The Health Inequalities Associated with Post-Stroke Visual Impairments

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by

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Abbreviations

ADL……*Activities of Daily Living*

AMD……*Age-related Macular Degeneration*

BIOS……*British and Irish Orthoptic Society*

BIT……*Behavioural Inattention Test*

BSV/BV……*Binocular single vision/Binocular vision*

CAT……*Cardiff acuity test*

CI……*Chief Investigator*

CLAHRC (NWC)……*Collaboration for Leadership in Applied Health Research and Care (North West Coast)*

CONSORT……*Consolidated Standards of Reporting Trials*

CRF……*Case Report Form*

CVI……*Certification of Visual Impairment*

DAG……*Diagrammatical acyclic graph*

DNA……*Did not attend*

ECLO……*Eye Care Liaison Officer*

EU……*European Union*

GRACE……*Good Research for Comparative Effectiveness*

HIAT……*Health Inequalities Assessment Toolkit*

HRA……*Health Research Authority*

IMD……*Index of multiple deprivation*

IRAS……*Integrated Research Application System*

IVIS……*Impact of Visual Impairment after Stroke*

MHRA……*Medicines and Healthcare products Regulatory Agency*

MDT……*Multidisciplinary team*

NIHR……*National Institute for Health Research*

NIHSS……*National Institute of Health Stroke Scale*

NHS……*National Health Service*

NRES……*National Research Ethics Service*

OA……*Ocular alignment*

OKS……*Oculokinetic Stimulation*

OM……*Ocular motility*

OT(s)……*Occupational Therapist(s)*

PRISMA……*Preferred Reporting for Systematic reviews and Meta-Analyses*

PROM……*Patient Reported Outcome Measure*

RAF rule……*Royal Air Force rule (measure of near point of convergence)*

RCT……*Randomised Control Trial*

SES……*Socioeconomic status*

SPSS……*Statistical Package for Social Science*

SSNAP……*Sentinel Stroke Audit Programme*

STROBE……*Strengthening the Reporting of Observational Studies in Epidemiology*

TIA……*Transient Ischaemic Attack*

VA……*Visual acuity*

VF……*Visual field*

VISA……*Visual Impairment Screening Assessment*

VN……*Visual neglect*

VP……*Visual perception*

VRT……*Visual Restoration Therapy*

VSURP……*Vision and Stroke User Reference Panel*

Abstract

Aim: The aim of this project was to explore the possible health inequalities facing visually impaired stroke survivors and any possible means of overcoming these.

Methods: This research consisted of three phases of work. The first phase included the development of three systematic reviews, investigating the overall health inequalities previously identified within this population, along with a review of the inequalities in assessing and treating post-stroke visual impairments. The second phase involved the recruitment of 1500 stroke admissions into an epidemiological clinical study across three hospital sites in the North West of England. Longitudinal follow-up assessments of their visual impairments was used to statistically analyse the recovery rates of post-stroke visual impairments between different patient groups. The third phase explored the long-term health inequalities facing stroke survivors as a result of their visual impairments. This was conducted using qualitative and thematic analysis of patient responses from telephone conversations regarding non-attendance of hospital appointments. Moreover, descriptive analysis of a nationwide survey of orthoptists was used to investigate an orthoptic home visit service as a potential means of addressing the health inequalities identified through the telephone conversations. Finally, thematic analysis of focus groups and one-to-one interviews with stroke survivors further explored additional, long-term issues caused by post-stroke visual impairments.

Results: Health inequalities exist before the onset of stroke, during hospital care and following hospital discharge. The findings from this research have identified older patients, those that suffer severe strokes and those discharged to supportive forms of living are most at risk of the following health inequalities: suffering visual impairment after stroke, poor access to outpatient services and poor recovery of the visual impairments. Patient gender, ethnicity, area deprivation and whether the patient had an infarction or haemorrhage were not found to be significant factors in the above inequalities. Additional, inequalities identified from interviews with

visually impaired stroke survivors were found to impact on the physical being, the psychosocial being, and the organisation of healthcare services.

Conclusion: Key recommendations from this research include the need to incorporate vision as a priority of stroke care nationally. Where patients struggle to attend appointments due to stroke and visual disabilities, efforts should be made to address the barriers to attending. A domiciliary orthoptic service and the contribution of vision services to early supported discharge teams could address a small number of the identified inequalities. Furthermore, addressing the possible long-term, physical and psychosocial impact of post-stroke visual impairments prior to hospital discharge could further reduce some of the health inequalities facing this population.

Chapter 1: Introduction

Stroke is the largest cause of complex disability in adults in the UK and causes a greater range of disabilities than any other condition (1). For those of working age, many individuals are unable to return to work. Even for those who are retired or not working, there are issues in returning to usual activities such as driving and reading (2). Thus, the complex problems arising from stroke coupled with visual impairment cause considerable wider and long-term implications.

Health inequalities differ from "variations" in health, which can be explained by genetics, the natural ageing process and luck (3). Health inequalities have been described as systematic, socially produced (and therefore, modifiable) and unfair (3). Together, "*these distinguishing features turn mere variations in health into a social inequity in health*" (3). Therefore, adversities as a result of post-stroke visual impairments constitute a health inequality if these requirements have been met, and should not be confused with genetic or natural deterioration of health due to age, for example.

Visual impairment is a deficit of visual function that can arise from a variety of causes. Following stroke, these impairments can encompass reduced central vision, visual field loss, eye movement disorders and perceptual deficits including visual neglect (4). The forms of visual impairment have been well established in previous literature (5) and the overall prevalence of these impairments following stroke has been estimated at 65%, ranging from 62-71% (6-9). If left untreated these impairments can significantly impact on the patient's quality of life, whilst links with depression and vision loss after stroke have further been documented (10-14).

Central visual deficits have been reported in up to 70% of stroke survivors, including cases where adequate refractive correction has not been provided (15). Central vision defects can affect near and distance visual acuity, often impacting on a patient's reading ability, activities of daily living and mobility tasks (16, 17). However, missing or broken glasses are often recognised as a false positive sign for reduced visual acuity after stroke (18), which may overestimate the current prevalence figures.

Visual acuity defects can also include impaired contrast sensitivity, which further hinders reading ability and activities of daily living for these stroke survivors (19, 20). Additionally, colour vision deficits have been documented following stroke although these have mostly been attributed to visual perceptual deficits (21, 22).

Visual field loss following stroke mainly consists of hemianopia, quadrantanopia and scotomas, amongst many others (23). These can consist of a complete or partial loss of vision, affecting either or both eyes (23). The prevalence of visual field loss is reported to be as high as 57% in studies which tested for deficits using confrontation or perimetry assessment (24). Considerably lower figures have been reported in studies where patients' symptoms of field loss were the only determining factor (25). Many issues can arise from the impact of visual field deficits including the loss of driving licenses, further reading impairments, and can often be associated with visual hallucinations (e.g. Charles Bonnet syndrome) (23, 26).

Eye movement disorders following stroke may include cranial nerve palsies affecting the third, fourth or sixth cranial nerves (5, 27). These frequently yield a range of eye movement disorders, often resulting in double vision due to acquired strabismus (prevalence of 16.5% to 52%) (8, 9, 28).

Further eye movement conditions can include horizontal or vertical gaze palsies (prevalence of 18-57%) (8, 9) and nystagmus (prevalence of 4-53%) (29, 30). Decompensated heterophorias or convergence insufficiencies have been reported to occur in 21% of cases following stroke, further adding to symptoms of intermittent diplopia and reading difficulties (16, 30).

Visual perceptual disorders following stroke most frequently includes visual neglect, in which the patient ignores one side of their vision, body and/or extrapersonal space (31). The reported prevalence of visual neglect ranges from 14% to 82% (32-35).

Other visual perceptual disorders can occur following stroke, although these are less frequently reported in the literature. These can include visual hallucinations, visual agnosia, alexia, simulatanagnosia and visual tilt, naming just a few of many. The prevalence of these conditions ranges from 2.5% to 76% (32, 36) and are often very distressing for the patients and families (32).

1.1: Health inequalities associated with post-stroke visual impairments

The World Health Organisation defines 'health inequalities' as, "*disruptions of health determinants between different population groups*." (37). Examples include, inadequate patient access to health resources dependent on their age, gender, race or social class (38). However, the fundamental causes of health inequalities relate to income, power and wealth (39). They further describe 'equity' as, *"the absence of avoidable or remediable differences among groups of people, whether those groups are defined socially, economically, demographically, or geographically*". Therefore, in order to achieve equitable healthcare, the conflicting inequalities must first be identified and tackled.

Before discussing inequalities within the study population of this PhD research, it is pertinent to acknowledge the wider context of health inequalities in the UK. From the mid-nineteenth century, social-theorists Friedrich Engles (40) and Karl Marx (41), developed their seminal body of critical theory on the social production of disease, which described health as a product of the way society is organised and that capitalist exploitation - namely of the working-class population - results in unfair morbidity and early mortality of this group (40, 42). Their work concluded that society plays a key role in determining who will be healthy and who will not, and ultimately, who lives and who dies (42). Their research further probed the question of whether inequalities resulted from sick people or "sick" societies (42).

Doyal and Pennell (43) extended this theory of class exploitation within the UK specifically. They wrote that ill health was found to be a product of social and economic organisation of society, such that medicine and research are strongly influenced by their roles in maintaining a healthy labour force that ultimately drives capitalism (43). Such work highlighting health disparities in the UK, including that of Richard Wilkinson, which illuminated class differences in death rates in the UK (44), led to the government's commissioning of the Black Report to further investigate patterns and causes of social health inequalities (45).

The Black Report was later produced in 1980 by the Department of Health and Social Security. This report demonstrated that socio-economic inequalities had not

narrowed, but instead, widened since the development of the NHS. However, the report concluded that these inequalities were not attributable to failings in the NHS, but rather to the many other social inequalities influencing health (i.e. income, education, housing, diet, employment, and conditions of work) (45, 46). The Black report was published at a time when psychosocial theories were not a credible body of academic work, and instead, focused on improving the "material conditions of poorer groups", particularly children and disabled persons (46, 47), concluding that inequalities arise from "cumulative deprivation of a life-time" (48).

This neo-materialist theory has been widely published in health inequalities research, and describes the impact of material possessions on public health, through access to goods, services and material risk factors (49). This theory focuses primarily on public service provision, such as transport, schools and welfare (49). However, researchers have argued if inequalities can be said to stem from an uneven distribution of resources, or from the 'psychosocial perceptions' of these inequalities, whereby people of lower social standing feel inferior and subordinated, and the subsequent impact these negative feelings have on their health (49, 50). This link between inequalities and the psychosocial being was later referred to as the "psychosocial pathway" (50).

The psychosocial pathway links income inequality and population health through the biology of chronic stress. This theory states that living in unhealthy and impoverished environments increases stress levels markedly, which in turn, increases unhealthy risk behaviours, such as smoking and drinking (51). Moreover, this increase in stress changes the bodily response to stress through the role of cortisol (52). The long-term effects of sustained stress and adrenaline have been shown to deteriorate the immune system, and have even been linked to hypertension, obesity and cardiovascular diseases including stroke (53). The psychosocial pathway, therefore, describes the state of society as the root cause of some disease, removing ownership from the individual.

Successively, the Acheson Report in 1998 and the Marmot Review in 2010 (47, 54) were developed, which explored inequalities further, focusing more prominently on psychosocial factors. The Acheson Report highlighted the need to reduce "psychosocial hazards" in the workplace and home life, including stress, crime,

violence, truancy and social support (47). The Marmot Review furthered this theory of psychosocial determinants and placed more emphasis on social isolation, sense of control, and individual and community empowerment (48, 54). These subsequent reports provided further critical thinking into the root cause of social injustices, in that material conditions are not necessarily the key to a better quality of life. Instead, social dominance, autonomy and psychosocial pathways could better explain inequalities (50).

All three aforementioned reports consider inequalities stemming from the following factors: lack of education; poor working conditions; poor transport links; unacceptable housing; the need to give all children the best start in life; reducing obesity, unhealthy food and promoting a healthy lifestyle; and the role of the NHS/public sector (46, 47, 54). Although none of the reports claim that the NHS should play a key role in tackling health inequalities (48), recommendations were made in relation to ensuring equal access to healthcare and services (46, 47).

All three reports commented on poverty and the redistribution of wealth (46, 47, 54) however, their recommendations mainly related to tackling income inequality (46) and introducing a minimum income of healthy living (54). Remarkably, none of the reports described the need to address excessively high incomes nationally (48). These findings support claims that the UK is tackling inequalities erroneously, and should be looking to reduce inequalities from top-down approaches and through policy changes, moving away from the "behavioural" downstream approach (whereby the public are expected to make lifestyle changes to improve their health and wellbeing), which has been deemed ineffective and costly (55).

All three reports described similar recommendations, supporting claims that a lack of progression has been made to reduce inequalities since the initial Black Report in 1980 (48, 56), which further questions the previous methods used. Wilkinson (57) conducted research into income distribution as a social determinant of health. This research concluded that a link exists between the level of income inequality and the population health in that area (57). A person's health is therefore, not only influenced by their own level of income, but also by the level of inequality in their residing area (58). The solution to the problem of socio-economic health inequalities therefore,

requires social and political change, which coincides with the findings of Marx (41) and Engels' (40) earlier work.

Income inequalities have further been associated with the Inverse Care Law (59). This body of work suggested that those most likely to require medical care are least likely to receive it (or will receive inadequate care, as is available to them in their residing area), whilst those with least need are more likely to utilise health services that are comparably of greater quality (59, 60). Evidence has shown that deprived areas tend to have fewer healthcare professionals working with larger caseloads and sicker patients (59). The likely impact of this is an ultimate widening of the health inequality "gap", that requires action targeting the population and areas most in need.

The NHS was designed to target health inequalities in 1948 and has been under recent attack by the UK government in failing to deliver on its aim to offer "a comprehensive service, available to all" (61). However, the NHS should not be blamed for socio-economic inequalities (3); reform is required socially and politically. Nevertheless, the NHS can play a role in tackling inequalities "on the ground" with the necessary support and funding (62). The 2019 NHS 10-year Plan aims to tackle avoidable health inequalities by allocating funding to services most in need (63), including stroke rehabilitation services (64). Furthermore, in a bid to reduce health inequalities, the plan requests that those affected areas devise a strategy for spending (64). Therefore, health inequalities and stroke care are at the forefront of research requirements to inform such change and makes this PhD research topic even more pertinent in present day research and politics.

