, Teasell, Foley, & Speechley 2004; De Haan, Limburg, van der Meulen, Jacobs, & Aaronson 1995; Eriksson et al. 2004; Fuh, Liu, Wang, Liu & Wang, 1997; Hermann, Black, Lawrence, Szekely, & Szalai 1998; Steffens, Krishnan, Crump, & Burke 2002; Tang, Ungvari, Chui, Sze, Woo, & Kay, 2002). In this study 15% of the ICH group scored over 5 on the GDS-SF, indicating the possibility of depression. This is a higher rate than is found in the general population (American Psychiatric Association, 2000) but is lower than that typically found three years post-stroke (Astrom, Adolfsson, & Asplund, 1993) and amongst ICH survivors who have had a haemorrhage in the basal ganglion at 18-months (Hai, Zhang, Wang, Jue-Feng, & Pan, 2010). Interestingly, there were no significant differences identified between the two groups on the GHQ-28 depression scale. This may be a consequence of the different elements of depression that the GHQ-28 and GDS-SF measure. Within the GHQ-28 scale of depression, four of the seven questions ask about suicidal ideation, whereas the GDS-SF does not ask about

suicidal ideation. This suggests that the depression experienced by ICH survivors does not include suicidal ideation. However, this study was not population-based and only used ICH survivors who had experienced a surgical intervention for a hypertensive haemorrhage in the basal ganglion. In addition, there was no control group with which to compare this finding. Within the present sample, there was no effect of age, gender or education on mood symptoms amongst the ICH group. There is a lack of consistent findings within the stroke literature relating to the role of gender in mood as both men and women have been found to have higher prevalence rates than those of the general population (Morrison, Pollard, Johnston, & MacWalter, 2005; Paradiiso & Robinson, 1998; Srivastava, Taly, Gupta, & Murali, 2010). In addition, evidence for there being no role of gender in prevalence rates of mood disorders in stroke has also been found (Astrom, Adolfsson, & Asplund, 1993; Damecour & Caplan, 1991; Thomas & Lincoln, 2008). Amongst ICH survivors, women are reported to have higher rates of depression at three months, (Christian Mayer, Ferran Kissela, 2009). However, no more recent information could be sourced that reported on the prevalence rates amongst males or females. Interestingly, there was no difference in the levels of anxiety or somatic symptoms amongst the ICH group. In addition, the mean rates of anxiety and somatic symptoms in the ICH group were very low being on average 0.5 and 1 respectively out of a possible 7. There have been varying results relating to the presence of anxiety in stroke survivors. Some studies have found very high rates of anxiety in stroke survivors (23%) at three years post stroke (Astrom, 1996), while others have found the rate to be very low (4%) at one year post-stroke (House, Dennis, & Moridge, 1991). However, neither of these studies reported findings relevant to the ICH sub-type of stroke nor were they population-based. Further, they reported outcomes at a much earlier stage post-stroke than did the present study. It is possible that, as a group, ICH survivors do not experience significant problems with anxiety at five years' post-stroke in comparison to matched controls from the general population.

Activities and Participation

There were significant differences amongst the two groups on measures of activities, with the ICH group producing significantly poorer scores on the MRS BI and FAI than their matched controls. Overall, the findings indicated that the ICH group were more likely to be dependent on others in basic ADLs such as moving, toileting, dressing and feeding. In addition, the ICH group was more likely to be limited in the extent to which they could engage in instrumental activities such as gardening, meal preparation and cleaning. Limitation in IALDS is a common finding in the stroke and ICH literature and this group is consistent with those findings (Chausson, Olindo, Cabre, Saint-Vil, & Smadja, 2010; Hankey, Jamrozik, Broadhurst, Forbes, & Anderson, 2002; Withall, Brodaty, Altendorf, & Sachdev, 2009). Interestingly there was no effect of age, gender or education on limitation in activities. Age (being over 70) has previously been found to be a factor in the degree of impairment in ADLs in a population-based study of ICH survivors (Nuutila & Vourela, 1992). However, in this study the time at which participants were tested varied hugely and had a median testing time of 32 months. It is possible that age becomes less of a factor in outcomes relating to ADLs at five years. However, a sensitivity analysis indicated that the present ICH sample differs from the original group surveyed in 2002-3 in that they were younger at the time of the ICH. It is possible that as this study is researching outcomes at five years post-ICH (which is a greater length of time post-ICH than in the other study), older participants who are likely to have been more disabled are likely to have died. Therefore, age becomes less of a factor in outcomes of ALDs at five years post-ICH. With regard to gender, there is varying evidence supporting its role in outcomes relating to ALDs. The outcome of this study (i.e. that there is no effect for gender on ADLs) is confirmed by another population-based study; the Sydney Stroke Study (Withall, Brodaty, Altendorf, & Sachdev, 2009), but contrasts with the finding of a New Zealand based study which showed that males had greater impairment in ADLS than females (Bonita, Solomon, & Broad, 1997). However, neither of these studies examined the role of gender by sub-type of stroke, neither were they reporting outcomes at five years. There is no current literature regarding the impact of

gender in the long-term outcomes of activities of ICH with which to compare the findings of this study. The finding that education does not have a role to play in activity outcomes is consistent with the findings of both the stroke and ICH literature (Withall, Brodaty, Altendorf, & Sachdev, 2009; Rost, et al. 2008).

While the ICH group also appeared to have significant restrictions in their ability to participate in life situations, according to the LHS, in many areas of HRQoL, there was little difference between the two groups as assessed using the SF-36. Within the area of HRQoL, there were significant differences between the two groups on the physical functioning and the overall physical component score. Physical functioning is measured by questions such as: Does your health limit you in activities such as pushing a vacuum cleaner? ... climbing stairs? bending...? ...carrying groceries? These questions tap into behaviours that are more commonly associated with the domain of activities which have been highlighted by the MRS, BAI, and FAI as areas where members of the ICH group experience limitations in comparison to the members of the control group. This significant difference on the physical component score is due to the difference between the two groups on the physical functioning scale, which is more a reflection of limitation in activity than differences in HRQoL participation. Therefore, for the large majority of the measures of HRQoL/participation, ICH survivors did not experience significantly poorer HRQoL than the healthy matched control group. Whilst this finding is not consistent with the general stroke literature which has reported a lower HRQoL in a population-based study of stroke survivors at two years (Sturm, Donnan, & Dewey, 2004), it is consistent with a population-based study of stroke survivors in New Zealand (Hackett, Duncan, Anderson, Broad, & Bonita, 1999). The authors found that at six years post-stroke, stroke survivors only differed from a control group on the SF-36 physical functioning subscale, which is the same as in this study. In addition, a study carried out on ICH survivors involving 122 centres in 22 counties found that 87% of ICH survivors at 3-months post-ICH had a similar level of HRQoL to the general populations of those countries, and also those that did have a lower HRQoL were depressed (Christensen, Mayer, Ferran, & Kissela, 2009). The lack of difference between the two groups in this study

is consistent with these findings. Possible reasons for this are that the ICH group is made up of largely older adults where changes in body structure and function, activities and participation is an aspect of aging, therefore there is not such a significant departure from their expected roles and functioning.

When considering the role of demographics on the findings above, there were no effects of gender, education or age. Whilst there has not been any reported effect of education on HRQoL, age and gender have been reported as negatively influencing HRQoL following a stroke. Age (being over 70) has previously been identified as a factor in The Auckland Stroke Study (a population-based study) (Hackett, Duncan, Anderson, Broad, & Bonita, 1999), but this was a study of stroke outcomes, not ICH outcomes, so age being a factor is possibly more reflective of other sub-types of stroke. Advanced age was identified amongst ICH survivors as being a predictor of poorer health quality of life however, this outcome was related to recovery at three months post ICH. Gender was also identified as a factor in the North East Melbourne Stroke Incidence Study (also a population-study) (Sturm, Donnan, & Dewey, 2004). However, this study measured outcomes at one year and only reported findings relating to stroke as a whole rather than to sub-types of stroke; it is not known whether, or not, this was a common finding amongst ICH survivors.

4.2 Change over Time in the ICH Group

Using data previously gathered during the ARCOS study, it was possible to examine whether there had been significant changes in activities, mood and HRQoL for the ICH group from a measure taken a baseline (at the time of ICH), and at one month and six months post-ICH. There was significant improvement in the level of dependence on others for activities such as toileting, dressing, and mobility in ICH survivors from one month to five years post-ICH. For the BI, this change was more reflective of improvement, rather than of total recovery, as the BI at five years revealed that, in comparison to the control group, there was still significant dependence on others in activities after five years. There was a significant drop in the level of IADLs performed (i.e. gardening, making meals, housework

etc) according to the FAI between the baseline reports of pre-ICH functioning and six months post-ICH functioning. This suggests that at six months post-ICH, survivors experienced a significant decline in carrying out IADLs. There was no significant difference between the level of engagement in IADLs between baseline, and five years post-ICH according to the FAI. However, the means for the two time points suggest that the ICH group do not return to their pre-ICH level of functioning. Recovery in ADLs has been documented in both the stroke and ICH literature. Withall, Brodaty, Altendorf, and Sachdev (2009) reported that in over the course of one year, the population-based Sydney Stroke Study stroke survivors experienced improvement in their ADLs. Similar findings were reported in the South London Stroke Study (Patel, 2001). However, neither of these studies reported their findings by stroke sub-type.