In 2016, the UK voted to leave the European Union (EU), which has since sparked extensive debate as to how this will impact the NHS (65, 66). The UK government has made promising predictions that leaving the EU would allow financial contributions previously directed to the EU to be redirect into services such as the NHS. However, some researchers claim that a smaller economy will, in fact, result in less funding for the NHS (66), while others more damningly postulate that the NHS will be abolished to make way for a fee-paying healthcare "market" (67). This latter outcome is already the case in other developed countries; and it is a move that will, arguably, widen the health inequality gap even further. In the United States, for example, which exercises a free-market healthcare system, medical expenditures are the leading cause of

personal bankruptcy (68). The NHS currently competes alongside a private, internal market that was established in the late twentieth-century to increase efficiency within the NHS (69, 70). However, researchers and clinicians argue that it has been neither effective nor cost-effective, and instead has culminated in privatisation of the UK health service, which would likely worsen current health inequalities (70).

Therefore, in exploring health inequalities within the visually impaired stroke population, the previous literature in this area has been considered during the study design and interpretation of the findings. Area deprivation will be considered an important variable of consideration as opposed to individual income level (57). The research study will not only focus on the social determinants of health, but also on possible issues within the healthcare system, and discussions will draw on social ideology to best place this research within the wider context of health inequalities. This research accepts recent claims that tackling health inequalities goes beyond the focus on disease and patient care alone, but instead, calls for reforms to the national healthcare system; it requires significant changes to economic philosophies that underpin our society (71). However, modifications to NHS services, has the potential to reduce the impact that inequalities have on patients at an individual level (3). Therefore, this research will explore inequalities within visually impaired stroke groups (at individual level), possible within the scope of PhD study.

1.1.1: Health inequalities in the visually impaired stroke population

There is very little published literature outlining the potential health inequalities met by stroke survivors with resultant visual impairments (72). Two studies describe the significant lack of stroke-vision services in the UK (2, 73), resulting in unequal provision of care. Adult patients (≥18 years old) who suffer a stroke and are admitted to a hospital that does not provide visual care at the acute stages of stroke (whereby symptoms have lasted ≥24 hours and ≤six months (74)), may not receive necessary rehabilitation, and may even go undiagnosed of their post-stroke visual impairments. This comprises hospital sites with no ward-based vision service or direct referral links to the orthoptic outpatient department for immediate vision assessment. In stroke, early visual management can alleviate troublesome visual symptoms or can allow for

compensation strategies to be put in place to aid management of these impairments and onward referral to other health professionals where required (73). This can subsequently affect the patient's general stroke rehabilitation, as identifying visual impairments will provide pertinent information to the patients and other healthcare professionals to help guide their overall management of resultant disabilities.

Two studies have reported demographic differences for stroke survivors with visual impairments with regards to patient gender. Males and females were found to present with distinct signs and symptoms of visual impairment after stroke, although reasons for these findings have not been well explained. Females often presented with deviated gaze and men frequently presented with nystagmus (75). It was further reported that more males experienced diplopia, resulting from ocular motility disorders, and photophobia (75, 76). These findings were from international epidemiological studies and, although found to be statistically significant, may not be generalisable to the UK stroke population due to factors including, differing populations and genetic predispositions to disease, cultural differences, and varied rates of stroke-risk factors, which are unlike that of the UK. There have been no further reports in the literature of demographic inequalities within the visually impaired stroke cohort specifically.

However, gender differences have been reported generally, and in stroke groups alone. It is well established that women tend to seek medical advice and treatment more frequently than men, resulting in better health and mortality. Researchers have blamed stereotypical masculine behaviours for gender variation in uptake of healthcare, due to denial, embarrassment and a desire to avoid situations that they are not in control of (77, 78). Only when medical conditions affect their quality of life are men better at seeking medical treatment early (79). This means that the initial symptoms are ignored until they are late into the course of a condition, which ultimately results in poorer outcomes (80). Furthermore, allied health professions may add to this issue by spending less time with male patients, providing them with less information and briefer explanations of their conditions, as they underestimate the patient's desire for information or misperception of the information given (78, 81).

Additionally, differing lifestyle factors (both healthy and damaging) have been reported between males and females in the UK and other developed countries, although these often depend on the study cohort, for example, socio-economic position, ethnicity/cultural norms and age (82). Men are reportedly more likely to be heavy alcohol drinkers, non-medial illicit drug users, smokers (and less likely to quit smoking), have cardiovascular disease, and tend to be more overweight compared to women (77, 83). High-risk/poor-health behaviours and a reduced likelihood in taking-up healthcare services are possible causes of the lower mortality rates in males in most developed countries.

However, it has been argued that the presenting signs of cardiovascular disease are more recognisable in males, and therefore, it is the females that present to hospital later with this specific condition (83). This presents a debate for research into gender inequalities and cardiovascular disease such as stroke.

Inequalities following stroke and those after loss of vision have often been discussed separately in the literature. It has been well documented that low socioeconomic status negatively influences outcomes for stroke survivors worldwide (84, 85), however additional inequalities have been reported in relation to gender, age, race and education (86, 87). These may be explained by the higher prevalence of stroke related risk factors and lifestyle choices within these populations, such as smoking, obesity and hypertension (88). It should be noted that the term socioeconomic status (SES) refers to a combined economic and sociological measure of a person's, or their family's, social position, and relates to key factors such as education, occupation, and income (89). Therefore, later mentions of this term include studies that have considered such factors to determine SES.

Similar subgroups have been identified as at risk of health inequalities within the visually impaired population including, but not exclusive to, age, gender, area deprivation and ethnicity (90-92). This may partly be due to associated health factors as well as demographic predispositions to particular eye conditions (93). The rate of visual impairment globally has increased from 161 million in 2002 (94) to 285 million in 2014, with 43% due to uncorrected refractive error (95). In the UK alone, four million people are expected to suffer from visual impairment by 2050 due to an increasing ageing population and the association of visual loss with older age (96).

The reported economic cost of stroke between 2006 and 2007 in the UK was £4.5 billion (97). Visual impairment was recorded to cost the UK £4.3 billion between 2009 and 2013, including the cost of resultant unemployment (96). It has been further reported that the cost of living with a visual impairment is three times higher for patients with additional cognitive impairments due to a stroke (98).

However, the cost of buying spectacles remains too high for many people. Research from the United States found evidence that ethnic minority groups (Black and Hispanic), those with lower education attainment and those of lower socio-economic standing were less likely to have an eye-care visit (99). Within the UK, testing for glasses is one of the only fee paying treatments within the UK National Health Service (NHS) (90), further widening the socioeconomic health divide across the visually impaired UK population.

Therefore, reducing health inequalities and lowering the rate of stroke and visual impairments, by targeting the most affected groups, could substantially reduce this economic burden.

Thus, to effectively conduct this research, careful consideration has been given to the most appropriate methods of research. It has been stated that an important requisite of this research is based on the statistical analysis of large datasets with a positivist epistemology, as this contributes to our awareness of the extent of the health inequalities and the factors associated with them (42). However, it is argued that knowledge is not limited to what can be directly measured, and underlying phenomena can only be ascertained through theoretical reasoning (100). Therefore, a multi-methods approach has been adopted to fully explore the potential health inequalities facing the visually impaired stroke population. Furthermore, epidemiology research arguably focuses too heavily on individual-level risk factors and has been criticised for ignoring the social and political processes that lead to disease (42). Therefore, later discussions will draw of social ideology to better place the research findings in the wider context of health inequalities.

1.2: Screening methods for post-stroke visual impairments

Health inequalities have been found to exist within the quality of the post-stroke visual assessments, in cases where these assessments have been offered to stroke survivors. The current models available for visual screening include ward-based assessments, whereby the patients are assessed for visual impairment and care provided on the stroke ward, or in outpatient services where the patient has been previously identified as having a visual impairment, and referred to the eye clinic (9, 101, 102). National orthoptic guidelines exist to support orthoptists working in these roles to ensure a national standard of care is provided (103, 104). However, great variation remains as to which screening methods are used, the methods of referral to the eye care services, and who conducts the screening assessment (73, 105). A range of health professionals involved in stroke care may assess visual function, including orthoptists, occupational therapists, physiotherapists and neurologists amongst many others. However, orthoptists have been deemed most likely to detect a visual impairment, followed by occupational therapists (73, 106). Where this is not possible, the sensitivity of detecting visual impairments after stroke drops significantly (102). One study has shown that orthoptists use a wider range of tests when screening for visual impairment after stroke reflecting their specific training in eye care (73).

Very little has been reported on the assessment of visual acuity in stroke cohorts specifically. The use of the MIS pocket vision guide after stroke has been discussed although the results were skewed due to significant lack of patients' refractive correction (15). It is possible that other tests are available and are being used in practice with no specific evidence base (105).

No research has been published which reports on specific screening methods for eye movement disorders, however some overall screening tools have included an assessment of ocular motility (101, 102, 107). However, these tools are limited without direct assessment of eye movements (102), without questioning of the patient's symptoms (101), or by failing to screen for all the possible eye movement disorders experienced after stroke (107).

The assessment of visual field loss can be conducted using automated perimetry, typically the Goldman, Octopus or Humphrey visual field machines (12, 108, 109), although these have not always been documented in the literature for use in stroke populations specifically. Alternatively, a confrontation visual field assessment can be used in cases where automated perimetry is not feasible, although, there is great variation in how this method is to be conducted to achieve optimum results (110-112).

Various tools exist for visual perceptual screening, which include the assessment for visual neglect/inattention as well as testing for additional perceptual disorders (113-115). However, some of the perceptual tools lack the ability to screen patients with cognitive disorders, which is quite often the case following stroke (116). Additional, bedside tests further exist for the screening of visual neglect specifically, including but not exclusive to the line bisection test, cancellation tasks and copying tasks (117). These tools, along with the individual bedside tests, have variable reported efficacy in the current literature. This is often seen in cases where the neglect is mild (118), the patient's dominant hand is on the neglected side or has been paralysed by the stroke (114, 119), or different versions of the test exist (120, 121). Therefore, clear guidelines on which tests to use for patients with specific stroke-related disabilities are required to ensure all case of visual neglect are detected and treated promptly.

Ideally, one tool that is capable of screening for all forms of post-stroke visual impairment would eradicate variation in the visual assessment of these patients. Although orthoptists were found to be the most accurate professional in testing for post-stroke vision impairments, this does not always appear to be possible due to lack of specific visual services in some stroke units (21, 122). In order to further reduce this inequality, visual screening assessment tools should be made accessible for other healthcare professionals involved in stroke care (105).

As discussed later in Chapter 4, the visual screening tools available are often unsuitable for use on stroke survivors. Most do not include assessment for all possible forms of visual impairment after stroke (15, 107, 123). For those tools that do screen for all impairments, one does not account for any patient reported symptoms (102), whilst another loses significant sensitivity when stroke survivors cannot report symptoms (101). Future tools would need to be able to address both

factors to accommodate for stroke survivors with cognitive and speech disabilities, who have the potential for acquiring any type of post-stroke visual impairment (105).

A health inequality exists where a stroke survivor is not being offered adequate visual screening (that considers all potential post-stroke visual impairments and is suitable for use on patients with cognitive and/or language impairment). Therefore, their visual impairments are undetected and untreated. This national variation means that some patients may receive complete visual care while others do not, dependent on the patient's area of residence and the facilities available at hospital admission. Continuity in how these patients are screened and treated would tackle this health inequality and ensure equity amongst the care provided to stroke survivors with post-stroke visual impairment (105). Currently, national stroke guidelines recommend that a screening assessment should be conducted on all stroke admissions, but there are no clear recommendations for which orthoptic assessments should be included in a test battery to identify post-stroke visual impairment (124), highlighting a clear cause of inequitable vision services. An objective of this research is therefore, to document the screening methods used in clinical practice and clarify the required tools for screening post-stroke visual impairment, to assist in equitable stroke service provision.

1.3: Rehabilitation for post-stroke visual impairments

A variety of rehabilitation options have been reported in the literature to aid post-stroke visual impairment (Chapter 5), although there is much dispute as to the efficacy of these treatments due to variation in time of baseline assessment, length of follow-up assessment and accuracy of testing (125).

For visual field loss, visual rehabilitation options include, compensatory methods to facilitate the patient in learning to compensate for impaired skills such as speed and accuracy of eye movements, substitutive therapies which are put in place to aid the symptom of field loss, and restitutive therapies which aim to restore lost visual function (126).

Compensatory methods for visual field loss can include computer-based or paper-based exploration training (127) and cognitive skill remediation (128). Substitutive therapies may include “Peli prisms” in which the patient uses a Fresnel prism to cue scanning into the blind hemifield (129), and restitutive therapies often involve computer-based training attempting to expand the field of missing vision (126).

The reported therapies of ocular motility disorders include conservative methods, such as prisms, occlusion and vergence exercises, pharmacological methods including botulinum toxin (BT) and drugs for nystagmus, or extra-ocular muscle surgery (27, 130-132).

The rehabilitation options for central vision loss after stroke have been less frequently reported in the literature compared with the management for other forms of post-stroke visual impairment. These methods can include spectral filters, low vision aids, refraction and spectacle correction (16, 18, 133).

The overall effectiveness of these rehabilitation options has been poorly documented in the literature. Spectacles are often not brought into the hospital after the patient has suffered a stroke, and when present, they are frequently scratched or damaged, further hindering the patient’s vision (18). Therefore, this lack of refractive correction may overestimate the prevalence of reduced vision as a result of stroke and provoke unnecessary assessment or treatment.

Management options for visual neglect or inattention can further be subdivided. Substitutive methods may include reading aids, typoscopes, and hemi-field eye patching (134, 135). Compensatory methods include prism adaptation and computerised or non-computerised visual scanning therapy (126, 136, 137).

The rehabilitation options for visual perceptual disorders other than visual neglect have been poorly reported (125). Word recognition training can be used to treat pure alexia and verbal advice has been reported as a successful therapy for various other perceptual disorders, most frequently for visual hallucinations (32, 138).

A recent survey showed that visual therapy after stroke varies dependent on the area of residence and the facilities available within that hospital (73). Vision advice and strategies proved most prevalent, whilst reading aids and referral for ocular motility treatment tended to be offered less frequently (73).

Currently, national guidelines recommend that visual rehabilitation should be offered to all stroke survivors identified as having post-stroke visual impairment, but there are no clear recommendations as to which proffered options are most suitable (124). Therefore, the findings of the research in Chapter 8 could support recommendations for the use of particular visual rehabilitation options after stroke. Thus, this research plans to analyse the visual rehabilitation options available for each visual impairment experienced after stroke.

1.4: Recovery of post-stroke visual impairments

Visual impairments can recover fully, partially or not at all during the time course following a stroke. Their recovery trajectories are unclear and the reported recovery rates vary greatly dependent on the type of impairment, the rehabilitation offered and the reporting study (6). Overall, prevalence, recovery rates, screening methods or rehabilitation options of reduced visual acuity following stroke have been poorly documented.

Recovery of visual field loss ranges from 0-44% for complete recovery (24, 139) and up to 72.2% for partial recovery (140).

The rate of recovery for ocular motility defects ranges from 7-28.5% for complete recovery, and up to 92% for partial recovery (8, 139, 141). Following stroke, sixth nerve palsies have the highest incidence of complete recovery of all the cranial nerve palsies (141).

Freeman and Rudge (8) reported a recovery rate of 71% for stroke survivors with reduced visual acuity although the extent of the recovery is unclear.

The reported recovery rates for visual neglect after stroke ranges from 29-78% (8, 142). Patients with visual neglect are more likely to require a longer hospital stay and have a poorer prognosis of functional recovery (34). The majority of recovery for visual neglect occurs within the first three months following stroke (139) with approximately 10% of the recovery seen within the first two weeks after stroke (143).

Recovery of other perceptual defects has been poorly documented. Poggel et al. (144) found a mean recovery of 28 days for visual hallucinations (Charles Bonnet

syndrome) and reported that spontaneous recovery of visual hallucinations will occur within the first 90 days following stroke.

Wide variability of recovery rates has been described due to variation in time of baseline assessment, length of follow-up assessment, accuracy of testing and exclusion of participants with severe communicative defects (6).

Depending on where the stroke occurs in the brain, the patient may suffer a range of cognitive and physical impairments including visual deficits (145). Furthermore, the extent and/or size of stroke can affect the severity of the impairments, and the rate of stroke recovery (146).

Few published articles have specifically reported visual recovery after stroke according to cerebral location, type (haemorrhage versus infarction) and extent/severity of the stroke. Where articles have reported recovery of post-stroke visual loss, the results are often variable and ungeneralisable.

Recovery of cognitive function after stroke was reportedly greater following left-sided infarctions, which the authors associate with the concept of left hemispheric dominance in the general population (147). This concept may apply to recovery of visual neglect, as higher prevalence and poorer recovery is frequently reported in right hemispheric strokes (148). Visual neglect is most commonly associated with parietal lesions, although middle cerebral artery strokes can affect several regions and so, neglect may also present following frontal and temporal damage (149, 150). However, these locations have not been compared in relation to the recovery of neglect.

One article reported no significant difference between type and location of stroke in relation to recovery of post-stroke hemianopia (151). Conversely, Gray et al. (24) reported that the extent of cerebral damage was likely to affect the recovery of post-stroke hemianopia, but acknowledged a limitation of their study, whereby they did not collect data on location or type of stroke. Celebisoy et al. (152) observed greatest recovery of hemianopia due to infarctions within the occipital pole region, and those within the striate area showed poorest recovery. However, this study only included patients with occipital lobe infarctions and is not generalisable to the entire stroke population.

The main locations of stroke resulting in ocular motility defects have been reported in the cerebellum, brainstem, thalamus, and internal and external capsules (141). However, the authors did not measure differences in recovery between these locations. A later study by Ali et al. (139) postulated that the recovery rate of eye movement disorders following stroke could be due to the size and location of the stroke (139). However, once more, the necessary data was not collected to accurately test this hypothesis (139).

There has been no published literature critically evaluating the recovery of visual acuity in relation to location, type and extent of stroke. Therefore, there is a need to robustly evaluate recovery rates of visual impairments after stroke, considering the aforementioned factors.

Visual impairments after stroke can reduce quality of life and functional outcome (139). Any group of people identified as poorly recovering from their visual impairments are, therefore, at greater risk of reduced quality of life after stroke. Where it is known that the type of stroke suffered will denote a poor prognosis on visual recovery, this information must be shared to inform rehabilitation planning.

Furthermore, various demographic factors have been noted to affect overall recovery after stroke, including age, education level, pre-stroke disability, smoking and socioeconomic status (146). A history of prior stroke, diabetes and older age were found to be associated with poorer recovery of post-stroke visual impairments specifically (139).

The main reasons for why these factors may affect recovery are explained in Chapter 3. The Black report suggested explanations for inequalities in health that included cultural/behavioural factors, natural selection and material conditions (46) amongst other reasons. It is possible that certain groups possess certain pre-requisites to stroke or are more likely to suffer severe disabilities post-stroke, hindering recovery. Likewise, there may be certain groups at greater risk of damaging health behaviours, which may affect stroke occurrence or compliance with rehabilitation, requiring consideration to address these issues. Only when issues impeding recovery are seen as *preventable* and *unfair* are they considered health inequalities, and should not be confused with natural “variations in health” (3).

This research aims to analyse the recovery rates for each of the visual impairments following stroke, and determine which have the best or poorest rates of recovery. This will support the investigation of health inequalities when compared to particular patient groups after stroke, and provide vital information that clinicians can share with patients when planning visual rehabilitation. Such knowledge can support efforts to provide equitable vision care nationally after stroke.

1.5: Overall aims of the research

This PhD research project aims to explore the possible health inequalities facing visually impaired stroke survivors and any possible means of overcoming these, through a range of stages in the stroke process:

1. Prior to stroke:
    a. To explore the demographic/lifestyle factors that could influence a person's chances of suffering post-stroke visual impairment
2. During their hospital stay/care:
    a. To explore the quality of visual care offered to patients (screening and rehabilitation methods)
    b. To explore differences in the recovery rates of the visual impairments suffered dependant on patient groups, and to provide vital information to support future and equitable planning of vision services.
    c. To explore differences in accessing visual services after stroke
3. Following discharge from hospital/long-term life after stroke
    a. To explore the lived experiences of life after stroke through stroke survivors' accounts

Chapter 2: Methodologies

2.1: The structure of the thesis

This section introduces the research design and structure of the thesis, to aid the reader in navigating and understanding the separate sections. The study rationale for this work explores unfair and preventable health inequalities facing visually impaired stroke survivors, in order to identify barriers and/or preferred means of providing an optimum standard of stroke care.

The methods chosen to research health inequalities considers both quantitative and qualitative inquiry. A mixed-methods design is considered an appropriate and effective means of researching such topics, as analysis of datasets contributes to our awareness of the extent of the health inequalities and the factors associated with them, whilst qualitative analysis can explore the underlying phenomena (42). The research project further deliberates a suitable philosophical ideology to underpin the multiple research approaches, which are described below in relation to the relevant sections of work.

This thesis comprises three main sections of work, which outline the methodological approaches to addressing the research aim. Each section focuses on the central concern of health inequalities in orthoptic care for post-stroke patients. However, each section is framed by a specific research tradition. The current chapter (Chapter 2) describes the methodologies within each of the three strands of research. The ethical implications of the research have been considered throughout the PhD study design, and these are described later according to the specific research method of each subsection.

The first section of the thesis (Chapters 3-5) introduces the background and aims of the study through three reviews of the literature, identifying the potential inequalities facing stroke survivors prior to suffering stroke, during their hospital care, and following discharge from the stroke unit. Attention is given to the patient demographics associated with stroke and visual problems, and the quality of visual

care offered to these patients, namely the vision screening process and proffered rehabilitation options.

Section two (Chapters 6-10) presents the findings from the epidemiology (IVIS) study. This section of the project follows a positivist ideology, of which knowledge obtained from the clinical findings can only be established empirically against observations and casual relationships. Statistical analysis of the quantitative data is, therefore, imperative in determining any differences in demographics.

The epidemiology study undertakes clinical work, consistent with departmental protocols and national guidelines, to explore the current profile of the stroke cohort in the North West of England (Chapter 6). This allows for identification of key demographic differences between the visually impaired and non-visually impaired stroke survivors, supporting analysis of inequalities within certain patient groups.

Furthermore, the clinical visual assessments and rehabilitation options used in current stroke care have been compared to the literature (section one) to explore any gaps or inequalities in healthcare, whereby orthoptists are using methods without sufficient evidence, or where patients are not being presented with the full range of evidence-based visual tools (Chapters 7-8). This section aims to explore the current state of orthoptic/stroke practice, and identify areas for improvement in patient care.

Alongside the clinical assessment and rehabilitation of these patients, this section of the research included contacting patients who were deemed “at risk” from their visual condition prior to routine hospital discharge. This data further allowed for exploration of inequalities in attending hospital after stroke to uptake the necessary visual care.

The final piece of work presented in this section (Chapter 10), displays the results from a service evaluation consisting of a national survey of the orthoptic professional body. The survey consisted of a scoping evaluation of orthoptic home-visit services nationally. This work was conducted in response to the findings of Chapter 9, which postulated home-visits as a means of tackling some of the inequalities identified. The survey consisted of both quantitative and qualitative responses, and so a thematic analysis approach was adopted to analyse the qualitative responses separately.

The third section of the thesis (Chapter 11) presents the findings from the qualitative arm of the research, through individual interviews and focus groups with visually impaired stroke survivors. This section of the research adopts a social constructionist ideology, exploring the lived experiences of stroke survivors through narratives and language, and attempts to neutralise power imbalance by giving the stroke survivors a voice in a way that the other chapters cannot. Social constructionism considers language and language-use to construct an approach to understanding the social world. Although this is a primarily clinical piece of research, discussion will draw on key philosophers and sociologists who asked questions about quality and inequality, to better place the research findings into the wider field of health inequalities.

The final chapter described in this thesis (Chapters 12), draws together the findings of the separate sections of research in a discussion of health inequalities, which illuminates the state of current stroke practice and highlights the required improvements to services moving forward.

2.2: Section one; the systematic literature reviews

Three systematic reviews were conducted during the initial stage of the project. The first review reported on the health inequalities associated with post-stroke visual impairments (Chapter 3). The second reported on the screening tools used to identify post-stroke visual impairment (Chapter 4). The third review reported on the rehabilitation options for post-stroke visual impairments (Chapter 5). The reviews were conducted according to the PRISMA guidelines (153). MeSH (Medical Subject Headings) terms were used to conduct the searches and the terms were carefully considered within the IVIS team, and developed from the key words reported in known, relevant articles. The MeSH terms were inputted to applicable search engines to ensure the known relevant articles were identified in the literature search before the final MeSH terms were agreed upon. The individual MeSH terms used for each review have been described fully in Chapters 3-5.

The Chief Investigator (CI) of the IVIS study and the second PhD student working within the IVIS study (see description of the IVIS study team: 2.3.1) contributed to

the screening and quality assessment (2.2.6) of the systematic reviews (with the exception of Chapter 3, which was conducted by the PhD student and CI only). Multiple authors ensured accuracy of results and reduced the risk of researcher bias. This followed recommendations by PRISMA, which stated that at least two authors should be contribute to a systematic review (154).

2.2.1: Included studies

The following types of studies were included: randomised controlled trials, controlled trials, cohort studies, observational studies and retrospective medical note reviews. Case reports were excluded due to the high risk of bias associated with these types of reports. Review articles were obtained from the search results but excluded from the final included numbers, as relevant articles relating to the research questions were extracted from the reviews and discussed separately. All languages were included and translation obtained where required.

2.2.2: Included participants

Studies of adult participants (aged 18 years or over) were included, where the subject had been diagnosed with a visual impairment as a direct cause of a stroke. Studies that included mixed populations were included if over 50% of the participants had a diagnosis of stroke and/or visual impairment, or if the stroke survivors had been discussed separately in the analysis, and data were available for this subgroup.

2.2.3: Types of outcome and data

Outcomes included clinical improvement, functional improvement in activities of daily living and quality of life measures, and visual assessment measurements.

2.2.4: Search methods for identification of studies

Systematic search strategies were used to search key electronic databases and the authors contacted known experts in the field. The search dates were kept as broad as possible to ensure maximum capture of relevant articles. This was in adherence to

the Cochrane handbook for systematic reviews (155). There have been no known previous systematic reviews exploring the same research question to provide specific dates from which an updated search can be conducted. The search dates were dependant on when the electronic databases were established, providing a varied range of dates to search within. The Cochrane Stroke Group Trials Register, the Cochrane Eyes and Vision Group Trials Register, the NIHR clinical trials gateway (for systematic reviews), the ISCRTN, the University of York trials centre and the following electronic bibliographic databases were searched:

- The Cochrane Central Register of Controlled Trials (CENTRAL, The Cochrane Library, latest issue);
- MEDLINE (1950 to February 2016);
- EMBASE (1980 to February 2016);
- CINAHL (1982 to February 2016);
- AMED (1985 to February 2016);
- PsycINFO (1967 to February 2016);
- Dissertations & Theses (PQDT) database (1861 to February 2016);
- British Nursing Index (1985 to February 2016);
- PsycBITE (Psychological Database for Brain Impairment Treatment Efficacy, www.psycbite.com).

In an effort to identify further published, unpublished and ongoing trials, the following methods were also undertaken:

1. Searched the following registers of ongoing trials:

   i) ClinicalTrials.gov (http://clinicaltrials.gov/);
   ii) Current Controlled Trials (www.controlledtrials. com);
   iii) Trials Central (www.trialscentral.org);
   iv) Health Service Research Projects in Progress (wwwcf.nlm.nih.gov/hsr_project/home_ proj.cfm);
   v) National Eye Institute Clinical Studies Database (http://clinicalstudies.info.nih.gov/cgi /protinstitute.cgi?NEI.0.html)

2. Hand-searched the British and Irish Orthoptic Journal, Australian Orthoptic Journal, and proceedings of the European Strabismological Association (ESA), International Strabismological Association (ISA), International Orthoptic Association (IOA) (http://pcwww.liv.ac.uk/~rowef/index_files/Page646.htm) and proceedings of Association for Research in Vision and Ophthalmology (www.arvo.org);
3. Performed citation tracking using Web of Science Cited Reference Search for all included studies;
4. Searched the reference lists of included trials and review articles about vision after acquired brain injury;
5. Contacted experts in the field (including authors of included trials, and excluded studies identified as possible preliminary or pilot work).