Interestingly there was no change in the MRS from one month, to six months to five years. It is important to note that the MRS is considered a global measure and whilst it can detect a difference between those who have experienced an ICH and those who have not (as it has done in this study), it may not be sensitive enough to detect nuances in recovery that the BI and FAI have done. Similarly, there was no significant difference between the GHQ-28 subscales measured at one month, six months or five years post-ICH. Given that symptoms of depression were being experienced by the ICH group but had not been detected by the GHQ-28, it is possible that, similarly to the MRS, the GHQ-28 is not sensitive to more subtle types of change. Given that the SF-36 mental health score was significantly worse at five years post-ICH in comparison to six months post ICH, it is possible that there is a decline in mental well-being to which the GHQ-28 is insensitive. According to the findings from the SF-36, there was no gross change in the HRQoL experienced by the ICH survivors from six months to five years, but a decline in mental health was significant. This is consistent with aging were a decline in mental well being is associated with increasing age due to factors such as loss of social supports, increased limitation in activites and decreasing health (DSM-IV, APA). Another significant finding of the SF-36 was an

improvement in physical functioning, this index is more reflective of engagement in physical activities and is similar to the findings of the FAI and BI.

It was also found that there were no effects of demographics such as age, gender and education on the performance recorded by the different measures at the varying time points. This finding contrasts with a population-based study of stroke (Pater, McKevitt, Lawrence, Rudd, & Wolfe, 2007) where, at one and three years, stroke survivors who were female, and those under the age of 65, were found to have poorer HRQoL. However, this study refers to stroke and not to ICH in particular; it also measured HRQoL at different time points than the present study. The Sydney Stroke Study (Withall, Brodaty, Altendorf, & Sachdev, 2009) found that those who were older tended to achieve less recovery in ADLs over a year, but found no effect for gender or education. However, a population-based study in Auckland between 1991-2 found that three years post-stroke, males were more likely to experience problems in ALDs. Whist these studies highlight the role of age, gender and education, they all refer to stroke and are measuring recovery at different time points. It is possible that demographic factors are less important in outcomes of ICH at five years post-ICH.

4.3 Relationships between Body Structure and Function, Activities and Participation Five Years post-ICH

Neurological functioning and neuropsychological functioning appear to be linked. In this study, poorer neurological functioning is associated with poorer information processing, executive functioning, verbal and visual memory, language and poorer overall cognitive functioning at five years. It has been previously reported that neuropsychological and neurological findings are co-morbid in ICH (Wiebers, Feigin & Brown, 2006). However, until now the relationship between neurological functioning and neuropsychological functioning has not been reported in ICH survivors or in the wider stroke literature.

There were a number of areas of cognition that were correlated with one another. Those who have better speeds of information processing have increased performance in

visual memory and visuoperception, and increased performance in verbal memory is associated with improved executive functioning, visual memory and visuopercpetion. These associations have not been documented in the literature before.

Mood and neurological functioning were not correlated. However, mood appeared to be associated with decreased cognition; reduced visuoperception and increased overall cognitive impairment were associated with increased rates of depressive symptoms. With regards to the lack of correlation between neurological functioning and mood this is not consistent with the stroke literature. Deficits in movement of limbs at one year are correlated with low mood (van de Port Kwakkel, Bruin & Linderman, 2007). Amongst those with an ICH, people who had a severe to moderate neurological impairment were more likely to have symptoms of depression at three months (Christensen, Mayer, Ferran, & Kissela, 2009). However, these findings relate to stroke and ICH survivors at very different time points within their recovery, in comparison to this study, and were not population-based. In addition, there is no certainty that stroke studies are reflective of outcomes relevant to ICH survivors. Further, the ICH study that links neurological impairment and depression relates to the very early stages of recovery where depression rates are higher (Christensen, Mayer, & Ferran, 2009) and survivors are in the midst of adjusting to what has occurred. It is possible that after five years, neurological impairment is not related to mood as ICH survivors have adapted to the change in the functioning of their body functioning.

In terms of neuropsychological functioning there was a significant correlation with mood. Poorer visual memory and greater overall impairment were associated with increased rates of depressive symptoms as measured by the GDS-SF at five years post ICH. Previous research on stroke has found correlations between neuropsychological deficits and depression at three months (Hoskng, March, & Friedman, 1996) and one year post-stroke (Rasquin, Lodder, & Ponds, 2004; Kauhanen, et al.1999).

There was a correlation between GHQ-28 anxiety and depression scale scores and the GDS-SF. Although there was no significant difference on the GHQ-28 anxiety scale between the ICH and matched control group, depression in ICH survivors did appear to be

linked to higher rates of anxiety symptoms. Post-stroke anxiety has been found to be co-morbid in stroke survivors who have depression at three years (Astrom, 1996). The correlation between the GDS-SF and GHQ-28 depression scales is expected given that they are both measuring depressed mood. There was also a correlation between anxiety and an increased incidence of somatic symptoms. Given that anxiety frequently has physical symptoms, this relationship is understandable. Further in older adults anxiety is frequently displaced into somatising behaviour (DSM-IV, APA)

With regard to the impact of neurological impairment on activities and participation, there were no significant correlations between the NHISS and any of the measures of activities and participation. This is a surprising finding given that there is an assumption that impairment in neurological functioning is what causes limitation in activities and participation. However, the NIHSS is a global measure that includes items across a variety of different components of neurological functioning; three of which relate to language and another to gaze and ability to recognise different items. It is possible that the measure includes items that dilute aspects of neurological functioning that are predominantly associated with outcomes relating to activities and participation, such as mobility, therefore reducing any possible relationship. It is also possible that the factors the ICF identifies as contextual such as personal factors (age, gender, personality) and the environment have a large moderating or mediating effect on the influence of neurological deficit on engagement in activities and participation.

Interestingly there were also no relationships between measures of ADLs and neuropsychological functioning. Within the wider stroke literature there is inconsistency in the role of cognition in the performance of ADLs. However problems with memory, visuospatial and executive functioning, attention and global cognition, have been associated with decreased ADLs. (Mercier, Audet, Herbert, Rochette, & Dubois, 2001; Stephens et al. 2005). However, none of the studies that examine the role of cognitive functioning in ADLs examined this relationship in ICH survivors or at five years post the stroke. In addition, this

study supports previous findings that there is no relationship between the two (Cederfeltac, Grosman-Hedstromac, Savborgb & Tarkowskibd, 2009).

When considering the relationship between neuropsychological functioning and HRQoL, executive functioning was found to influence a number of areas of HRQoL as measured by the SF-36. Poorer executive functioning was associated with difficulties in fulfilling roles related to physical functioning and emotional functioning. In addition, those with poorer executive functioning had greater difficulty in social functioning and decreased MCS (however social functioning is a sub-scale that contributes to the MCS). Also, both poorer executive functioning and slower information processing speed was associated with greater difficulty in participating in life roles, as measured by the LHS. Poorer information processing speed was also negatively correlated with overall physical HRQoL There has been one population-based study of stroke survivors where the relationship between cognition and outcomes of the SF-36 has been explored. Here Pater, McKeitt, Lawrence, Rudd and Wolfe, (2007) found that cognitive impairment was associated with poorer outcomes on the physical and mental component scores of the SF-36 at one year post-stroke. However, they did not differentiate between areas of cognitive functioning, nor were the results reported according to sub-type. According to the SF-36, better executive function may allow the ICH survivor to more successfully solve problems and organise their lives in order to meet their expectations regarding roles they wish to fulfil and thus to enjoy greater overall mental well being. In addition, for a variety of reasons, those who experience greater problems with executive functioning may experience difficulties in social functioning, such as difficulties with arranging to meet up with others. Another reason may be that part of the problem with executive function may be a reduction in social awareness. It may not be as pleasant for others to be around them so they are not involved in social activities to the same extent as those who do not have problems with executive functioning. In another measure of poor executive functioning and participation, information processing was also negatively correlated with LHS, indicating that deficits in these areas cause problems in participating in a broad range of areas of their life. Problems in this area pertaining to executive functioning

have been highlighted above. The role that processing speed may have in this is that having problems in this area can make it difficult for an individual to keep up with the delivery of information and the ability to make a response mentally or physically within an appropriate time frame; this affects their ability to participate fully in society.

When considering the role of mood in activities and participation, depression and anxiety were found to play a role. Those who are less dependent on others (BI) are less likely to experience symptoms of depression (GDS-SF) It also appears that they are less likely to experience symptoms of anxiety. In engaging in IADLs, those who experience less depressive symptoms engage more frequently in instrumental activities such as gardening, preparing meals and shopping, as assessed by the FAI. The relationship between depression and activities has been well documented within the stroke literature and the findings in this study concur with findings for stroke survivors at three and six months post-stroke (Chemerinski, Robinson, & Koiser, 2001). While the findings of the present study help to establish this depression/activity relationship as occurring in ICH survivors, this requires further confirmation.

Mood was also found to be related to aspects of HRQoL, as measured by the SF-36. Those who fewer symptoms of anxiety (GHQ-28) and depression (GDS-SF) were more likely to perceive they had better general health and mental health. In addition, those who had more depressive symptoms, as measured by the GDS-SF, were more likely to have poorer overall physical and mental HRQoL and increased rates of body pain. These findings are similar to those of the North East Melbourne Stroke Incidence study (Sturm, Donnan, & Dewey, 2004) which found that depression was associated with poorer physical quality of life. Another aspect of mood; the experience of somatic complaints as measured by the GHQ-28 also appeared to affect quality of life. Interestingly, those who reported greater somatic symptoms (GHQ-28) also experienced a decrease in their sense of vitality and poorer social functioning. It was also found that increased rates of depressed symptoms were associated with greater limitations in roles due to emotional problems and poorer overall mental HRQoL, as measured by the MCS. These findings make sense as lower

mood can result in reports of lowered well-being and poor well-being often resulting in a report of lowered mood. However, findings relating to the profile of mood in relation to ICH survivors HRQoL have not been highlighted until now.