Search terms included a variety of MeSH terms and alternatives in relation to stroke and visual conditions.

2.2.5: Selection of studies

The titles and abstracts identified in the primary review were independently screened by the PhD student (KH) and second screened by the PhD supervisor/CI of the IVIS study, using the inclusion criteria discussed previously. Where it was not possible to establish if a study met these criteria from the title or abstract, the full paper was obtained. A secondary review of the full papers was then undertaken in this same manner to determine which studies should be included.

2.2.6: Quality assessment

Assessment of the quality of the studies included in this review consisted of the use of the following four checklists, and the quality assessment were undertaken by the PhD student (KH) in all cases, with additional, second assessments undertaken by the CI or second PhD student in the IVIS team for accuracy.

For the evaluation of the quality of evidence in randomised control and control trials, an adapted version of the CONSORT (Consolidated Standards of Reporting Trials) statement was used. The CONSORT statement covers 25 items within the following domains; title/abstract, introduction, methods, results, discussion and other information (156).

An adapted version of the STROBE statement was used to assess the quality of cross-sectional, cohort and control studies. The STROBE statement covers 22 items from introduction, methods, results and discussion (157). The adapted version of the STROBE statement used in this review included 18 items.

The GRACE (Good Research for Comparative Effectiveness) statement was used for observational studies with comparative effectiveness. This statement covers 11 items within the domains of data and methods. There is no formal scoring system used in this checklist, but it is suggested that if a paper addresses the majority of the checklist items, then it is deemed reliable (158).

Finally, the PRISMA (Preferred Reporting for Systematic reviews and Meta-Analyses) statement was used to assess quality of evidence in review articles. This covers 27 items within title, abstract, introduction, methods, results, discussion and funding (153).

All domains covered in these checklists are important factors to consider when evaluating the quality of evidence and risk of bias in the aforementioned articles. These domains were graded 'high risk', 'low risk' or 'unclear risk'. If it was clear the domain was performed, then this was described as "reported" and recorded as having a low risk of bias. If it appeared the domain was not included, this was described as "not reported" and deemed a high risk of bias. Insufficient evidence was labelled as an "unclear" risk.

The final Systematic reviews were published in 2016-2018 (105, 125, 159).

2.3: Section two, part one: The IVIS clinical study

The IVIS (Impact of Visual Impairment following Stroke) study was a prospective epidemiological study across three separate stroke units in the North West area of England: Hospital 1, Hospital 2 and Hospital 3. The names and areas of these hospital sites have been anonymised. Each hospital yields a different catchment area in order to achieve a more accurate representation to the general UK stroke population. Hospital 3 houses an acute stroke unit, whilst Hospital 1 and Hospital 2 contain hyper-acute stroke units. Census data were used to decipher the ethnic variations between these three surrounding areas prior to the study commencing (160-162).

Hospital 3 covers an area of 200,228 people (100,300 males vs. 101,928 females). The vast majority are White British, Irish or other (95.9%), with very few Black, Asian, Arab or mixed ethnicities (0.3%, 2.4%, 0.1% and 1.1% respectively) (161).

The 2011 census data reported a population of 233,933 in Area 2 with 90.1% of these White British, Irish or other; 4% Asian; 2.8% Black; 0.6% Arab and 2% of mixed ethnicities (162). However, Hospital 2's NHS Trust is a tertiary referral centre and takes admissions from outside of the Area 2. Therefore, the population sample recruited from Hospital 2 likely represents a greater proportion of the North West of England; not just the local population in Area 2.

Area 1 (surrounding Hospital 1) has a population of 466,415 (230,483 males vs. 235,935 females) (163). The ethnic spread in Area 1 is majority White British, Irish or other (88.9%), with significantly fewer numbers of Asian, Black, Arab or mixed ethnic groups (4.2%, 2.6%, 1.2% and 2.5% respectively) (160). Area 1 shows slightly more ethnic variation compared to the Areas 2-3.

A population sample of 1500 stroke admissions was determined based on the recruitment data of previous studies (32, 101). There are approximately 1000 new strokes per year across the three aforementioned stroke units. An average of 66% (61-71% with 5% confidence interval) of these stroke survivors are assumed to have a visual impairment (2). Furthermore, previous studies reported the exclusion of 25% of stroke survivors due to the inability to consent, death and non-attendance (32). Therefore, the recruitment of 1500 stroke admissions was required in order to ensure sufficient capture of all stroke survivors with visual impairment, and offer a

maximum follow-up of 12 months from the date of stroke onset. Patients were recruited between July 2014 and September 2015. As a maximum follow-up of 12 months was offered to each stroke survivor, the clinical study closed in September 2016.

2.3.1: The IVIS research team

A team of four orthoptic researchers were involved in the IVIS study: The chief investigator and primary supervisor to this PhD work; two orthoptists and PhD students, including the PhD student of this thesis work (KH); and a further specialist orthoptist at Hospital 2. The CI was responsible for overseeing the running of the IVIS study across the three sites. All members of the team were qualified orthoptists with specialised extended roles in stroke and acquired brain injury, and had undertaken NIHR Good Clinical Practice training. Additionally, all members of the IVIS team obtained honorary clinical contracts from the recruiting hospital sites, in order to conduct the orthoptic screening and vision care under supported clinical contracts (not research passports). All members of the team screened new stroke admissions for visual impairments and offered suitable visual rehabilitation. Where required, referrals were made by the orthoptic researchers to the hospitals' outpatient departments for continued visual follow-up. Each of these hospital sites had a pre-established orthoptic/stroke service, of which the IVIS team either took over from (to avoid unnecessary duplicated assessments in the inpatient units), or worked alongside the current clinical orthoptists (in the outpatient departments).

The CI and two PhD students undertook individual research projects within the IVIS study. The CI explored the prevalence and incidence of post-stroke visual impairments, using data collected from the three named hospital sites. The PhD student that researched the current thesis work aimed to explore health inequalities within this population through analysis of the data collected from this same cohort. The second PhD student working in the IVIS team developed a patient reported outcome measure (PROM) and recruited to the IVIS study as a research assistant to the CI. For the PROM research, this student required separate written, informed consent from the IVIS patients, and from those recruited at eight additional hospital

sites for the sole purpose of her PhD research (164). This PROM research was conducted under a second NHS ethics approval, separate to the PhD research described in this thesis.

Therefore, for the purpose of the PhD project described in this thesis, only the data collected from the three recruiting sites (Hospitals 1-3) were obtained and analysed by the PhD student (KH).

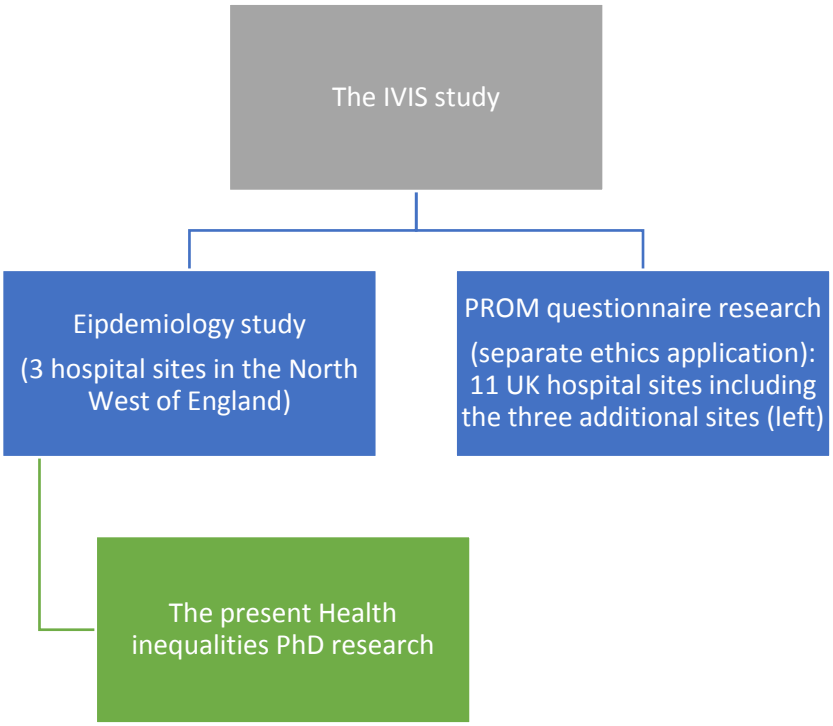


Figure 2.1 The IVIS study research projects

2.3.2: Ethical approval

Research with patients requires ethical approval (Appendix 1). Key ethical principles underpinning the IVIS project included informed assent, autonomy (the right to choose to opt in/out at any time), with clear distinction between the research and their care. This required transparency, integrity and honesty at all times, adhering to the Data Protection Act and research governance principles. The IVIS study required the collection of results from routine visual assessments for those patients who had been screened for visual impairment in addition to reasons for non-completion of screening. Currently the use of assent is established clinical practice when

approaching a patient to offer visual screening. In some cases where assent was not provided, but previous assessment detected a visual impairment that was known to affect the patient's quality of life or subsequent rehabilitation, treatment may have been provided in the patient's best interests (165). For example, in cases where patients admitted to the stroke ward were assessed by the orthoptist and identified as having glaucoma, an appropriate referral was made to ophthalmology for formal evaluation.

A standard format of recording assent occurred across all recruiting sites: the patient gestured agreement/was unable to provide assent due to lack of capacity/cognitive impairment/low Glasgow comma score etc. Of note, this statement is already part of routine clinical care and was not introduced as part of this study. The IVIS study did not intend to depart from routine clinical practice.

Ethical approval was attained from the NHS Health Research Authority (HRA) on the use of patient data for research (IRAS ID: 150590). Ethical approval was required to collect vision data in anonymised numerical format where patients assented to vision screening and follow-up assessment, in order to calculate the incidence of vision impairment and prevalence of types of visual impairments in the stroke population. It was essential for the research to protect confidentiality and to do no harm. For the purpose of this research, all identifiable information was removed from the data so that no link could be made with the individual that it came from. As no link could be made, the data could be shared within the IVIS research team without further consent (166). In addition, patient and public involvement was considered throughout the study period. The national Vision and Stroke User Reference Panel (VSURP) were consulted on the use of patient data without written consent, for which they gave their approval.

Using the NRES No Material Ethics Issue Toolkit (NMEIT), the IVIS study fitted within category 1: Research using data or tissue that is anonymised to the researcher.

Additional ethical approval was required for the qualitative arm of this research project and is described in detail in 2.5.3.

2.3.3: Potential harms/risk

An adverse event is described as any untoward medical occurrence in a patient or clinical study subject (167). A serious adverse event is described as any untoward or unexpected medical occurrence or effect that results in death, is life threatening, requires hospitalisation or prolongation of existing inpatient's hospitalisation, or results in a congenital or birth defect (167).

It was planned that any adverse event from the IVIS study would be reported and directed to the CI in the first instance. Furthermore, serious adverse events were to be reported to the CI within 24 hours. However, relapse and death due to stroke and hospitalisations for the elective treatment of a pre-existing condition did not require reporting as a serious adverse event. All serious adverse events were to be reported to the University clinical governance committee where, by the decision of the CI and the stroke team, the event was related to the study.

No adverse events were expected prior to the study commencing, as the study followed routine clinical practice for these patients with regards to the screening assessments and management options. All patients were cared for with usual local NHS care. No procedures were planned in addition to normal clinical care.

2.3.4: Data storage

A site file containing essential study documentation was held at each of the hospital sites. Data collection used paper CRFs completed by the personnel named on the delegation log as authorised to do so. All CRFs were photocopied: the photocopy was held securely at the University of Liverpool for data inputting and analysis and the original returned to the hospital site within seven days, where it was held securely within the research office. Hard copy data and computer data will be kept in its anonymous form for 15 years post cessation of the study, in accordance with the University of Liverpool's clinical governance procedures. The data will be stored securely at the University of Liverpool during this time, in accordance with the Data Protection Act (168).

2.3.5: Funding

The CI obtained funding through the NIHR for the IVIS study as a five-year fellowship award. The work undertaken for this PhD research exploring health inequalities has been supported through funding granted by the NWC CLAHRC as a three-year PhD stipend.

2.3.6: Recruitment

All stroke admissions were identified by a stroke research nurse at each of the recruiting hospital sites (as part of the approval granted by the regional Clinical Regional Network), and notified the orthoptic research team of the patient details. Current orthoptic practice mandates that each patient is routinely screened as per the national stroke guidelines (104) to determine whether or not they have a visual impairment. A confidential study identity number was given to each new stroke admission and recorded on a screening log, which was kept securely on the hospitals' stroke wards.

Currently, when patients are screened following stroke, there are a number of patients that cannot be assessed due to the severity of the stroke. Reasons may include various health conditions, unconsciousness or lack of mental capacity. These patients were given an identifier number, and reasons for why assessment was not possible was recorded confidentially in coded format. Over time, mental capacity can fluctuate or the patient's health can improve. Therefore, it was possible to revisit the patient on another day when mental capacity and health status was sufficient for visual assessment. The Data Protection Act, the Mental Capacity Act and national codes of conduct were adhered to at all times (165, 168-170).

For conscious stroke survivors, current orthoptic practice involved asking the patient if they wished to receive an eye examination. Where the patient assented, the vision screening went ahead. Where the patient did not provide assent, the visual assessment was not conducted at that time and a screen may have been attempted on another occasion. As before, each patient was given an identifier number, and reasons for why assessment was not possible was recorded in coded format.

Stroke survivors identified as having a visual impairment were monitored (as per national guidelines (104) and in line with the local hospital policies and procedures) on the stroke ward whilst they remained as an inpatient, or using routine NHS outpatient appointments when they had been discharged from inpatient care.

2.3.6.1: *Inclusion criteria*

Patients were recruited following admission to one of the above hospital sites with a clinical diagnosis of an acute or chronic stroke (lasting more than 24 hours to exclude TIAs) or if they were thrombolysed. Stroke term was defined by Bernhardt et al. (74), and an acute stroke was classified as within the first 6 months post-stroke. Chronic stroke was classed as greater than six months post-stroke. The stroke patients were 18 years of age or older with the ability to assent to vision screening using verbal or non-verbal indications of agreement. For later statistical analysis (Chapter 6) of new visual impairments, only those diagnosed as acute stroke were included, as the differing stroke conditions and recovery at these two stages are not comparable.