The relationship between activities and participation was also explored in this research. The WHO (2002) identified that there is fluidity between these two areas and overlap is likely. There was a correlation between the FAI, BI and MRS indicating that those who are less likely to engage in basic and instrumental activities are also more likely to be dependent on others and experience greater global disability. The FAI and MRS correlated with the LHS. This is unsurprising given that the LHS also measures aspects of activities such as mobility. However, it also measures economic self-sufficiency, social integration and independence indicating that those who have limitations in their ability to engage in ADLs and IADLs, also have difficulties in participating in life situations. Those who had difficulty in the areas measured by the LHS also had poorer general health on the SF-36. The SF-36 physical functioning score (PF), and physical component score (PCS) were correlated with the BI FAI, MRS, and LHS. Frequently these correlations were very high, as these variables, all measure function related to physical ability this is not too surprising. The PF is a component sub-scale of the PCS. The PF scale contains questions that relate to activities, so the PF and PCS correlation with the BI FAI, MRS, and LHS is likely to be reflective of that. Within measures of participation, increased vitality (SF-36 VT) was associated with increased social functioning, according to the GHQ-28; a similar finding neared significance on the SF-36 SF. This suggests that those who feel as though they have more energy are more socially active. Within the SF-36, there were many correlations between the sub-scales. Those with better mental HRQoL had better, social functioning, general health, had less body pain and felt more vital in their lives. They were also less likely to experience problems in meeting expectations associated with physical and emotional life roles. Those with better physical HRQoL had better physical functioning, less body pain, felt more vital in their lives, engaged in more social activities and had better mental and general health. They were also less likely to encounter difficulties in engaging in

expectations around physical and emotional roles. A sense of vitality also appeared to be important in HRQoL as an increased sense of vitality was also associated with less body pain and better general health. The finding of this study that limitations in activities and a reduction in HRQoL, concurs with the findings of the North East Melbourne Stroke Study (Sturm, Donnan, & Dewey, 2004) where limitations in activity were found to reduce HRQoL at two years post-stroke. However, this study is the first to explore this relationship in ICH survivors.

4.4 Clinical Implications.

This is the first population-based study to examine the long-term (five-year) outcomes of primary ICH, in relation to body structure and function, activities and participation when contrasted to a matched control group. The findings suggest that the effects of ICH are far reaching and ICH survivors continue to experience difficulties in neurological functioning particularly executive functioning, and information processing. They are also more likely to experience symptoms of depression. In addition, they continue to experience significant limitations in activities and restrictions in their ability to participate. They also experience poorer HRQoL in relation to their physical difficulties, but are relatively unaffected in other areas of HRQoL. Interestingly, difficulties in ADLS, IADLs, and in some areas of HRQoL, appear to be unrelated to neurological functioning (as measured by the NIHSS), suggesting that mood and the interplay between carrying out activities and HRQoL have a greater effect on a person's engagement in activities and participation than actual neurological function at a basic level.

To date, there has been a lack of information available as to the kinds of outcomes likely to be experienced following an ICH, and almost none with regard to long-term outcomes. This study provides information for clinicians, ICH survivors, and scientists regarding a broad spectrum of possible outcomes. The findings from this research suggest that a long-term view should be taken toward rehabilitation or interventions that assist the ICH survivor in mitigating or managing the outcomes of ICH. In the later stages of recovery,

(i.e. 5-years post-ICH) improving mood, and engaging in social activities may make a significant contribution to those who are experiencing poor HRQoL. In addition, assistance in achieving greater independence in ADLs (e.g. through homes aids) may also improve outcomes. Given that engagement in recovery frequently reduces following discharge from rehabilitation, and that there is often an ensuing reduction in ADLs, it may be useful to have booster sessions for recovery where the factors limiting engagement in ADLs can be tackled.

4.4 Limitations and Strengths of this Study

Limitations

During the recruitment phase, there were a proportion of participants who could not be contacted (34%) and of the original sample who participated in the initial ARCOS study; only 27% of that original group took part in this study. However, it is common for longitudinal studies to have a much smaller population than at the original start point (Srikanth, Quinn, Donnan, Saling, & Thrift, 2006) and given that the sensitivity analysis showed that this group was not different from those who declined to take part in terms of stroke severity, age, gender, or ethnicity, the problems associated with this have been mitigated to some extent.

A further limitation to this study is the lack of a pre-morbid estimation of each ICH participant's cognitive performance. Frequently pre-morbid estimations of ability are gleaned from performance on verbal tests or tests of reading. Estimating pre-morbid ability in the manner presents problems in New Zealand. Barker-Collo, Bartle, Clarke, van Toledo, Vykopal and Willets (2008) explored two commonly used tests to estimate pre-morbid ability the National Audit Reading Test (NART) and Spot the Word (STW). They found that in New Zealand, that the likelihood of the tests correctly predicting cognitively ability as measured by the WAIS-III varied according to cultural background. In addition, there was a regression towards the mean when estimating pre-morbid ability meaning the NART and STW over estimated low cognitive ability and under estimated high cognitive ability. A further difficulty with accurately estimating pre-morbid ability in stroke survivors using tests is that many of

the tests are language based which is one of the areas that is most affected by stroke and so performance is unlikely to be indicative of pre-morbid performance.

A further limitation of this study was that there was a considerable demand on the participants' time and the battery of tests was burdensome. This may have deterred some ICH participants from taking part and subsequently been a factor in reducing the sample size. It is also possible that this was a reason for some of the postal questionnaires not being returned. However, the breadth of the tests used can also be seen as one of this study's strengths as this allowed a fuller picture of overall outcomes for this patient group.

As mentioned previously, there were a number of ICH participants who were too impaired to complete the tests for neuropsychological functioning. This means that the overall level of cognitive impairment is likely to have been understated. In addition, the role that neuropsychological functioning has on other areas, such as activities and participation, may have also been understated as correlations were generated based on those who could complete the neuropsychological assessments. A further limitation of this study is that, although it is a population-based study, the sample size is small which limited the nature of statistical analysis. It was not possible to explore predictive relationships between the variables at five years, and due to the risk of type one errors, it was not possible to carryout correlations between measures taken at baseline, one month and six months, to explore how early outcomes may impact later outcomes at five years.

Strengths

There are a number of strengths to this study. Probably the most significant is that this is the first study to comprehensively explore long-term outcomes of ICH. In addition, the study was undertaken using a population-based ICH sample and a matched control group. As a population based study, we can expect to have garnered a better picture of actual ICH outcomes as the study was not limited to those who needed rehabilitation or extensive inpatient care that is what has occurred in other studies. The inclusion of matched controls allows the exclusion of a number of variables that are well known to impact studies of

comparison exploring outcomes of stroke. This study has also bridged the gap between the ICIDH model and the ICF model and has fitted well-known measures of stroke into the categories of the ICF. In addition, several measures have been used to explore the outcomes within each domain. It transpires that this is particularly significant for the understanding of nuances in outcomes within neuropsychological functioning, where some tests proved sensitive to deficits, while others did not. Further, the use of well-known tests, particularly within the domain of neuropsychology, means that clinicians will have a good understanding of the outcomes.

4.6 Future Directions for Research

At the beginning of this research, it had been hoped that differences in the ICH group relating to lesion location and hematoma size, and level of consciousness at admission could be explored, as these factors have been shown to influence outcomes in ICH survivors (Rost, et al. 2008). However, recording of hematoma size and lesion location was variable and often, unavailable, thus an examination of these variables was not pursued. Nevertheless, these variables have frequently been identified as predictors of outcomes in ICH and therefore warrant further exploration.

Given the small sample size, it was also not possible to examine predictive relationships between the data collected at earlier stages of the ARCOSS study and the five-year outcomes assessed here. By having a larger sample size, these relationships could be better understood. It would be possible to look at whether individual items on scales examining activities and participation, such as the ability to feed oneself independently, or to be independent in toileting, have predictive relationships with other outcomes such as social functioning or mood. Having a clear understanding of such relationships can assist clinicians in structuring rehabilitation programmes which target areas predictive of outcomes.

One of the areas not fully explored in this study is the aspect of the ICF model that describes contextual factors such as the person's environment and themselves personally on the outcomes of body structure and function, activities and participation.

An area that also warrants further exploration is the impact of the process of psychological adaptation on the chronic outcomes of ICH. Psychological adaptation to the chronic outcomes of a stroke is a process that almost all stroke survivors have to undertake (Joanna Briggs Institute, 2009). It would be interesting to explore how variations in the ability to adapt affect outcomes in body structure and function, activities and participation. Finally, the findings of this study would benefit from confirmation by studies in other ICH populations.

4.6 Conclusion

This research highlights the fact that those who survive a primary ICH still continue to experience a wide variety of difficulties across a number of areas five years following the haemorrhage. They continue to face problems in the functioning of their body, in cognition and are more likely to experience symptoms of depression. They also experience problems in activities of daily living and restriction in behaviours associated with participating in their lives and in society. However, HRQoL remains largely unaffected apart from the areas where physical abilities are concerned. In the course of the study, relationships were found between outcomes; poorer neurological functioning was found to be correlated with deficits in information, processing speed, and greater overall cognitive impairment. In addition, it was found that deficits in information processing speed and executive functioning reduced HRQoL, and that those with depressed mood were more likely to have difficulties in ADLs and a poorer HRQoL in some areas. There were no differences associated with age, gender or education in neurological function, mood activities, or participation and only for education in preserving cognitive function. When considering performance on measures over time, there was generally an improvement in the level of engagement with ADLs, however there was no change in HRQoL

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Appendix A:

Measures of Body Structure and Function

NIH STROKE SCALE

Patient Identification. ___ ___-___ ___ ___-___ ___ ___

Pt. Date of Birth ___ ___/___ ___/___ ___

Hospital _____(___ ___-___ ___)

Date of Exam ___ ___/___ ___/___ ___

Interval: [ ] Baseline [ ] 2 hours post treatment [ ] 24 hours post onset of symptoms ±20 minutes [ ] 7-10 days
[ ] 3 months [ ] Other _____(___ ___)

Time: ___ ___:___ ___ [ ]am [ ]pm

Person Administering Scale _____

Administer stroke scale items in the order listed. Record performance in each category after each subscale exam. Do not go back and change scores. Follow directions provided for each exam technique. Scores should reflect what the patient does, not what the clinician thinks the patient can do. The clinician should record answers while administering the exam and work quickly. Except where indicated, the patient should not be coached (i.e., repeated requests to patient to make a special effort).

Instructions	Scale Definition	Score
1a. Level of Consciousness: The investigator must choose a response if a full evaluation is prevented by such obstacles as an endotracheal tube, language barrier, orotracheal trauma/bandages. A 3 is scored only if the patient makes no movement (other than reflexive posturing) in response to noxious stimulation.	0 = **Alert;** keenly responsive. 1 = **Not alert**; but arousable by minor stimulation to obey, answer, or respond. 2 = **Not alert**; requires repeated stimulation to attend, or is obtunded and requires strong or painful stimulation to make movements (not stereotyped). 3 = Responds only with reflex motor or autonomic effects or totally unresponsive, flaccid, and areflexic.	_____
1b. LOC Questions: The patient is asked the month and his/her age. The answer must be correct - there is no partial credit for being close. Aphasic and stuporous patients who do not comprehend the questions will score 2. Patients unable to speak because of endotracheal intubation, orotracheal trauma, severe dysarthria from any cause, language barrier, or any other problem not secondary to aphasia are given a 1. It is important that only the initial answer be graded and that the examiner not "help" the patient with verbal or non-verbal cues.	0 = **Answers** both questions correctly. 1 = **Answers** one question correctly. 2 = **Answers** neither question correctly.	_____
1c. LOC Commands: The patient is asked to open and close the eyes and then to grip and release the non-paretic hand. Substitute another one step command if the hands cannot be used. Credit is given if an unequivocal attempt is made but not completed due to weakness. If the patient does not respond to command, the task should be demonstrated to him or her (pantomime), and the result scored (i.e., follows none, one or two commands). Patients with trauma, amputation, or other physical impediments should be given suitable one-step commands. Only the first attempt is scored.	0 = **Performs** both tasks correctly. 1 = **Performs** one task correctly. 2 = **Performs** neither task correctly.	_____
2. Best Gaze: Only horizontal eye movements will be tested. Voluntary or reflexive (oculocephalic) eye movements will be scored, but caloric testing is not done. If the patient has a conjugate deviation of the eyes that can be overcome by voluntary or reflexive activity, the score will be 1. If a patient has an isolated peripheral nerve paresis (CN III, IV or VI), score a 1. Gaze is testable in all aphasic patients. Patients with ocular trauma, bandages, pre-existing blindness, or other disorder of visual acuity or fields should be tested with reflexive movements, and a choice made by the investigator. Establishing eye contact and then moving about the patient from side to side will occasionally clarify the presence of a partial gaze palsy.	0 = **Normal.** 1 = **Partial gaze palsy;** gaze is abnormal in one or both eyes, but forced deviation or total gaze paresis is not present. 2 = **Forced deviation,** or total gaze paresis not overcome by the oculocephalic maneuver.	_____

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N I H STROKE SCALE

Patient Identification. ___ ___-___ ___ ___-___ ___ ___

Pt. Date of Birth ___ ___/___ ___/___ ___

Hospital _____(___ ___-___ ___)

Date of Exam ___ ___/___ ___/___ ___

Interval: [ ] Baseline [ ] 2 hours post treatment [ ] 24 hours post onset of symptoms ±20 minutes [ ] 7-10 days
[ ] 3 months [ ] Other _____(___ ___)

3. Visual: Visual fields (upper and lower quadrants) are tested by confrontation, using finger counting or visual threat, as appropriate. Patients may be encouraged, but if they look at the side of the moving fingers appropriately, this can be scored as normal. If there is unilateral blindness or enucleation, visual fields in the remaining eye are scored. Score 1 only if a clear-cut asymmetry, including quadrantanopia, is found. If patient is blind from any cause, score 3. Double simultaneous stimulation is performed at this point. If there is extinction, patient receives a 1, and the results are used to respond to item 11.	0 = **No visual loss.** 1 = **Partial hemianopia.** 2 = **Complete hemianopia.** 3 = **Bilateral hemianopia** (blind including cortical blindness).	_____
4. Facial Palsy: Ask – or use pantomime to encourage – the patient to show teeth or raise eyebrows and close eyes. Score symmetry of grimace in response to noxious stimuli in the poorly responsive or non-comprehending patient. If facial trauma/bandages, orotracheal tube, tape or other physical barriers obscure the face, these should be removed to the extent possible.	0 = **Normal** symmetrical movements. 1 = **Minor paralysis** (flattened nasolabial fold, asymmetry on smiling). 2 = **Partial paralysis** (total or near-total paralysis of lower face). 3 = **Complete paralysis** of one or both sides (absence of facial movement in the upper and lower face).	_____
5. Motor Arm: The limb is placed in the appropriate position: extend the arms (palms down) 90 degrees (if sitting) or 45 degrees (if supine). Drift is scored if the arm falls before 10 seconds. The aphasic patient is encouraged using urgency in the voice and pantomime, but not noxious stimulation. Each limb is tested in turn, beginning with the non-paretic arm. Only in the case of amputation or joint fusion at the shoulder, the examiner should record the score as untestable (UN), and clearly write the explanation for this choice.	0 = **No drift;** limb holds 90 (or 45) degrees for full 10 seconds. 1 = **Drift;** limb holds 90 (or 45) degrees, but drifts down before full 10 seconds; does not hit bed or other support. 2 = **Some effort against gravity;** limb cannot get to or maintain (if cued) 90 (or 45) degrees, drifts down to bed, but has some effort against gravity. 3 = **No effort against gravity;** limb falls. 4 = **No movement.** UN = **Amputation** or joint fusion, explain: _____ **5a. Left Arm** **5b. Right Arm**	_____ _____
6. Motor Leg: The limb is placed in the appropriate position: hold the leg at 30 degrees (always tested supine). Drift is scored if the leg falls before 5 seconds. The aphasic patient is encouraged using urgency in the voice and pantomime, but not noxious stimulation. Each limb is tested in turn, beginning with the non-paretic leg. Only in the case of amputation or joint fusion at the hip, the examiner should record the score as untestable (UN), and clearly write the explanation for this choice.	0 = **No drift;** leg holds 30-degree position for full 5 seconds. 1 = **Drift;** leg falls by the end of the 5-second period but does not hit bed. 2 = **Some effort against gravity;** leg falls to bed by 5 seconds, but has some effort against gravity. 3 = **No effort against gravity;** leg falls to bed immediately. 4 = **No movement.** UN = **Amputation** or joint fusion, explain: _____ **6a. Left Leg** **6b. Right Leg**	_____

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NIH STROKE SCALE

Patient Identification. ___ ___-___ ___ ___-___ ___ ___

Pt. Date of Birth ___ ___/___ ___/___ ___

Hospital _____(___ ___-___ ___)

Date of Exam ___ ___/___ ___/___ ___

Interval: [ ] Baseline [ ] 2 hours post treatment [ ] 24 hours post onset of symptoms ±20 minutes [ ] 7-10 days
[ ] 3 months [ ] Other _____(___ ___)

7. Limb Ataxia: This item is aimed at finding evidence of a unilateral cerebellar lesion. Test with eyes open. In case of visual defect, ensure testing is done in intact visual field. The finger-nose-finger and heel-shin tests are performed on both sides, and ataxia is scored only if present out of proportion to weakness. Ataxia is absent in the patient who cannot understand or is paralyzed. Only in the case of amputation or joint fusion, the examiner should record the score as untestable (UN), and clearly write the explanation for this choice. In case of blindness, test by having the patient touch nose from extended arm position.	0 = **Absent.** 1 = **Present in one limb.** 2 = **Present in two limbs.** UN = **Amputation** or joint fusion, explain: _____	_____
8. Sensory: Sensation or grimace to pinprick when tested, or withdrawal from noxious stimulus in the obtunded or aphasic patient. Only sensory loss attributed to stroke is scored as abnormal and the examiner should test as many body areas (arms [not hands], legs, trunk, face) as needed to accurately check for hemisensory loss. A score of 2, "severe or total sensory loss," should only be given when a severe or total loss of sensation can be clearly demonstrated. Stuporous and aphasic patients will, therefore, probably score 1 or 0. The patient with brainstem stroke who has bilateral loss of sensation is scored 2. If the patient does not respond and is quadriplegic, score 2. Patients in a coma (item 1a=3) are automatically given a 2 on this item.	0 = **Normal;** no sensory loss. 1 = **Mild-to-moderate sensory loss;** patient feels pinprick is less sharp or is dull on the affected side; or there is a loss of superficial pain with pinprick, but patient is aware of being touched. 2 = **Severe to total sensory loss;** patient is not aware of being touched in the face, arm, and leg.	_____
9. Best Language: A great deal of information about comprehension will be obtained during the preceding sections of the examination. For this scale item, the patient is asked to describe what is happening in the attached picture, to name the items on the attached naming sheet and to read from the attached list of sentences. Comprehension is judged from responses here, as well as to all of the commands in the preceding general neurological exam. If visual loss interferes with the tests, ask the patient to identify objects placed in the hand, repeat, and produce speech. The intubated patient should be asked to write. The patient in a coma (item 1a=3) will automatically score 3 on this item. The examiner must choose a score for the patient with stupor or limited cooperation, but a score of 3 should be used only if the patient is mute and follows no one-step commands.	0 = **No aphasia;** normal. 1 = **Mild-to-moderate aphasia;** some obvious loss of fluency or facility of comprehension, without significant limitation on ideas expressed or form of expression. Reduction of speech and/or comprehension, however, makes conversation about provided materials difficult or impossible. For example, in conversation about provided materials, examiner can identify picture or naming card content from patient's response. 2 = **Severe aphasia;** all communication is through fragmentary expression; great need for inference, questioning, and guessing by the listener. Range of information that can be exchanged is limited; listener carries burden of communication. Examiner cannot identify materials provided from patient response. 3 = **Mute, global aphasia;** no usable speech or auditory comprehension.	_____
10. Dysarthria: If patient is thought to be normal, an adequate sample of speech must be obtained by asking patient to read or repeat words from the attached list. If the patient has severe aphasia, the clarity of articulation of spontaneous speech can be rated. Only if the patient is intubated or has other physical barriers to producing speech, the examiner should record the score as untestable (UN), and clearly write an explanation for this choice. Do not tell the patient why he or she is being tested.	0 = **Normal.** 1 = **Mild-to-moderate dysarthria;** patient slurs at least some words and, at worst, can be understood with some difficulty. 2 = **Severe dysarthria;** patient's speech is so slurred as to be unintelligible in the absence of or out of proportion to any dysphasia, or is mute/anarthric. UN = **Intubated** or other physical barrier, explain:_____	_____