2.3.6.2: *Exclusion criteria*

Patients were excluded if they were less than 18 years old, had severe cognitive impairment preventing screening (e.g. vascular dementia), or if the individual was placed on end-of-life care. The cut-off age at 18 years was used to exclude cases of congenital stroke, due to the vastly diverse diagnoses and management observed in childhood stroke, for example, sickle cell anaemia, moyamoya disease and cerviocephalic arterial disease (171). Furthermore, the 24-hour window used to exclude TIA is only applicable for adult patients, as many congenital infarcts mirror the brief symptoms of TIA. Therefore, it was crucial to exclude any possibility of congenital stroke or childhood onset stroke.

2.3.7: Outcome measures

It was important that the vision tests used were appropriate for stroke survivors who may have added cognitive and/or communication difficulties and orthoptists have considerable experience of how to adapt clinical tests for this use. Validated tests

were chosen that have been previously used in stroke/vision studies (141). When gathering information about visual symptoms, open-ended questions were asked regarding what the patients could see. In the presence of communication difficulties, alternative options were used, such as, thumbs up/down along with direct yes/no questions about the presence of visual impairment symptoms, and support from families, carers and the other members of the stroke MDT such as, speech and language therapists.

Moreover, investigation of medical case notes, interpretation of brain imaging, thorough case history questions (including family members and carers) and MDT discussions aided the orthoptic investigation and diagnosis of pre-existing ocular conditions and pre-existing strokes. This multi-disciplinary approach to the data collection, such as interpretation of the location of stroke, aided the diagnoses of new visual impairments secondary to the current stroke, as previous literature has established the likelihood presence of certain visual impairments depending on the cerebral location of the stroke.

Where a previous ocular condition was identified, for example, visual field loss secondary to glaucoma or reduced central vision due to cataracts, the patient was still screened for new stroke-related visual loss, which could often be distinguished from the previous condition. See section 2.3.7.1 for identification of new and partially new visual impairments and how these were followed-up.

2.3.7.1: *Visual assessment outcome measures*

Visual acuity was assessed using logMAR or Snellen's charts where possible, with a matching card if necessary, for aphasic patients or when English was not the first language. Distance visual acuity was measured at 3m on the hospital ward and 6m in the outpatient clinic (employing routine distance conversion measures), and near visual acuity was measured with a near vision chart at 40cm. Normal visual acuity was recorded as 0.200logMAR at 6m and 0.300logMAR at a third of a meter. The cut off value for visual acuity aimed to leave vision better than the current driving level (172) and correlated with the well-established, normative values in adult orthoptic patients (173, 174).

If visual impairment was present and the patient could communicate their vision as being less than the letters presented on the card, counting fingers, hand movements or perception of light were used to assess the level of vision. These were recorded as 2.00 and 2.50 logMAR respectively. When linear acuity testing was not possible, acuity was tested using the Cardiff-City grating cards to assess preferential looking. If the patient was predominantly unresponsive, the "fixing-and-following" technique was used, and vision recorded as 2.00 logMAR. Where non-LogMAR tests were used, the final visual acuity score was converted to LogMAR decimal using the Royal College of Ophthalmologists' guidelines, for consistency in later analysis.

Colour vision was assessed using the City University colour vision test (third edition). The test was scored out of ten and a score of eight or less was considered impaired (175). If present, the defective colour type was recorded: deuteranopia, protanopia or tritanopia. Contrast visual acuity was assessed using the Mars letter chart and the patients' rate of reading was measured with the Radner reading book, with the reading speed, size of print and number of errors documented on the CRF. Normative values were recorded as ≥1.00Log for contrast sensitivity, and a print size ≥N8 with the Radner reading test, as per previously reported adult-age norms (176, 177).

Ocular alignment and ocular movements were measured using an objective observation of eye position with the cover/uncover and alternate cover test in primary and cardinal positions of gaze. Limitations of eye movements were graded on a scale of 1-4 (1=minimal, 2=small, 3=moderate and 4=severe restriction of eye movement), as per well-established orthoptic practice (178). Smooth pursuit and saccadic eye movements were measured in horizontal and vertical positions and an orthoptic assessment and observation of eyelids and pupils conducted for each patient. Lids were observed for unilateral and bilateral ptosis and palpebral fissures were measured in centimetres. The direct and consensual pupil responses were observed to a light. Binocular convergence was measured against age-matched normative levels as recorded on the RAF rule scale (179). Moreover, if the patient had adopted a head posture following ocular motility impairment, the details of this were recorded and the severity graded.

Assessment of binocular single vision (BSV) was performed on the appropriate patients (those with potential for BSV) using Bagolini glasses, fusion range measurement and with the stereoscopic Frisby test. Each of these methods require subjective patient responses although, where this was not possible in cases of aphasia or reduced cognition, an objective measure of their BSV was performed using fusional vergence and by overcoming a 20 prism dioptre (PD), 15PD, or 10PD loose prism. Additionally, a gross assessment of BSV using preferential looking or pointing to the Frisby circle was also used in cases of reduced cognition, speech or fatigue.

Visual field assessment was conducted using the confrontation method at the acute stage of stroke on the in-patient ward and again, in outpatient clinics in cases where automated perimetry could not be undertaken by the patient. Red targets mounted on pale, wooden sticks, were used as the target for the confrontation visual field assessment. The Octopus 900 visual field machine was used to quantifiably measure the area of visual field binocularly, using semi-kinetic and suprathreshold static perimetry. Normal binocular visual field function was classed as less than four missed points in any cluster, within 120° horizontally and 40° vertically, with no defect in the central 40°. This was in accordance with the national DVLA guidelines using the Esterman programme (180). One of the known benefits of using this machine is that it allows the orthoptic examiner to pause the test and readjust the patient. This allows the examiner to reiterate the test method, which was often necessary in this cohort due to impaired memory or cognition. Moreover, it allows the examiner to manually place additional static or kinetic points during the test whilst the test is running, to accurately investigate the area of field loss.

Visual neglect/inattention assessments were conducted using tests taken from the paper-and-pencil Behavioural Inattention Test (181); the line bisection test, clock drawing and a cancellation task. Patients were asked not to move the page in front of them to avoid them moving the page away from their neglected side. If their handgrip had been affected by the stroke, they were asked to point to the line or cancellation targets on the page and the examiner marked the page where the patient had pointed. The clock drawing assessment was attempted in cases where

the patient could not hold a pen but could communicate verbally, as they were asked to point on the clock face and say the number. The examiner could then draw the clock face as directed by the patient.

However, in cases where reduced cognition, aphasia or paresis prevented formal examination or hindered the tests' reliability, an objective observation of the patient's visual responses, to confrontation and visual extinction, was used without need for verbal input.

Visual perception was assessed through careful questioning of the patient, asking them to report the presence of hallucinations, visual illusions or disturbances (listed below). For example, "are you seeing anything that you think might not be real?", "do people or objects appear distorted or tilted?", and "can you describe what your vision looks like?" Simultanagnosia and colour perception deficits were assessed by asking the patient to describe pictures of objects or scenes. Additionally, defects with reading and colour were identified using the Radner reading tests and City University colour vision test. The visual perceptual disorders screened are described in Table 2.1.

Visual impairment was deemed present where the patient was able to report an impact of their visual symptoms and/or where there was a deficit of visual acuity worse than 0.300logMAR (6/12 Snellen), where there was presence of visual field loss, visual inattention, acquired strabismus and/or an eye movement abnormality.

2.3.7.2: *Orthoptic follow-up schedule*

The long-term follow-up of the stroke survivors identified as having a visual impairment (as per national guidelines and considering the individual needs of the patients) determined the natural history in terms of recovery of visual function. Full recovery was defined as a return of vision to age-matched normative values (these have been reported in respect to the type of visual function; see 2.3.7). Partial recovery was defined as a reduction in visual symptoms and/or reduction in measurements of visual impairment but outside normal limits of visual function. A "partly/partially recovered" impairment consisted of several various scenarios. This included impairments that recovered beyond the initial visual state seen on first assessment, but did not recover to "normal" levels, as described in 2.3.7.

Table 2.1 The visual perceptual disorders screened in the IVIS study

Visual perceptual disorder	Definition
Alexia	The inability to read or recognise words or letters
Polyopia	The patient observes several images for one object
Formed hallucinations	The patient describes specific objects, images/unformed hallucinations (e.g. lights, colour or indistinct objects)
Palinopsia:	The image of an object or person persists after the object has been removed
Perserveration (apraxia)	The inability to perform skilled sequential purposeful movement
Akinetopsia	The patient cannot perceive movement
Altered image size	Image size appears incorrect; too big or too small
Colour perception (Achromatopsia)	The patient sees colours as "washed out" although would successfully pass a formal colour vision assessment
Object agnosia	The inability to recognise common objects
Face recognition (Prosopagnosia)	The inability to recognise previously known faces e.g. family members
Depth perception	Impaired depth/three dimensional perception
Motion perception	The inability to correctly determine the speed and direction of moving objects
After images	Images continue to appear after it has ceased
Visual tilt	Objects appear tilted with no torsional ocular motility defect
Visual illusions	Observing an object as something other than it is
Simultanagnosia	Patient fails to describe all elements of a scene
Visual crowding	The inability to recognise objects in clutter
Visual disorientation	Personal, sub personal or spatial
Alexia	The inability to read or recognise words or letters

Additionally, if a previous visual impairment was known, for example, glaucoma-related VF loss identified from hospital case notes, then full recovery was reached when the patient's visual status returned to their previous, abnormal state.

Furthermore, a patient's visual state was recorded as "partially recovered" if they suffered multiple impairments, and some recovered fully or partially whilst others did not. Therefore, their visual condition was better than first seen on baseline assessment, but some stroke-related visual impairments remained. No recovery described cases where the patient showed no signs of recovery from the visual impairment measured at the baseline assessment.

For those with limited recovery, follow-up plotted their outcome and interventions required for visual impairment. Follow-up visits were planned once a week while the patient was an inpatient in hospital to closely monitor recovery, or at 1-, 3-, 6-, 9- and 12-months post baseline assessment if the patient had been discharged in order to follow usual clinical care and capture this data.

At the patients' initial assessments, baseline information and first clinical assessment results were recorded on a clinical record form (CRF): see Appendix 2. After initial examination, the outcome was recorded and coded as to whether or not full assessment was possible and if not, the possible reasons for this. Any management plans or rehabilitation offered to the patient, and the planned date of follow-up, were subsequently recorded. If the patient was discharged, their discharge destination was documented, where this information was obtainable from the hospital notes or from discussion with the patient at their next follow-up appointment.

2.3.7.3: *Additional outcome measures for the investigation of health inequalities*

A measurement of socioeconomic deprivation was calculated using the English Index of Multiple Deprivation (IMD), in order to assess whether or not social deprivation was a determining factor of stroke outcome, in relation to the presence and recovery of the post-stroke visual impairments, using the patients' postcodes at time of stroke (Chapter 6).

Additionally, the IMD scores for those individuals who failed to attend their hospital outpatient appointments were compared to investigate whether or not those individuals from more deprived areas were less likely to attend their hospital appointments (Chapter 9). The level of area deprivation is described by stating which 10th percentile within which an area falls. These deprivation "deciles" rank all areas in England from most deprived to least deprived on a scale of 1-10 (182). Furthermore, comparison of deprivation score with outpatient hospital attendance allows for analysis as to whether or not area of residence is a predictor of poor hospital attendance (91). Various methods for deprivation analysis exist however, the IMD has been chosen as the most relevant to the IVIS study. The IMD has been described as a guide to resource allocation and provision of services in the UK (183). As the overarching aim of this study is to identify health inequalities, in which to inform commissioning and planning of stroke services, the IMD was deemed the most appropriate assessment tool.

The IMD "postcode lookup" tool was used to calculate the IMD score associated with the postcode of each of the study participants (184). The postcodes were converted with the tool between November 2016 and January 2017 and so, the IMD scores were representative to the deprivation levels during that time.

Additionally, patient data including date of birth, date of stroke onset, ethnicity, Barthel index (severity of stroke), and discharge destination, were recorded on the CRF to help profile the visually impaired population of this study, and aid the investigation of health inequalities. The patient demographic data were compared between those with post-stroke visual impairment and those without visual impairments, to determine whether one, or any, patient group is more at risk of encountering post-stroke visual impairment, and thus, the negative impact of these impairments.

2.3.8: Statistical analysis of the clinical study

The Statistical Package for Social Science (SPSS) version 24.0 (185) was used to report the descriptive statistics and regression analyses displaying the presence or absence of visual impairments, adjusted for determinants/potential health inequalities.

Additionally, survival analysis was used to report the recovery of the post-stroke visual impairments and any potential impact from variables representing patient demographics, which could indicate potential health inequalities.

2.3.8.1: *Descriptive statistics reporting on the patient demographics*

The overall project followed a mixed-methods design, as both qualitative and quantitative methods were used to enhance the overall quality of the results (186). The IVIS project was initially analysed through quantitative statistical methods and further explored through qualitative analysis of focus groups and patient interviews (Chapters 10-11).

The first stage of analysis was conducted from the patient follow-up assessments. The results of these clinical visits were recorded confidentially onto standardised case report forms (CRFs) and the details inputted onto a secured MACRO database for analysis. All elements of patient information were coded for to ensure confidentiality was maintained. After patient recruitment ceased, the database underwent quality checks and was reviewed for missing information, which was recovered and inputted.

Initially, frequency tables were observed from the full database using SPSS, to aid planning of further analysis. Descriptive statistics were used to report the profile of the visually impaired stroke cohort compared to those found to have normal vision after stroke. Additionally, the number of patients with each of the visual impairments, or multiple impairments, were described. Furthermore, the number of patients who died before assessment was possible, or the number that could never be assessed due to poor health was reported.