Rev 10/1/2003

N I H STROKE SCALE

Patient Identification. ___ ___-___ ___ ___-___ ___ ___

Pt. Date of Birth ___ ___/___ ___/___ ___

Hospital _____(___ ___-___ ___)

Date of Exam ___ ___/___ ___/___ ___

Interval: [ ] Baseline [ ] 2 hours post treatment [ ] 24 hours post onset of symptoms ±20 minutes [ ] 7-10 days
[ ] 3 months [ ] Other _____(___ ___)

11. Extinction and Inattention (formerly Neglect): Sufficient information to identify neglect may be obtained during the prior testing. If the patient has a severe visual loss preventing visual double simultaneous stimulation, and the cutaneous stimuli are normal, the score is normal. If the patient has aphasia but does appear to attend to both sides, the score is normal. The presence of visual spatial neglect or anosagnosia may also be taken as evidence of abnormality. Since the abnormality is scored only if present, the item is never untestable.	0 = **No abnormality.** 1 = **Visual, tactile, auditory, spatial, or personal inattention** or extinction to bilateral simultaneous stimulation in one of the sensory modalities. 2 = **Profound hemi-inattention or extinction to more than one modality;** does not recognize own hand or orients to only one side of space.	_____

_____

_____

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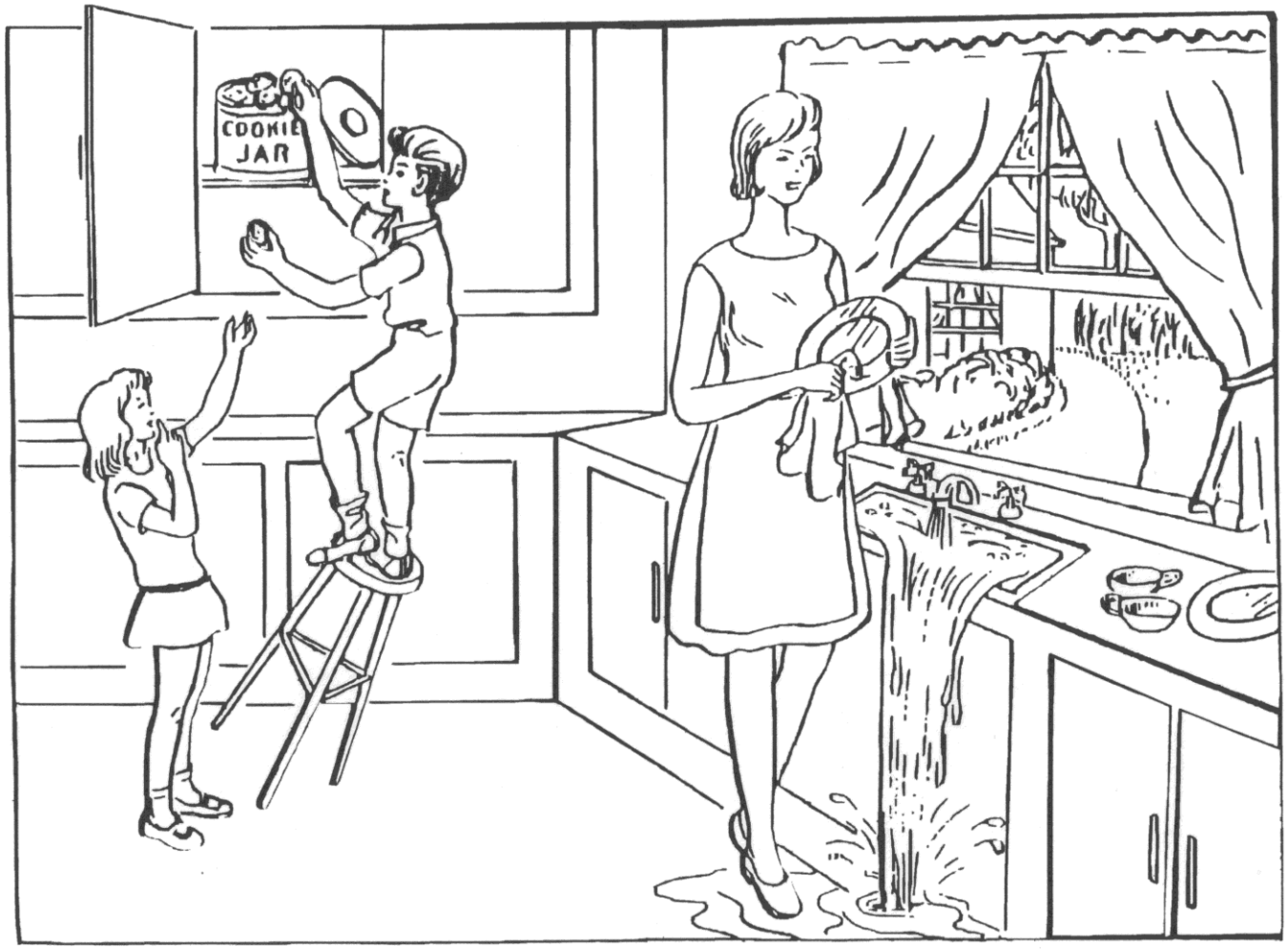
COOKIE
JAR

You know how.

Down to earth.

I got home from work.

Near the table in the dining room.

They heard him speak on the radio last night.

MAMA

TIP – TOP

FIFTY – FIFTY

THANKS

HUCKLEBERRY

BASEBALL PLAYER

Geriatric Depression Scale (short form)

Instructions: Circle the answer that best describes how you felt over the past week.

1.	Are you basically satisfied with your life?	yes	no
2.	Have you dropped many of your activities and interests?	yes	no
3.	Do you feel that your life is empty?	yes	no
4.	Do you often get bored?	yes	no
5.	Are you in good spirits most of the time?	yes	no
6.	Are you afraid that something bad is going to happen to you?	yes	no
7.	Do you feel happy most of the time?	yes	no
8.	Do you often feel helpless?	yes	no
9.	Do you prefer to stay at home, rather than going out and doing things?	yes	no
10.	Do you feel that you have more problems with memory than most?	yes	no
11.	Do you think it is wonderful to be alive now?	yes	no
12.	Do you feel worthless the way you are now?	yes	no
13.	Do you feel full of energy?	yes	no
14.	Do you feel that your situation is hopeless?	yes	no
15.	Do you think that most people are better off than you are?	yes	no

Total Score _____

GENERAL HEALTH QUESTIONNAIRE

We would like to know if you have any medical complaints, and how your health has been in general, over the past few weeks. Please answer ALL questions on the following pages simply by ticking one block for the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those you have had in the past.

Have you recently….

(tick one block only)

		Better than usual	**Same as usual**	**Worse than usual**	**Much worse than usual**
1	Been feeling perfectly well and in good health?				

		Not at all	**No more than usual**	**Rather more than usual**	**Much more than usual**
2	Been feeling in need of a good tonic?				
3	Been feeling run down and out of sorts?				
4	Felt that you are ill?				
5	Been getting any pains in your head?				
6	Been getting a feeling of tightness or pressure in your head?				
7	Been having hot or cold spells?				
8	Lost much sleep over worry?				
9	Had difficulty in staying asleep?				
10	Felt constantly under strain?				
11	Been getting edgy and bad tempered?				
12	Been getting scared or panicky for no good reason?				
13	Found everything getting on top of you?				
14	Been feeling nervous and uptight?				

(tick one only)

		More so than usual	**Same as usual**	**Rather less than usual**	**Much less than usual**
15	Been managing to keep yourself busy and occupied?				

(tick one only)

		Quicker than usual	**Same as usual**	**Longer than usual**	**Much longer**
16	Been taking longer over the things you do?				

(tick one only)

		Better than most	**About the same**	**Less well than usual**	**Much less well**
17	Felt on the whole you were doing things well?				

(tick one only)

		More satisfied	**About the same**	**Less satisfied**	**Much less satisfied**
18	Been satisfied with the way you've carried out your tasks?				

(tick one only)

		More so than usual	Same as usual	Rather less than usual	Much less than usual
19	Felt that you were playing a useful part in things?				
20	Felt capable of making decisions about things?				
21	Been able to enjoy your normal day-to-day things?				

(tick one only)

		Not at all	No more than usual	Rather more than usual	Much more than usual
22	Been thinking of yourself as a worthless person?				
23	Felt that life is entirely hopeless?				
24	Felt that life isn't worth living?				

(tick one only)

		Definitely not	I don't Think so	Has crossed my mind	Definitely have
25	Thought of the possibility that you might do away with yourself?				

(tick one only)

		Not at all	No more than usual	Rather more than usual	Much more than usual
26	Found at times you couldn't do anything because your nerves were too bad?				
27	Found yourself wishing you were dead and away from it all?				

(tick one only)

		Definitely not	I don't think so	Has crossed my mind	Definitely have
28	Found that the idea of taking your own life kept coming into your mind?				