2.3.8.2: *Directed acyclic graphs*

Chapter 6 introduces the statistical analysis of the data collected in the study, and describes the first of two Directed Acyclic Graphs (DAG) used in the research design. A DAG is a causal diagram, which has been formally developed for epidemiology research (187, 188) and aims to minimise potential bias in studies by considering all potential confounding variables, determining an unbiased estimate of the effect by making causal inferences about the exposure variable (188-190). Traditionally,

researchers would identify the associations between variables in an equation, and all variables are then adjusted for in a multiple regression model (188). Adjusting for the covariate confounders changes the effect estimate of the model. However, recent advances in epidemiology research have proved these traditional methods to be insufficient, as there is no consideration for causation, and thus a lack of careful discrimination of all potential variables that must be adjusted for (188). It has been suggested that the traditional approach of adjusting for confounders may introduce bias as opposed to minimising it, as it may lead to inappropriate data analysis and interpretation (188). The DAG approach can be used to help choose which covariates should be included in traditional statistical approaches in order to minimise the magnitude of the bias in the estimate produced (188).

A DAG displays assumptions about the relationship between variables. The assumed relationship takes the form of a line between the variables of interest (191). These lines are "directed", meaning they move in one, linear direction, and the lines must relate to 'time', such that the potential cause occurs prior to the potential outcome (190, 191). The DAG represents the effect that one variable may have on the other but there are no feedback loops or cycles, as the DAG can only move forward (191). The causal lines on the DAG represent a direct relationship between the exposure variable and the outcome variable, whilst the biasing lines represent a relationship between the mediators impacting on the dependent, exposed variables that could still cause an outcome based on the biasing path. Traditional analysis defines confounders as variables associated with both the exposure and outcome, which are not part of the causal path between the exposure and outcome variables. Mediators are variables that lie in the causal path, between the exposure and outcome. Adjusting for confounders in regression analyses reduces bias, however, adjusting for mediators removes the part of the effect of exposure and outcome, which is explained by the mediator (190). As DAGs consider the causal path as a whole, they refer to overall confounding in the model rather than individual variables as confounders (190). Therefore, each line signifies an effect on the outcome, but only those variables directly or indirectly affecting the outcome for each variable of interest, must be adjusted for in the regression analysis. Of note, there can still be confounding if variables are not included in the model or if they have not been

measured (190), therefore, the DAG approach reduces possible bias but may not eradicate it entirely.

In order to create the DAG, prior to undertaking the regression analyses, topological sorting is required to ascertain the order of the relationships between the aforementioned variables (192). The current evidence described in the results of the systematic review (Chapter 3) identified the variables of interest and guided the initial topological sorting of the variables into the DAG model. The preliminary DAG model was presented to the IVIS research team and the VSURP group for discussion and re-organisation where necessary, until the final model was deemed an accurate representation of the causal pathway.

The DAGs used in this study were created using the online programme DAGitty.net (189), to identify the 'minimum adjustment set' (the minimum set of factors to eliminate confounding), required for later regression analyses exploring the presence or absence of post-stroke visual impairments, and the attendance of the orthoptic outpatient appointments (see Chapters 6 and 9). The selection and topological ordering of variables for both DAGs have been described in detail in their relevant chapters (Chapters 6 and 9).

2.3.8.3: *Survival analysis*

Visual function measures have been compared longitudinally for stroke survivors with visual impairment, and changes in visual acuity, eye movement, visual perception including neglect, and visual field loss explored. Using SPSS, survival analysis investigated how many patients recovered from the visual impairments and at which time point this event occurred. This was further observed for various health inequality determinants/groups to investigate whether certain groups were more likely to recovery from their visual impairments, using Cox's proportional hazards regression model. Kaplan Meier curves were further used to display these findings.

2.3.9: Inequalities in the assessment and rehabilitation of post-stroke visual impairments

Where stroke survivors have presented to hospital, the efficacy and accuracy of their visual screening assessment was explored, along with the range and suitability of the visual rehabilitation options offered.

A comparison was made between the screening assessments and management offered in the IVIS study and those offered a decade before in a similar, large-scale vision/stroke study. These were further compared to the published literature identified through the systematic reviews conducted in the first phase of the study, to investigate whether or not stroke survivors are receiving the most appropriate and up-to-date care, in instances where a vision service is being provided.

2.3.9.1: *A comparison of the visual assessment methods*

A comparison was made between the screening methods used in the IVIS study (2.3.7) and those identified from the systematic review (Chapter 4). A description of the methods and screening tools identified in the systematic review are described in Chapter 4 and have been published elsewhere (105).

The results were then compared to the VIS study (32). The VIS study was a prospective, observational multi-centre cohort study, which aimed to review and define the visually impaired stroke population, to determine the prevalence of post-stroke visual impairments and identify the associations and outcomes for this population. In total, 915 stroke survivors were recruited from 20 recruiting sites in the UK. They were ≥18 years old and suspected of having a visual impairment. Of the 915 recruits, 92% (n=840) had a confirmed visual impairment. Standardised referral and investigation protocol included assessment of patient demographics, stroke and ocular history, visual acuity, ocular alignment and motility, visual field and visual perception, with capture of rehabilitation options. A full description of the methods and materials used in the VIS study has been reported elsewhere (32). The VIS study has also been compared to the results of the systematic reviews (Chapter 4-5) to identify key changes to orthoptic practice, and the inclusion/exclusion of visual tools, over the last ten years (see below). However, it must be noted that the key methodological differences between the VIS study and the IVIS study yield vastly

different prevalence figures, and thus, the intention is not to compare these findings. The VIS study was conducted in outpatient clinics, where patients had previously been screened by non-eye specialists for post-stroke visual impairments and referred to the orthoptic department for formal assessment. The VIS study population therefore reflects visually impaired stroke survivors. The IVIS study was conducted on acute wards where screening was performed by the stroke-specialist orthoptists, and therefore, the findings reflect a general stroke cohort, not only those identified as having a visual impairment. The incidence figures from IVIS are thus, more realistic of the general stroke population.

The assessment tools used in the IVIS study and the VIS study represent those used in a rigorous, orthoptic-stroke research service, and substantiated through either clinical evidence or clinical experience. The reported tools screened for each of the possible visual impairments following stroke; central visual acuity defects, ocular alignment and motility defects, visual field loss and visual perceptual deficits including visual neglect. The screening assessments used in the IVIS study were part of the routine clinical practice at each of the recruiting sites, which abided by the BIOS extended practice guidelines for stroke and neurological patients.

2.3.9.2: *A comparison of the visual rehabilitation options*

The visual interventions used in the IVIS study were reported and compared against the rehabilitation options identified in a comprehensive synthesis of the published literature (Chapter 5). Prior to the IVIS study commencing, a broad range of orthoptic management options (stroke and non-stroke specific), were anticipated by the IVIS team and therefore, coded for inputting to the CRF and database if used. These methods were known to the clinical orthoptists through clinical experience and/or through the published literature. The orthoptists treating the patients in the IVIS study were aware of the full range of available options. However, in practice not all treatments coded for the CRF were used during the study. Only those offered to patients during the study period have been reported in Chapter 8. The methods used in practice reflect those used at each of the recruiting sites as part of their normal

clinical practice, and were found to be useful in treating stroke impairments specifically.

A comparison was made between the rehabilitation options offered in the IVIS study and those identified from the systematic review (Chapter 5). The full description of the methods used in this systematic review and the results of the quality analysis of the included articles are described in Chapter 5 and have been published elsewhere (125).

The results of this comparative review were then compared against the VIS study, as described above (2.3.9.1) to support recommendations for the use of particular visual rehabilitation options after stroke.

2.3.10: Inequalities in outpatient attendance

The final strand of the second phase of this PhD research explored inequalities in attending the orthoptic follow-up appointments offered to patients following discharge from the stroke unit. Routine clinical practice at each site included contacting non-attending patients by phone that were deemed "at risk" to explore support options or alternative means of attendance. This part of the research was embedded within the IVIS clinical study (phase 2) and thus, covered by the ethical approval granted to conduct normal clinical orthoptic practice at each of the hospital sites.

Not all patients could be contacted for a variety of reasons described in chapter 9, but attempts were made to contact all patients where it was known that they had a (potentially disabling) visual impairment and were going to be routinely discharged from orthoptic care.

A CRF (Appendix 3) was created to ensure the collection of information from the phone conversations was consistent between the three sites, as various clinical orthoptists could have conducted the phone calls. The CRF questions were circulated between the IVIS team and the orthoptic stroke lead at each hospital, to ensure the questions covered usual areas of concern and were a true reflection of normal departmental practice. The CRF was altered where necessary, to ensure the final

questions asked were an accurate representation of usual practice at each site. This further aided consistency between phone calls to reduce potential bias.

Stroke survivors who had been accurately identified as having post-stroke visual impairments were offered an outpatient orthoptic appointment following discharge from the stroke units. Each patient that failed to attend or cancelled their appointment with a request for no further follow-up were routinely contacted by telephone, where it was believed that they were "at risk" of coping with their new impaired visual status. These patients were asked of any difficulties in attending their appointments, which could reveal potential inequalities with their visual care, which could possibly be remedied to allow for hospital attendance. All responses from the telephone conversations were anonymously documented on the recording sheet and this information was later inputted onto a secured Microsoft Excel database. Patients were then offered assistance, where possible, such as postponing further appointments to a more suitable date or arranging hospital transport.
Additionally, it was noted during the clinical study that a number of patients were deemed unsuitable for follow-up of their visual impairments. Reasons for this were documented prospectively where possible, or retrospectively through medical note review and included in the overall analysis of health inequalities.

2.3.10.1: *Statistical analysis of outpatient attendance*

A password-secured database was created on Microsoft Excel to keep an anonymised record of reasons for non-attendance. This database was created in order to identify recurring issues and potential health inequalities relating to reasons causing patients with stroke-related visual impairments to miss their outpatient appointments.
Information was coded before inputting to the database to further maintain patient confidentiality and aid future analysis (Appendix 4). Their final hospital attendance code was recorded as one or more of the following:

1. Did not attend appointment
2. Cancelled appointment
3. Medically unwell
4. Patient refusing appointments

5. Discharged from inpatient ward (with no plan to follow-up in outpatient clinic)
6. Put on end of life treatment
7. Lives out of area

Furthermore, details were recorded as to whether or not each patient could be contacted following two missed appointments, as sufficient contact details were not always available from the hospital file or patient's general practice. If for any reason a patient could not be contacted, the reason for non-attendance was coded as "unknown". The patients who could be contacted provided their reason for non-attendance, which was recorded as one or more of the following options:

1. Too unwell to attend appointment
2. Transport difficulties
3. Patient/carer has no visual concerns
4. Already attends an eye clinic/own optician regularly
5. Forgot about their appointment
6. Other reason (reason recorded)

Additionally, a routine clinical decision was made not to contact a number of patients after discharge, which was normal practice at each of the sites. This was often because the patient's general health was extremely poor prior to discharge, or it was known that the patient would have difficulty attending an outpatient appointment from their final hospital report. Difficulty attending was often apparent through discussions with the nursing home staff or the carers, who reported the patient's refusal to attend appointments as a result of reduced cognition, low mood or failure to manoeuvre them from a hospital bed into suitable transport. These patients were therefore, not contacted to enquire about poor attendance, as this would stray from the normal hospital procedures.

If it was known that the discharge destination was too far from the hospital site, such as in cases where patients were discharged to a nursing home closer to relatives in a different town or county, these patients were also not offered an orthoptic outpatient appointment. These patients were coded as "*clinical decision as*

unsuitable for follow-up" along with one of the above codes where possible, to better describe the clinician's reasoning for this decision. Once again, this was the standard procedure at each of the hospital sites and so, could not be altered for the purpose of the research.

The demographics of those that were discharged and offered an appointment and those not offered an appointment across each of the hospital sites were compared in order to identify any significant differences that may infer a health inequality within a particular group. Moreover, of those offered a follow-up appointment, an analysis was conducted between those that attended their appointments and those that did not attend (cancelled/DNA). The details of these patients were analysed using the Pearson's Chi-squared test of association. Fisher's exact test was used to assess associations with gender (which produced a 2x2 cross tabulation table with an expected count less than five) as this was a more appropriate test due to the small cell sizes (see 9.3.1).

A second DAG was used to explore all possible confounding variables when exploring the effect of patient demographics on post-stroke visual impairment (see 2.3.8.2). The results from the second DAG development are described in Chapter 9 (9.3.1), along with the rationale for the included variables. The resulting DAG provided the covariates required for the subsequent regression analyses in 9.3.1.1-9.3.1.7.

2.3.10.2: *Appointment reminders*

The receptionists, orthoptists and booking departments at each hospital site were contacted via email or in person, and asked to confirm whether or not reminders are used and if so, which type and at what time are the reminders sent out. Each of the sites was asked to provide the following information for uniform comparison:

1. Do your ophthalmology patients receive appointment reminders?
2. If so, what type of reminder do you send (text/phone/postal)?
3. How long before their appointment do they receive the reminder?

2.4: Section two, part two: Service evaluation of the national orthoptic professional body members

A service evaluation was conducted in this research project to explore the provision of home visits by orthoptists registered with the professional body, the British and Irish Orthoptic Society (BIOS). The service evaluation aimed to explore the use of a home visits service within the UK and Irish orthoptic departments, to manage visual disorders (Chapter 10). The rationale for this arm of the research was to explore possible means of overcoming some of the issues facing the visually impaired stroke population, as identified in the second phase of the research (Chapter 9).

Service evaluations have been described as, "'a study in which the systematic collection and analysis of data is used to judge the quality or worth of a service or intervention, providing evidence that can be used to improve it' (193). By evaluating current practice through service evaluations, researchers can generate useful information to aid local decision making (194).

A service evaluation was chosen as the method of choice for this portion of the research, as the overarching aim was to evaluate if and how this service is being conducted nationally, that could inform future service delivery for stroke care. This research did not aim to produce new, generalisable findings, and as such, was not classed as "research" by the Health Research Authority (195).

Therefore, formal research ethics committee approval was not required, however ethical consideration was given at all stages of the research to ensure no harm comes to the participating orthoptists and the researcher. HRA and the NIHR guidance was closely adhered to in the method design and research conduct (195). This included obtaining permission from BIOS, who, once approved internally, distributed the survey to all registered persons, (including practicing and non-practicing orthoptists, academics, students and orthoptists working in private practice). Although the focus of the survey was aimed at NHS employed orthoptists providing home visits for visual conditions, of which the questions (see 10.2-10.3) aimed to capture this information, the survey also allowed for exploration of a home visits service being conducted in other forms, such as in private practice. If the service described could be translated to NHS stroke care, then this information would still be relevant to collect. Therefore,

circulation across the entire registered body was an inclusive means of collecting all, or any, relevant information.

Facilitators and barriers to conducting such a service could, arguably, be obtained solely through evaluation of the views of heads of services. However, as the survey reached a range of orthoptic professionals registered with BIOS, including both heads of departments and practicing clinical orthoptics, the information collected is able to consider two key viewpoints. Heads of departments or specialist leads may be able to shed light on facilitators and/or barriers to conducting home visits at a service level, whilst the clinical orthoptists could comment on their motivations/individual hesitations to undertaking this role. Both viewpoints are crucial in delivering an efficient service and should be considered in service planning. Careful considered was applied to the survey questions, to collect pertinent information from both service leads and clinical orthoptists on the ground (see below, 2.3.11).

2.4.1: Development of the survey

A web-based survey was developed through Survey Monkey [460]. Online surveys are the method of choice to quickly obtain vast amounts of data accurately, as they are relatively inexpensive and eliminate the risk of error, as manual data entry is not required [461]. The initial survey questions were presented to stroke specialist orthoptists (IVIS team) and the visually impaired stroke survivor panel (VSURP), to ensure the questions were clear and accurate in exploring this topic. The questions followed recommendations of using a variety of closed and open questions [461]. Closed questioning would elicit a more factual response from orthoptists, while giving a range within the choice of answers would attract a lower refusal rate [462]. Therefore, questions were kept concise with additional, voluntary comments allowed for most questions to encourage all responders to complete the questionnaire. Additionally, the survey retained complete anonymity as recommended, as lack of confidentiality can result in dishonest responses or no response at all [461, 463]. It has been further recommended that shorter surveys ensure maximal responses [461], therefore the survey was contained to a maximum of ten minutes, which was advertised before the survey commenced.

The survey consisted of 14 questions, with any participant answering a maximum of eight questions depending on the flow of answers (Figure 10.1). If the survey responders were already providing home visits, they were asked to report which patients they see, how often they see them and what assessment and management options they provide. If they were not currently providing home visits, they were asked why this was the case and if their department would consider providing this service in the future.

The questions were designed to explore whether orthoptists were conducting orthoptic home visits for any particular patient group, which was not exhaustive of stroke and neurological cases. The intent was to identify if orthoptists were performing this service for stroke patients, or for another patient cohort that could be transferable to a stroke service. Where respondents reported an established home visits service, they were asked to state the type of patient they would assess at home. Furthermore, respondents not currently conducting this service were asked which, if any, patient they felt would benefit from a home visit.

At the end of the survey, respondents were invited to input their email address if they were consenting to be contacted for further information at a later stage. This method is supported by Ritchie et al. (196), who stated that it is often routine practice for surveys to ask permission to re-contact participants.

2.4.2: Approval and national circulation of the survey

The survey was sent to the BIOS administrator in November 2015, who relayed this to the BIOS chair, and BIOS lead and steering committee for the stroke and neurological rehabilitation special interest group for approval and registration. The survey was later granted approval and circulated to all registered persons (Appendix 5).

In accordance with the HRA guidelines for conducting a service evaluation, careful ethical consideration was given to this section of the research. All data collected was fully anonymised and could not be traced back to the respondent, or cause any foreseen damage and distress. The data were only used to inform this part of the PhD research and was not shared with any additional parties.

Following approval from BIOS, the survey was emailed to all orthoptists registered with BIOS, between January and March 2016. This included those orthoptists registered as members of the BIOS stroke and neuro-rehabilitation special interest group. After a period of 6 months, which was deemed sufficient time for orthoptists to respond if intending to, the survey was closed for analysis.

2.4.3: Analysis of the survey

The results of the survey were exported to Microsoft Excel for descriptive analysis of the quantitative findings. A thematic analysis approach was undertaken for the written responses in the free-text boxes of the survey (see 10.2). These brief survey answers were exported into a Microsoft Word document before comments were coded, line-by-line, and analysed using the NVivo 10 software package (197).

2.4.4: Risk assessment

Those respondents that were identified as conducting established home visits through the survey, and who provided their email address indicating permission to be contacted, were later emailed. The respondents were asked whether they could share any information regarding guidelines, policies or procedures for conducting this service, along with any risk assessment put in place to ensure staff safety whilst on a home visit. These responses would be discussed alongside any concerns raised by the orthoptists not currently performing home visits in order to identify proven methods to overcome these concerns.

The orthoptist at each of the hospital sites thought to be undertaking home visits were contacted with the same structured email enquiring further information on their service protocol (if using one).

2.5: Section three; the qualitative research methods

2.5.1: Study design

The qualitative arm of this research project was underpinned with a social constructionist approach. Social constructionism explores the social world of those

being studied, to produce/construct knowledge based on their meanings and interpretations (196). Green and Thorogood (198) reported a longstanding tradition in the social sciences that considers a positivist view to be unachievable and inappropriate when researching human behaviour compared to natural science, as humans make sense of their place in the world, have views about the researchers studying them and behave in unpredictable ways. The authors further deduce a preference for the tradition of constructionism in qualitative health and social sciences research; although they acknowledge that there is no definitive approach to research (198). A social constructionist approach encourages the researcher to accept that reality is an outcome of the human processes, thus including open questioning that may not necessarily be considered core to the research, but generates relevant findings that explain the lived experiences of the participants (198). This school of thought informs the PhD research that the knowledge extracted from the qualitative research is actively constructed by the interviewed stroke survivors, rather than being passively received by them.

Considering this definition, this arm of the PhD research focuses on understanding the lived-experiences from the visually impaired stroke survivors from their points of view. The work undertaken in Chapter 11 has been developed through knowledge constructed during the research and interview process, whilst drawing on social theory and a previous knowledge of health inequalities.

The qualitative work of this thesis was conducted subsequent to the quantitative work, in an attempt to better understand the findings noted in Chapter 6 and further explore possible inequalities experienced by the visually impaired stroke population. Due to faster recruitment than anticipated with the quantitative arm of the study, time was available to conduct focus groups and interviews with stroke survivors.

Nevertheless, rigorous consideration was given to the recruitment process, conduct of the focus groups/interviews and data collection. The results of Chapters 3, 6, 9-10 relating to health inequalities following post-stroke visual impairment, informed the topic guide used to frame the focus groups and interviews.

A topic guide is a list of topics or issues that are to be pursued in the interviews/focus groups (199). A topic guide consists of words or phrases to prompt the moderator of the topic of interest. This differs from the planned questioning route, which consists

of a sequence of questions in complete sentences (199). One benefit of using a topic guide includes the flexibility of this approach, which allows the moderator to adapt the questioning style to the participants' colloquialisms (199). Topic guides work best with the same moderator conducting each interview/focus group as individual questioning styles can yield very different answers (199), therefore, only the PhD student conducted all focus groups and interviews in this research project.

2.5.2: Development and ethics

Ethical approval to conduct the focus groups was sought through The University of Liverpool research ethics committee in April 2016. Ethical approval was granted in September 2016 (reference number 0418); see Appendix 6. A participant information sheet and consent form was created and approved by the University of Liverpool's research ethics committee (Appendices 7-8). This was amended in December 2016 to extend the ethical approval until April 2017 in order to accommodate for slower than anticipated recruitment.

2.5.3: Sample selection (inclusion and exclusion criteria)

Any stroke survivor with a visual impairment as a direct cause of stroke was invited to take part in a focus group or interview. Visual impairments could include reduced visual acuity, visual field loss, ocular motility disorders and/or visual perceptual disorders including visual neglect. It was decided that the presence of the visual impairment was not required at the time of the focus group/interview and those who had previously experienced full or partial recovery of their visual impairment could still be included as their insight to potential health inequalities during that time would still be valuable. However, it was ideal if the participants suffered their stroke-related visual impairments during the time of the IVIS study period, as this would reflect relevant experiences of the same NHS care. However, recruitment difficulties in a population that often struggle to engage in research (200) meant that the inclusion criteria was widened to allow stroke survivors, whose strokes pre-dated the IVIS study, to participate. To the interviewer's knowledge, qualitative health inequalities research has not been conducted previously within visually impaired stroke groups,

and therefore, any new information would still be valuable, and their experiences will be discussed appositely in relation to their year of stroke.

All participants were adults aged ≥18 years as per the inclusion criteria for the IVIS study and the health inequalities systematic review (Chapter 3) as it is possible that younger stroke survivors would experience different inequalities due to differences in type and outcome of stroke (201, 202). All ethnicities, ages and genders were included and participants must have been admitted to a stroke unit in the North West of England. Those with severe aphasia, but who met the inclusion criteria to participate, were still invited to take part. Aphasic patients were given the option to bring a carer or family member with them on the day of the focus group to aid communication if preferred, although in practice this was not required as many of the other participants in the group were able to help. Aphasic participants were given sufficient time to speak and could use props or written text, such as on a mobile phone, to communicate if required.

Those unable to travel to the focus group location were excluded. However, to limit this risk the focus groups and interviews were conducted in the location of their choice, to encourage attendance and participation.

2.5.4: Recruitment and participants

Participants were invited to take part in semi-structured interviews. Recruitment was made through various stroke charities and group meetings including: the Stroke Association in the North West of England; the Macclesfield and District Young Stroke Society (MADYSS); and through an advert in the Citizen Scientist Hospital 2's newsletter and social media page. It is imperative that participants fully understand what they are consenting to (203), therefore written information was provided to potential recruits to re-read at home with a family member or carer if necessary (Appendix 7). Further information was provided verbally over the phone, email or face-to-face before recruiting the participants, answering any question or concerns. For those recruited at the stroke charity meetings, they were initially visited by the interviewer and provided with information. They were then given a week to decide and were recruited when the interviewer returned to the following meeting a week

later. An incentive of lunch and refreshments were offered to the participants on the day of the focus group. For those recruited through a newsletter advertisement, they initially contacted the interviewer to express their interest and ask questions. They were then sent the PIS and consent form in the post. It was planned to contact these participants a week later to discuss potential recruitment, but in reality, they always contacted the interviewer on receiving the PIS to express willingness to participate.

The recommended numbers for focus groups varies from as little as four participants (204) to as many as 15 (205), with six to ten being the average recommended sample size (206). After meeting the focus group participants at an introduction event, it was decided that an average of four to six participants would be included in each group, in order to accommodate the expressive dysphasia disability of many of the participants. The aim of interviewing a smaller number of people per group was to allow each stroke survivor ample time to discuss health inequalities whilst keeping to the recommended time frame: typically no more than two hours duration (207). The recommended length of focus groups with children is shorter than that for adults, at 45-60 minutes (208), to accommodate for reduced levels of attention and fatigue. Therefore, when considering the possible cognitive impairment and fatigue of some of the stroke participants, a shorter period of between 45-90 minutes was chosen.

These likely impairments further highlighted the need to keep to small numbers in order to conduct the group efficiently within a shorter period. Additionally, participants were encouraged to ask for breaks during the interviews when required, as the tapes could be paused and restarted.

Additionally, stroke survivors were invited to take part in individual, semi-structured interviews in a convenient location to them, if they were unable to travel to the community centres holding the focus groups due to stroke, visual or other disabilities/difficulties. This applied to three of the participants. Participants were contacted by letter, phone or email and a suitable meeting place of their choice was arranged to accommodate any potential disabilities. The location of the interviews are described later (see 2.5.5.1). Previous research has identified similar difficulties in recruiting participants to focus groups resulting in a “substitution” of individual interviews (209). It is suggested that choosing a time and location that best suits the

participants can overcome such difficulties. Whilst these limitations are recognised in this PhD research, the authors of Happell (209) specifically referred to recruitment of nursing staff during work hours. In the case of this PhD research, despite originally agreeing on a suitable time and location, the individual, physical needs of the participants were variable and unpredictable. Therefore, a flexible approach had to be used to accommodate their requirements to ensure inclusion in the research, by offering alternative interviews (210).

Reimbursement of travel expenses, including taxis to and from the local centre on the day of the focus group, were offered as an incentive and to reduce the risk of selective bias. This was important as some may participants may not have been able to afford taxis or feel confident using public transport, which only makes their inclusion in the discussion of health inequalities all the more important.

2.5.5: Conducting the focus groups and interviews

2.5.5.1: *Environment and settings*

Before discussing the data collection process, it is important to note the variable settings in which the interviews and focus groups took place. It has been suggested that the environment in which interviews are conducted is an important factor to consider, and one that is often neglected in qualitative research (211, 212). It is important that the participants feel comfortable to share their thoughts, especially around sensitive or personal topics (209), such as the individual nature of their stroke condition.

For those recruited through stroke charities, the participants expressed a desire to remain at the community centres after their weekly meeting had finished, which would prevent an additional trip to an unfamiliar location, as well as minimising risk of fatigue prior to the focus group commencing. The two focus groups and one of the interviews took place in a community centre in which the charity holds a weekly support group. On all three occasions, different rooms were offered to hold the interviews.

The first focus group was held in a comfortable, well-lit room, most often used for arts and crafts activities. The second focus group was held in a boardroom, as the

initial room was unavailable. The three male participants spread themselves out around a large meeting table, despite being asked to sit close together at one end. Reasons for this may include their acquired physical impairments that required aids such as wheelchairs and walking sticks that took up more space around the table. Another possible reason for their dispersed seating was the fact that the three men were not "friends" outside of the stroke association (unlike many of the female participants of the first focus group). It was clear before the focus group began that the men did not feel as comfortable with one another, and the interviewer was aware that their engagement within the focus group could be affected.

The interviewer therefore, had to employ methods to encourage conversation and attempt to neutralise differences in conversation due to the variability in the room environments (204). The interviewer's background in orthoptics assisted in this situation, as clinicians often work in a wide range of settings and have to adapt testing procedures to fit the locales. Furniture was repositioned and the interviewer moved seat when the participants would not, in an attempt to form a circle for the focus group discussion. The tape recorders had to be placed on either end of the long table to ensure their voices were heard and captured on tape.

One interview was conducted in an orthoptic clinic room at Hospital 2 and the rest were conducted in the patients' homes. The variable settings for the focus groups and interviews (a hospital, community centres and home settings) each posed individual implications to conducting research. However, these were acknowledged and addressed, where possible, by the interviewer to ensure interviews and focus groups were conducted as consistently as possible.

One challenge of interviewing participants in a hospital setting is the reported power relations between healthcare providers and patient participants (211). Despite the PhD role as researcher and interviewer, the participant knew the researcher's clinical capacity as an orthoptist at the hospital site. Care was made to ensure the participant interviewed at one of the recruiting hospital sites understood the confidentiality of research, and her rights to speak freely about her previous hospital care, which would not impede her current care.