Appendix B:

Measures of Activities and Participation

MODIFIED RANKIN SCALE (MRS)

Patient Name: _____
Rater Name: _____
Date: _____

Score	Description
0	No symptoms at all
1	No significant disability despite symptoms; able to carry out all usual duties and activities
2	Slight disability; unable to carry out all previous activities, but able to look after own affairs without assistance
3	Moderate disability; requiring some help, but able to walk without assistance
4	Moderately severe disability; unable to walk without assistance and unable to attend to own bodily needs without assistance
5	Severe disability; bedridden, incontinent and requiring constant nursing care and attention
6	Dead

TOTAL (0–6): _____

References

Rankin J. "Cerebral vascular accidents in patients over the age of 60."
Scott Med J 1957;2:200-15

Bonita R, Beaglehole R. "Modification of Rankin Scale: Recovery of motor function after stroke."
***Stroke* 1988 Dec;19(12):1497-1500**

Van Swieten JC, Koudstaal PJ, Visser MC, Schouten HJ, van Gijn J. "Interobserver agreement for the assessment of handicap in stroke patients."
***Stroke* 1988;19(5):604-7**

BARTHEL (ADL) INDEX

The next series of questions relate to your current level of activity: **(tick one box only)**

1. Feeding

	Independent: Able to use any necessary device; feeds in a reasonable time; able to cut up food, use condiments, spread butter etc. on his/her own. Food may be placed within reach
	Need help: eg with cutting or spread butter
	Dependent: need to be fed

2. Bathing

	Independent: Able to wash self all over; may be by using shower, a full bath or standing and sponging all over. Includes getting into and out of bath, or shower room
	Dependent: Need some help with personal care

3. Grooming

	Independent: Doing all personal activities, eg. Washing hands and face, combing hair. Includes shaving and teeth. Not needing any help
	Dependent: Need some help with personal care

4. Dressing

	Independent: Able to dress, includes (buttons, zip, laces), getting clothes out of closet/ Drawers. No help needed at all, may use rail for stabalizing.
	Needs help: Need minor help verbal or physical managing clothes and balancing
	Dependent: Unable to dress without major assistance

5. Bowels

	Continent: If needs enema, suppository, must manage him/herself
	Occasional accident: Maximum once per 24 hours; needs help with device.
	Incontinent or catheterized and unable to manage

6. Bladder

	Continent: Able to use any device (e.g. catheter) if necessary
	Occasional accident: Maximum once per 24 hours; needs help with device
	Incontinent or catheterized and unable to manage

7. Toilet

	Independent: Able to handle clothes, wipe self, flush toilet, empty commode completely unaided. Able to get on and off alone.
	Needs help: Able to manage with minor help balancing, handling clothes or toilet paper. However, still ale to use toilet
	Dependent: Unable to manage without major assistance

8. Chair/Bed Transfers

	Independent: No help; includes locking wheelchair if necessary.
	Minimal help: Includes verbal supervision and minor physical help such as might be given by a not very strong spouse.
	Major help: Able to sit unaided, but needs much help (two people).
	Dependent: Needs hoist or complete lift by two people. Unable to sit.

9. Mobility on level surfaces

	Independent: May use any aid; speed is not important. Able to mobilise about house.
	Needs help: Verbal or physical supervision, including help up into walking frame or other help standing.
	Independent in wheelchair: Must be able to negotiate corners alone.
	Immobile: Including being wheeled by another.

10. Stairs

	Independent: Must carry walking aid if used
	Needs help: Physical or verbal supervision
	Unable: Needs lift (elevator), or cannot negotiate stairs

FRENCHAY ACTIVITY INDEX

These questions relate to your usual level of activities.

In the last **three months,** how often did you undertake:

		Never	**Under once weekly**	**1-2 times a week**	**Most days**
1	Preparing meals				
2	Washing up				

		Never	**1-2 times in 3 months**	**3-12 times in 3 months**	**At least weekly**
3	Washing clothes				
4	Light housework				
5	Heavy housework				
6	Local shopping				
7	Social outings				
8	Walking outside>15 mins				
9	Actively pursuing hobby				
10	Driving car/bus travel				

In the last **six months**, how often did you undertake:

		Never	**1-2 times months**	**3-12 times months**	**At least weekly**
11	Outings/car rides				

		None	**Light**	**Moderate**	**All necessary**
12	Gardening				
13	Household/car maintenance				

		None	**1 in 6 months**	**Less than 1 a fortnight**	**Over 1 a fortnight**
14	Reading books				

		None	**Up to 10 hours/week**	**10-30 hours/week**	**Over 30 hours/week**
15	Gainful work				

The London Handicap Scale

Overview: The London Handicap Scale can be used to determine the effect of chronic disorders on a person's functional ability using a self-completion questionnaire. The authors are from the Royal Free Hospital in London.

Development:

- Each degree of handicap along a 6-point interval was assigned a scale weight.
- The scale weights were assigned using conjoint analysis with the derivation process described on page 12.

Parameters:

(1) mobility: "getting around"

(2) physical independence: "looking after yourself"

(3) occupation: "work and leisure activities"

(4) social integration: "getting on with people"

(5) orientation: "awareness of your surroundings"

(6) economic self-sufficiency: "affording the things you need"

Parameter	Finding	Value
mobility	no disadvantage	0.071
	minimal disadvantage	0.038
	mild disadvantage	0.000
	moderate disadvantage	-0.036
	severe disadvantage	-0.072
	most severe disadvantage	-0.108
physical independence	no disadvantage	0.102
	minimal disadvantage	0.011
	mild disadvantage	-0.021
	moderate disadvantage	-0.053
	severe disadvantage	-0.057
	most severe disadvantage	-0.061
occupation	no disadvantage	0.099

	minimal disadvantage	-0.004
	mild disadvantage	-0.014
	moderate disadvantage	-0.024
	severe disadvantage	-0.035
	most severe disadvantage	-0.060
social integration	no disadvantage	0.063
	minimal disadvantage	0.035
	mild disadvantage	0.007
	moderate disadvantage	-0.022
	severe disadvantage	-0.029
	most severe disadvantage	-0.041
orientation	no disadvantage	0.109
	minimal disadvantage	-0.008
	mild disadvantage	-0.038
	moderate disadvantage	-0.051
	severe disadvantage	-0.063
	most severe disadvantage	-0.075
economic self sufficiency	no disadvantage	0.100
	minimal disadvantage	0.067
	mild disadvantage	0.033
	moderate disadvantage	-0.023
	severe disadvantage	-0.067
	most severe disadvantage	-0.111

from Table 1 page 13

London handicap scale = SUM(all 6 utility values) + 0.456

where:

- The sum of all "no disadvantage" values is 0.544 which when added to 0.456 gives 1.00.
- The sum of all "most severe disadvantage" values is –0.456 which when added to 0.456 gives 0.00.

SF-36(tm) Health Survey

Instructions for completing the questionnaire: Please answer every question. Some questions may look like others, but each one is different. Please take the time to read and answer each question carefully by filling in the bubble that best represents your response.

Patient Name: _____

SSN#: _____ Date: _____

Person heling to complete this form: _____

1. In general, would you say your health is:

- ❑ Excellent
- ❑ Very good
- ❑ Good
- ❑ Fair
- ❑ Poor

2. Compared to one year ago, how would you rate your health in general now?

- ❑ Much better now than a year ago
- ❑ Somewhat better now than a year ago
- ❑ About the same as one year ago
- ❑ Somewhat worse now than one year ago
- ❑ Much worse now than one year ago

3. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

a. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports.
- ❑ Yes, limited a lot.
- ❑ Yes, limited a little.
- ❑ No, not limited at all.

b. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf?
- ❑ Yes, limited a lot.
- ❑ Yes, limited a little.
- ❑ No, not limited at all.

c. Lifting or carrying groceries.
- ❑ Yes, limited a lot.
- ❑ Yes, limited a little.
- ❑ No, not limited at all.

d. Climbing several flights of stairs.
- ❑ Yes, limited a lot.
- ❑ Yes, limited a little.
- ❑ No, not limited at all.

e. Climbing one flight of stairs.
- ❑ Yes, limited a lot.
- ❑ Yes, limited a little.
- ❑ No, not limited at all.

f. Bending, kneeling or stooping.
- ❑ Yes, limited a lot.
- ❑ Yes, limited a little.
- ❑ No, not limited at all.

g. Walking more than one mile.
- ❑ Yes, limited a lot.
- ❑ Yes, limited a little.
- ❑ No, not limited at all.

h. Walking several blocks.
- ❑ Yes, limited a lot.
- ❑ Yes, limited a little.
- ❑ No, not limited at all.

i. Walking one block.
- ❑ Yes, limited a lot.
- ❑ Yes, limited a little.
- ❑ No, not limited at all.

j. Bathing or dressing yourself.
- ❑ Yes, limited a lot.
- ❑ Yes, limited a little.
- ❑ No, not limited at all.

4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

a. Cut down the amount of time you spent on work or other activities?
☐ Yes ☐ No

b. Accomplished less than you would like?
☐ Yes ☐ No

c. Were limited in the kind of work or other activities
☐ Yes ☐ No

d. Had difficulty performing the work or other activities (for example, it took extra time)
☐ Yes ☐ No

5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

a. Cut down the amount of time you spent on work or other activities?
☐ Yes ☐ No

b. Accomplished less than you would like
☐ Yes ☐ No

c. Didn't do work or other activities as carefully as usual
☐ Yes ☐ No

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?
- ❑ Not at all
- ❑ Slightly
- ❑ Moderately
- ❑ Quite a bit
- ❑ Extremely

7. How much bodily pain have you had during the past 4 weeks?
- ❑ Not at all
- ❑ Slightly
- ❑ Moderately
- ❑ Quite a bit
- ❑ Extremely

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

- ❑ Not at all
- ❑ Slightly
- ❑ Moderately
- ❑ Quite a bit
- ❑ Extremely

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks.

a. did you feel full of pep?
- ❑ All of the time
- ❑ Most of the time
- ❑ A good bit of the time
- ❑ Some of the time
- ❑ A little of the time
- ❑ None of the time

b. have you been a very nervous person?
- ❑ All of the time
- ❑ Most of the time
- ❑ A good bit of the time
- ❑ Some of the time
- ❑ A little of the time
- ❑ None of the time

c. have you felt so down in the dumps nothing could cheer you up?
- ❑ All of the time
- ❑ Most of the time
- ❑ A good bit of the time
- ❑ Some of the time
- ❑ A little of the time
- ❑ None of the time

d. have you felt calm and peaceful?
- ❑ All of the time
- ❑ Most of the time
- ❑ A good bit of the time
- ❑ Some of the time
- ❑ A little of the time
- ❑ None of the time

e. did you have a lot of energy?
- ❑ All of the time
- ❑ Most of the time
- ❑ A good bit of the time
- ❑ Some of the time
- ❑ A little of the time
- ❑ None of the time

f. have you felt downhearted and blue?
- ❑ All of the time
- ❑ Most of the time
- ❑ A good bit of the time
- ❑ Some of the time
- ❑ A little of the time
- ❑ None of the time

g. did you feel worn out?
- ❑ All of the time
- ❑ Most of the time
- ❑ A good bit of the time
- ❑ Some of the time
- ❑ A little of the time
- ❑ None of the time

h. have you been a happy person?
- ❑ All of the time
- ❑ Most of the time
- ❑ A good bit of the time
- ❑ Some of the time
- ❑ A little of the time
- ❑ None of the time

i. did you feel tired?
- ❑ All of the time
- ❑ Most of the time
- ❑ A good bit of the time
- ❑ Some of the time
- ❑ A little of the time
- ❑ None of the time

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?
- ❑ All of the time
- ❑ Most of the time
- ❑ Some of the time
- ❑ A little of the time
- ❑ None of the time

11. How TRUE or FALSE is each of the following statements for you?

a. I seem to get sick a little easier than other people
- ❑ Definitely true
- ❑ Mostly true
- ❑ Don't know
- ❑ Mostly false
- ❑ Definitely false

b. I am as healthy as anybody I know
- ❑ Definitely true
- ❑ Mostly true
- ❑ Don't know
- ❑ Mostly false
- ❑ Definitely false

c. I expect my health to get worse
- ❑ Definitely true
- ❑ Mostly true
- ❑ Don't know
- ❑ Mostly false
- ❑ Definitely false

d. My health is excellent
- ❑ Definitely true
- ❑ Mostly true
- ❑ Don't know
- ❑ Mostly false
- ❑ Definitely false

Appendix C:

Participation Information Sheet and Consent Form

DEPARTMENT OF PSYCHOLOGY

THE UNIVERSITY OF AUCKLAND
NEW ZEALAND
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The University of Auckland
Private Bag 92019
Auckland, New Zealand

PARTICIPATION INFORMATION SHEET

Title: Cognitive abilities and general well being of adults in New Zealand
Researcher: Helen Vykopal

Dear potential participant,

My name is Helen Vykopal and I am post graduate student enrolled in the Doctor of Clinical Psychology at the University of Auckland. I am undertaking a research project being conducted in the Department of Psychology. The research is partially funded by Research Expenses Funding for Doctoral Students, Department of Psychology and aims to examine the neuropsychological and functional outcomes of healthy New Zealand adults.

You are invited to participate in a study about cognitive abilities and general wellbeing. Cognitive abilities include performance on tests of memory, attention, language and visual problem solving. We are asking individuals who speak English and live in New Zealand to participate in individual assessment sessions that include tests of these abilities. Participants will carryout one assessment session of up to 150 minutes. Assessments will take place in accessible facilities within the University of Auckland or in your home. The assessment will be conducted by myself.

You are under no obligation to participate. Your participation is **voluntary** and you may withdraw at any time. Your name and identifying information will not be associated with published results.

The tests to be administered are commonly used by clinicians in the field. As such participation in this study could influence how you perform if you are referred for a neuropsychological assessment following participation in the study. Therefore, all the test data will be held in secure storage on university premises for a period of 10 years, and if you are referred for neuropsychological assessment during this period, a summary of your test results can be made available following written request from your GP. After the 10 years has elapsed all data will be shredded.

Participants can withdraw their information from the study by contacting the researcher at any time before May 1st 2010. There are no risks associated with the study though people often find

the tasks involved slightly boring, and it is expected that you may find some of the items difficult. Participants will be given a nominal gift of approximately $ 5 on participation.

If you would like to participate please complete the attached consent form and return in the freepost envelope provided <u>OR</u> contact me using the information below to obtain further information and a consent form.

Thank you for your time and help in making this study possible. If you have any questions or would like to discuss participation, please contact me or Mrs Helen Vykopal at the address/ phone number below:

Contact persons:

Helen Vykopal
Department of Psychology
The University of Auckland
Private Bag 92019, Auckland, New Zealand
Mobile: 021 1177 396
Home: 09 424 7140
Email- misshlbw@hotmail.com

The head of the department 2007 is:
Fred Seymour
Department of Psychology
The University of Auckland
Private Bag 92019
Auckland, New Zealand
(09) 373 7599 ext (88516)

If you have any concerns of an ethical nature you can contact: Chair, The University of Auckland Human Participants Ethics Committee, Office of Vice Chancellor, University of Auckland, Private Bag 92019, Auckland. Telephone (09) 373 7599 ext. 87830

Approved by University of Auckland Human Participants Ethics Committee on 20th June 2007 for a period of 3 years from June 2007 to June 2010. Reference: 2007/206.

DEPARTMENT OF PSYCHOLOGY

THE UNIVERSITY OF AUCKLAND
NEW ZEALAND
Te Whare Wānanga o Tāmaki Makaurau

Building 721, Tamaki Campus
261 Morrin Road, Glen Innes
Auckland, New Zealand
Telephone 64 9 373 7599
Facsimile 64 9 373 7000

The University of Auckland
Private Bag 92019
Auckland, New Zealand

CONSENT FORM

THIS CONSENT FORM WILL BE HELD FOR A PERIOD OF SIX YEARS

Title: Cognitive abilities and general well being of New Zealand adults
Researcher: Helen Vykopal

I have been given and have understood an explanation of this research project. I have had the opportunity to ask questions and have them answered.

I understand that I may withdraw myself or any information traceable to me at any time up to May 1st 2010 without giving a reason.

I understand that all information collected will be held in secure storage on University premises for a period of 10 years.

I understand that, with my permission, the information collected will be available to my GP.

- I agree to take part in this research
- I understand that participation will involve one session lasting up to two and a half hours.

Signed:_____ Date:_____
(Signature)

Name:_____
(Please Print)

Contact Phone(s):_____

Approved by the University of Auckland Human Participant Ethics Committee on 20th June 2007 for a period of 3 years from June 2007 to June 2010 Reference Number 2007/206

ASTRO
Auckland Stroke Outcomes Study

THE UNIVERSITY OF AUCKLAND
NEW ZEALAND

Clinical Trials Research Unit
The University of Auckland

Level 4, School of Population Health
Tamaki Campus
Morrin Road, Glen Innes, Auckland
Private Bag 92019
Auckland
NEW ZEALAND
Telephone: 64 9 373 7599
Facsimile: 64 9 373 1710
Email: v.feigin@ctru.auckland.ac.nz
www.ctru.auckland.ac.nz

Participant Information Sheet

Project title: ASTRO: Auckland **S**troke **O**utcomes Study
Researcher Name: Associate Professor Valery Feigin

An invitation

You are invited to take part in a research study because you had a stroke about 5 years ago and participated in the ARCOS III study (Auckland Regional Community Stroke 2002-2003 study). This study is a follow-up of stroke survivors initially participated in the ARCOS III study. By conducting this follow-up study we hope to determine a long-term impact of stroke on stroke survivors and carers that is important for improving health care organisation and reducing stroke burden on stroke families and the society. We also hope to learn new information about the effects of stroke on your various cognitive functions (e.g. memory, language) and mood. By conducting interviews we hope to find out about life after stroke, what costs, both in financial terms and personal terms have occurred and what impact this has had on your family. This study is coordinated by the Clinical Trials Research Unit at the University of Auckland.

Your participation is entirely voluntary (your choice). You do not have to take part in this study. If you choose not to take part, any care or treatment that you are currently receiving will not be affected. If you do agree to take part, you are free to withdraw from the study at any time, without having to give a reason. Withdrawing at any time will in no way affect your future health care. To help you make your decision please read this information brochure. You may take as much time as you like to consider whether or not to take part. If you require an interpreter this can be arranged.

What are the aims of this study?

The main aim of the study is to:

- Determine the broad long-term (5 to 6 years) impact of stroke by documenting very carefully the frequency, characteristics and effects on all people who participated in ARCOS III study (from March 2002 to February 2003).

The study also aims to find out what the effects of stroke are on:

- Neuropsychological (cognitive) functioning
- Disability, handicap and physical function
- Mood and emotions
- Quality of life and daily activities
- Your family and work
- Your role within your community

- Your perception of how life is for you
- Direct and indirect costs associated with stroke

What types of people can be in the study?

All people who were part of the ARCOS III 2002-2003 study and who have had a stroke about five years ago while living in Auckland are able to participate in the study. If the person who has had the stroke is unable to consent to participate in the study, we ask a representative (you) to take part in the study.

How many people will be in the study?

We estimate about 700 people will be involved in this study.

What happens if I do decide to take part?

If you decide you would like to take part, your participation would be for a short time. Research nurse and neuropsychologists, who have been specially trained for this project, will interview you in your own home or place of residence. You will be asked to discuss what it has been like to have had a stroke, what kind of services you have had contact with, who helped you the most after your stroke, what it has been like for your family to have been with you during this period, and what are your hopes and fears for the future. You will also be asked questions about your recovery, mood, treatments, care and services that you have received after your stroke in 2002-2003.

How many interviews/procedures will there be?

There will only be two interviews - one telephone interview by a research nurse and one face-to-face interview by a study neuropsychologist. We would also like to speak with your family members and will ask them if they are willing to speak with the interviewer. We would like to double-check some information with you after the interview if necessary. The telephone interview will take about 30 minutes, and the face-to-face interview will take about two and half hours. Should you feel tiered during the face-to-face interview, you will be offered a break. You will also be asked to complete self-administered questionnaires to assess various aspects of your health and recovery. Completing these questionnaires will take approximately 30 minutes. A neuropsychologist will also measure your blood pressure and pulse rate and evaluate your physical functioning. These measurements will take approximately 20 minutes.

What is the time-span for the study?

The study is expected to start on 1 February 2007 and will continue until 31 August 2008.

The risks and benefits of the study

Taking part in this study will take some of your time and require you to answer a series of questions. There are no known risks caused by this study. Your usual medical care will not be affected in any way by participating in the study, or by declining to participate or withdrawing from the study at any stage. Your participation in this study will be stopped should any harmful effects appear or if the doctor feels it is not in your best interests to continue. Similarly your doctor may at any time provide you with any other treatment he/she considers necessary.

This study will be of benefit to the wider population. There is no guarantee that you will benefit directly from being involved in this study. However, you will be given an opportunity to discuss your disease with a stroke nurse and neuropsychologist – health professional who know a lot about stroke. You will also be given results of your blood pressure and pulse measurements. The results obtained from your participation may help others with this condition in the future.

Compensation

In the unlikely event of a physical injury as a result of your participation in this study, you will be covered by the accident compensation legislation with its limitations. If you have any questions about ACC please feel free to ask the researcher for more information before you agree to take part in this trial.

Confidentiality

The study files, any notes taken and all other information that you provide will remain strictly confidential. No material that could personally identify you will be used in any reports on this study. Upon completion of the study your records will be stored for 16 years in a secure place at the central coordinating centre in Auckland. All computer records will be password protected. All future use of the information collected will be strictly controlled in accordance with the Privacy Act.

Your rights

If you have any queries or concerns about your rights as a participant in this study, you may wish to contact a Health and Disability Advocate at the Health Advocates Trust, telephone 0800 555 050, or Maori Health Services: Mata Forbes RGON: Coordinator/Advisor, Maori Health Services Auckland Hospital, Grafton; Mobile 021 348 432; telephone 307 4949 Ext. 7292.

Finally

This study has received Ethical Approval from the Auckland Ethics Committee XX September, 2006. If you would like some more information about the study please feel free to contact the ASTRO Study Manager XXXXXXXXX at the Clinical Trials Research Unit, Faculty of Medicine and Health Sciences, University of Auckland on 373 7599 extension XXXXX.

Study Investigators

The principal investigator for this study is:

Associate Professor Valery Feigin, MD, PhD
Clinical Trials Research Unit
Faculty of Medicine & Health Sciences
School of Population Health
University of Auckland
Private Bag 92019
Auckland
Tel: (09) 373 7599 ext. 84728

Please keep this brochure for your information.
Thank you for reading about this study.
Version 1 Date: 4 October 2006

ASTRO
Auckland Stroke Outcomes Study

THE UNIVERSITY OF AUCKLAND
NEW ZEALAND
Clinical Trials Research Unit
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Level 4, School of Population Health
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CONSENT FORM
for Stroke Survivors

Project title: ASTRO: Auckland Stroke Outcomes Study
Researcher Name: Associate Professor Valery Feigin

REQUEST FOR INTERPRETER			
English	I wish to have an interpreter.	Yes	No
Maori	E hiahia ana ahau ki tetahi kaiwhakamaori/kaiwhaka pakeha korero.	Ae	Kao
Samoan	Oute mana'o ia iai se fa'amatala upu.	Ioe	Leai
Tongan	Oku ou fiema'u ha fakatonulea.	Io	Ikai
Cook Island	Ka inangaro au i tetai tangata uri reo.	Ae	Kare
Niuean	Fia manako au ke fakaaoga e taha tagata fakahokohoko kupu.	E	Nakai

1. I have read/had explained to me, and understand, the Information Sheet dated 4 October 2006 for stroke survivors, their families, representatives and carers taking part in the ASTRO study. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.
2. I understand that taking part in this study is voluntary (my choice). I realise the study involves an interview with medical and lifestyle questions, that I may choose not to answer any questions or withdraw from the study at any time and this will in no way affect my future health care.
3. I agree to an approved auditor appointed by either the ethics committee, or the regulatory authority or their approved representative, and approved by the Auckland Ethics Committee reviewing my relevant medical records for the sole purpose of checking the accuracy of the information recorded for the study.
4. I give my approval for information regarding my present illness to be obtained from medical records.
5. I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study.
6. I understand the compensation provisions for this study.

7. I have had time to consider whether to take part.
8. I know whom to contact if I have any questions about the study.

I am indicating my approval (or otherwise) for the following:

I wish to receive a copy of the results. I understand that there may be a significant delay between data collection and the publication of the study results.	Yes / No

I _____ hereby consent to take part in this research.

OR

I am a representative of _____ (the participant), being a person who is lawfully acting on the participant's behalf or in his or her interests. My relationship to the participant is _____.
I agree to health information about the participant being disclosed for the purposes of this research. I also agree to participate in this research.
(Please draw a line through the statement above that is not relevant).

Signature (or representative)..... Signature of witness.....

Date: ..... Name of witness.....

Project explained by..... Project role .....

Signature ..... Date .....

Note: A copy of the consent form to be retained by participant and a copy to be placed in the medical file.

Approved by the Auckland Ethics Committee
Version 1 Date: 4 October 2006

Appendix D:

Demographic Information

3.02 19 Date of birth
day month year

3.021 Current Age

3.03 Sex

○ Male or ○ Female

Which ethnic groups do you belong to? **(answer every question)**

	Yes	No	
3.05	○	○	NZ Māori
3.06	○	○	NZ European
3.07	○	○	Other European
3.08	○	○	Samoan
3.09	○	○	Cook Island
3.10	○	○	Tongan
3.11	○	○	Niuean
3.12	○	○	Chinese
3.13	○	○	Indian
3.14	○	○	Other
3.15	→		If Other, please specify

	Yes	No	
3.16	○	○	Is English your first language?
	Yes	No	
3.17	○	○	If No, do you need an interpreter
3.18	→		If Yes, what language?

3.19 At what age did you leave school?

3.20 Did you pursue further education after school such as a Degree or Diploma?

Yes

No

3.21 How many years did this take you?

2.01 What is your current marital status? **(tick one only)**

- ○ Married, civil union, or living with partner
- ○ Separated, divorced or widowed
- ○ Never married (single)

	Yes	No	
2.02	○	○	Do you live alone?

→ **If No:**

	Yes	No	
2.03	○	○	Living with family or partner
2.04	○	○	Living with others

2.05 What is your usual dwelling place? **(tick one only)**

- ○ Rented
- ○ Own home
- ○ Family or friend's home
- ○ Retirement village or similar
- ○ Rest home
- ○ Private hospital
- ○ Boarding house
- ○ Other

2.06 → If Other, please specify

16.01 Which of the following is your current work situation? (tick one only)

- ○ Full time paid work
- ○ Part time paid work
- ○ Retired
- ○ Unemployed or redundant
- ○ Beneficiary
- ○ Homemaker
- ○ Other

16.02 → If Other, please specify

16.03 If you are employed what is your current occupation?

Yes No

9.06 ○ ○ High cholesterol

Yes No

9.07 → ○ ○ If Yes, have you been taking any cholesterol lowering medication?

9.08 ○ ○ Atrial fibrillation (fluttering, irregularity of the heart)

9.09 → If Yes, have you been using any of the following blood-thinning medication for atrial fibrillation? (tick one only)

- ○ Warfarin
- ○ Aspirin
- ○ Both warfarin and aspirin

Yes No

9.10 ○ ○ Heart attack

9.11 ○ ○ Angina

9.12 ○ ○ Other forms of heart disease

9.13 ○ ○ Dementia or cognitive problems

9.14 ○ ○ Parkinson's disease

9.15 ○ ○ Arthritis of legs or hips that limit mobility

9.16 ○ ○ Shoulder arthritis that limits mobility

9.17 ○ ○ Cancer

9.18 ○ ○ Bedsores

9.19 Which of these best describes your smoking status? (tick one only)

- ○ **Never** smoked
- ○ **Ex-smoker**; smoked cigarettes, ready made or roll your own; cigars, cigarillos or pipe more than once per day for at least one year
- ○ **Current smoker**; currently smokes cigarettes, ready made or roll your own, cigars, cigarillos or pipe) more than once per day for at least one year

Yes No

9.20 ○ ○ Did you regularly drink any type of alcohol in the **last 3 months**?

Yes No

9.21 → ○ ○ If No, did you **ever** drink alcohol regularly (at least once a month)?

9.22 → If Yes, which of the following best describes how often (tick one only)

- ○ Four or more times a day
- ○ Two or three times a day
- ○ Once a day
- ○ Every 2 days
- ○ Every 3 or 4 days
- ○ Every 5 or 6 days
- ○ Once a week
- ○ Every 10 days
- ○ Once a fortnight
- ○ Once a month

9.23 → ⌊__⌋ If Yes, average number of standard units of alcohol consumed on each occasion. One standard unit of alcohol is equivalent to approximately: 1 can of beer, 1 glass of wine, or 30ml of straight spirits.

Do you take any of the following medication

(answer every question)

	Yes	No	
9.24	○	○	Warfarin
9.25	○	○	Heparin injections
9.26	○	○	Aspirin
9.27	○	○	Dipyridamole (Persantin)
9.28	○	○	Clopidogrel (Plavix)
9.29	○	○	Do you take medications regularly as prescribed?

Have you seen a health specialist for any of the following problems? (answer every question)

	Yes	No	
9.30	○	○	Cognitive problems
9.31	○	○	Depression
9.32	○	○	Epilepsy
9.33	○	○	Joint stiffness (contractures)
9.34	○	○	Heart disease
9.35	○	○	Parkinson's disease
9.36	○	○	Urinary or bowel problems
9.37	○	○	Other
9.38	→		If Other, please specify