Community-organisations, such as the stroke charity organisation centres, act as a middle ground between healthcare settings and home settings (211). It allows the

participants to view the interviewer, not as a clinician, but as an interested researcher, which might encourage confidence in discussing personal issues (211). However, privacy has been suggested as a possible complication when conducting interviews in community settings, and this issue did present itself during the research study.

One interview took place in the same community centre as mentioned previously. Initially, a room was offered that could not accommodate the participant's wheelchair and the organisers asked if he could remain outside the doorway and talk to me with the door open. Due to the confidential nature of the interview, it was decided that the interview would be postponed by one week until a more suitable room became available.

The remaining interviews were conducted at the participants' homes, which despite being most convenient for the participant, is not always the case for the interviewer. Additional travel was required to complete the interviews across the North West of England, and a lone-worker policy had to be followed to ensure interviewer safety. However, providing patients with a choice on where they would like to be interviewed provides an "equal relationship" and a safe space to share personal experiences (211).

2.5.5.2: *The role of the interviewer in moderating the focus groups and interviews*

Moderation followed the steps outlined in Morgan and Scannell (213), including arranging the locations, operating the recording equipment and simultaneously taking notes. Non-verbal responses, such as head nodding to indicate agreement, were recorded in the field notes. Likewise, the interviewer, for clarity, verbally repeated unclear responses due to poor speech, and the participant asked to confirm whether this was a correct account of what they said for the tape recording.

Furthermore, the role of the moderator included designing and following a topic guide (Appendix 9) for ensuring consistently between focus groups and interviews, refocusing the discussion back to the main topic of interest (health inequalities). The topic guide provided a semi-structured question plan, that followed a common style

guide as reported by Holloway and Wheeler (214). All focus groups and interviews began with an introduction, an overview of the topic, “ground rules” with assurance of confidentiality, and a brief plan for the session (215); see Appendix 9. Questioning followed recommendations in the literature and remained open-ended, clear and sensitive in nature, drawing on the participants experiences, feelings, knowledge and background details (214, 216).

The first item was to ask all participants what they understood of the term “health inequalities” as this may not be a common term to most people. This helped to inform the participants on the topic of interest and focus the discussions around health inequalities, which provided richer and more relevant data.

Any subject matter has the potential to become sensitive (217), however the term “sensitive” research has been defined as eliciting distress, causing risk or harm to the participants and evoking emotional responses (218). When planning for the focus groups and interviews, a further role of the interviewer involved considering the potential sensitivity of the discussion topic and how this may affect the researcher and participant. The participants were informed of the potential distress that could be caused by the discussion of inequalities, in the PIS and again prior to giving written consent. To address these issues, an empathetic yet professional rapport was built and maintained with the participants, drawing from the researcher’s role as a clinical orthoptist, which frequently involves discussing sensitive and distressing topics with patients regarding their health and wellbeing. Furthermore, this background clinical experience provided the PhD researcher with the knowledge of various support charities and organisations, in which to signpost to participants when they disclosed emotive information resulting from a lack of care or support.

2.5.5.3: *Recording of the focus groups and interviews*

The focus group was facilitated and written notes were taken along with an audio recording of the discussion. A minimum of two tape recorders were used per focus group and were spread across the table to ensure each person’s voice was recorded clearly as well as providing security in the case of one recorder failing. Although the use of recording devices was reiterated before each focus group and interview, the small, black tape recorders were discrete so as not to distract the participants or

make them feel uncomfortable. Spare batteries were brought to all focus groups in case one or both recorders failed. In reality, this was not required as both recorders ran efficiently throughout the duration of the groups. Sufficient time was allowed for processing questions and expressing thoughts, as recommended in a population with issues such as aphasia (219).

Before transcribing the audio recordings, each recording was listened to from start to finish, in order for the researcher to become familiar to the entirety of the discussion. This helped the researcher to remain focused on the subject of health inequalities and prevent the researcher from digressing off-topic when later coding the transcript.

2.5.5.4: *Transcribing the audio recordings*

The audio recordings were then translated into verbatim scripts. The transcripts were re-read whilst listening to the audio recording twice to ensure thorough transcription had been achieved. This initial reading of the transcripts, prior to undertaking coding, helps to refocus the research question. The names of the participants, the hospitals in which they received their care, and any other source that may lead the data to the participant were anonymised using unidentifiable signifiers to ensure confidentiality was maintained. The previous literature recommends that the interviewer also transcribes the focus groups or interviews, although recognises that this is not always feasible (220). For this study, the interviewer transcribed both focus groups and all but two of the interviews. However, where an independent typist (staffed by the University of Liverpool) assisted in the transcription of two interviews, each script was re-read by the interviewer, whilst listening to the recording to check for any errors and ascertain accuracy. It was ensured that the focus groups with numerous participants, and the interviews with stroke survivors with speech or cognitive impairments that may have been difficult for an independent typist to fully understand, were transcribed by the interviewer. Notes taken during the interview were not included as part of the analysis but assisted in understanding the audio. These were later used by the interviewer during transcription to interpret and describe the participants' responses, emotions, non-verbal cues (such as hand gestures or head nodding) and any interruptions heard on the tapes.

Line-by-line, manual coding was first employed to evaluate the transcripts and extract codes. Later, converging themes were established using the NVivo 10 qualitative software package (197).

Section 1

Chapter 3: Health inequalities facing stroke survivors with visual impairment

3.1: Background

An estimated 111,000 new strokes occur in the UK every year (97). In 2009, stroke mortality rate in the UK was recorded at 53,000 per year with premature death rates shown to be three times higher in the most economically deprived areas than the least deprived (97) largely due to the association of risk factors such as smoking, obesity and poor diet (221). Preventable visual impairment is a significant public health issue and sight loss is predicted to affect four million people in the UK by 2050 due to an increasing ageing population and the association of visual loss with older age (96). Further to age and social deprivation, health inequalities of stroke and visual impairment may include gender, race and educational attainment.

The reported economic cost of stroke between 2006-7 in the UK was £4.5 billion (97). In addition, visual impairment was recorded to cost the UK £4.3 billion between 2009-13 including the cost of resultant unemployment (96). Reducing health inequalities and lowering the rate of stroke and visual impairments by targeting the most affected groups could reduce this economic burden (96). The aim of this review is to report the health inequalities facing stroke survivors in the United Kingdom and Ireland with visual impairments as described in the current literature.

3.2: Methods

A systematic review was planned, aiming to collate evidence relating to health inequalities experienced by visually impaired stroke groups in the UK and Ireland. For the full methodology of this systematic review, see section 2.2: Methods. The MeSH terms used for this review are displayed in Table 3.1.This review is conducted according to the PRISMA guidelines (153).

Table 3.1 Search terms for health inequalities systematic review

Cerebrovascular disorders/ Brain ischaemia/ Intracranial Arterial Disease Intracranial Arteriovenous Malformations/ Intracranial Embolism and Thrombosis/ Stroke/	Eye Movements/ Eye/ Eye Disease/ Visually Impaired Persons/ Vision Disorders/ Blindness/ Diplopia/ Vision, Binocular/ Vision, Monocular/ Visual Acuity/ Visual Fields/ Vision, Low/ Ocular Motility Disorders/ Blindness, Cortical/ Hemianopsia/ Abducens Nerve Diseases/ Abducens Nerve/ Oculomotor Nerve/ Trochlear Nerve/ Visual Perception/ Nystagmus/ Strabismus/ smooth pursuits/ saccades/ depth perception/ stereopsis/ gaze disorder/	Health inequality/ Health equity/ Socioeconomic/ Sociodemographic/ Gender/ Male/ Female/ Age/ Ethnicity/ Race/ Transport/ Education/ Occupation/ Access to services/ Access to care/
OR	OR	OR
AND		

3.3: Results

The results of the literature search identified 157 articles reporting on worldwide health inequalities in stroke populations and populations with visual impairments (Figure 3.1). Only four were found which directly discussed health inequalities in stroke survivors with a visual impairment. However, a further 93 were found which discussed health inequalities in stroke populations only and 60 were identified as reporting on health inequalities in populations with visual impairments, which could further identify possible inequalities facing stroke survivors with visual impairment. Collectively, these categories included:

- Socioeconomic and income
- Race/ethnicity
- Gender
- Age
- Education level
- Occupation
- Transport
- Access to services

The four articles directly discussing health inequalities in visually impaired stroke survivors were included in the review, two of which were UK studies and thus met the inclusion criteria. However, as both articles were co-written by the primary supervisor of this thesis, all four articles were included in the review to address potential perceived bias. Consideration of the national health services in these countries (Australia and US) was given to these two additional articles.

Of the remaining 153 articles, only those reporting on population samples from the UK and Republic of Ireland would be included in this review due to their direct relevance to our current healthcare system. After exclusion, the final numbers included four articles reporting on health inequalities due to post-stroke visual impairment, along with an additional 22 articles discussing stroke related health

inequalities only and a further nine articles reporting on health inequalities in non-stroke populations with visual impairment.

3.3.1: Quality of the evidence

The majority of the included articles (n=29/35) were of population-based studies (22 were prospective, five were retrospective and two were unclear), along with two surveys, three questionnaires, and one article reporting on a series of prospective focus groups. A quality of evidence assessment was completed for each using the STROBE tool (Table 3.2). Evidence was deemed to be of good quality if the article reported ≥75% of the items on the relevant assessment checklist. Overall, 16 of the reported articles scored 100% in the quality of evidence assessment. The remaining 19 articles included in this review reported between 75 and 99% of the checklist items assessed and were deemed to have good quality. No article scored less than 75%.

Figure 3.1: Flowchart of pathway for inclusion of articles for health inequalities systematic review

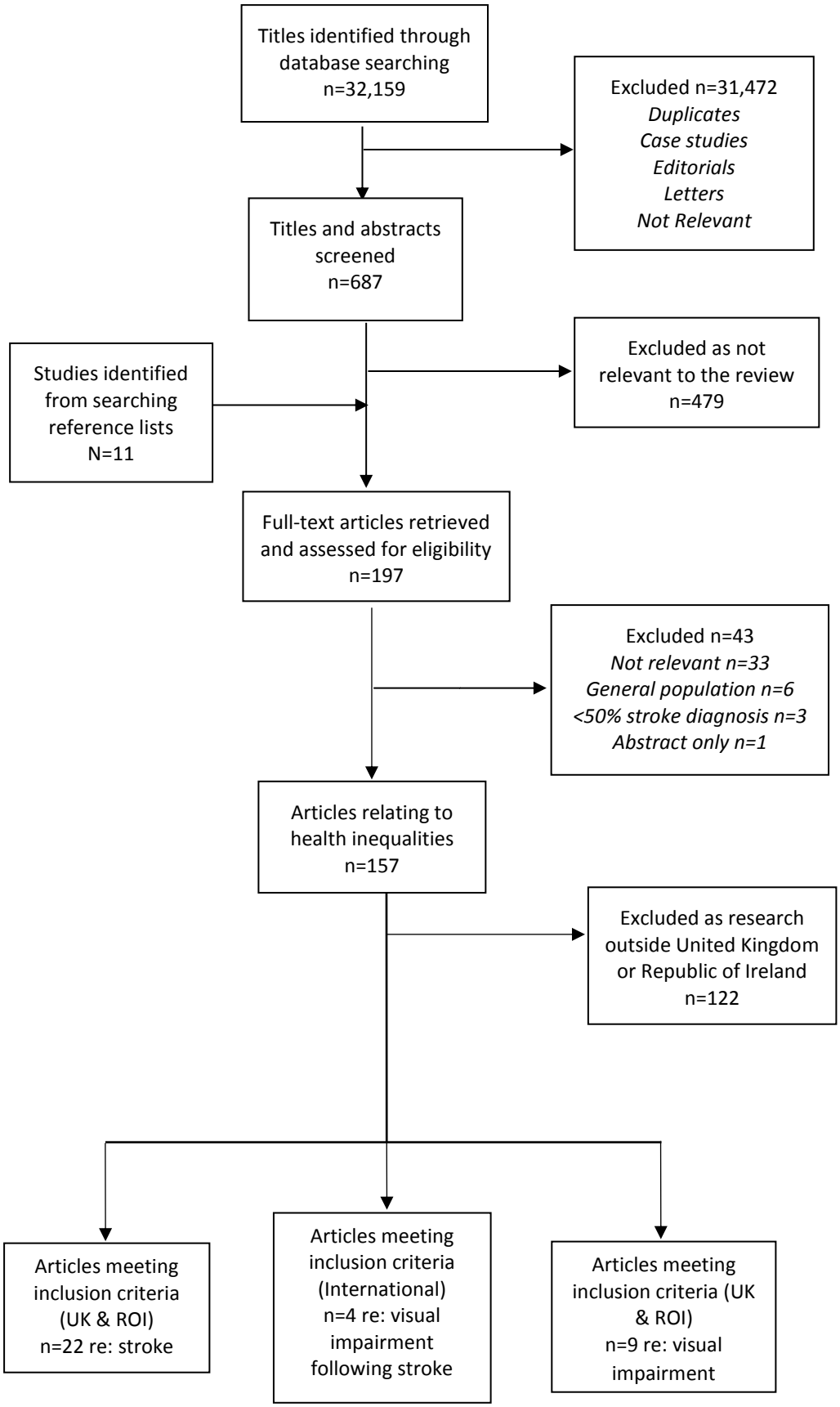


Table 3.2: Quality appraisal of papers using the STROBE checklist for health inequalities systematic review

	Methods									Results					Discussion		
	Study design	Participants	Variables	Data source	Bias	Study size	Quantitative variables	Statistical methods	Participants	Descriptive data	Outcome data	Main results	Other analyses	Key results	Limitations	Interpretation	Generalisability
	4	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21
Addo et al. (222)	+	+	+	+	?	+	+	+	+	+	+	+	n/a	+	+	+	+
Banjeree et al. (223)	+	+	+	+	?	+	+	+	+	+	+	+	n/a	+	+	+	+
Bhopal et al. (224)	+	+	+	+	+	+	+	+	?	+	+	+	n/a	+	?	+	+
Busch et al. (86)	+	+	+	+	?	+	+	+	+	+	+	+	+	+	?	+	+
Chen et al. (225)	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Chen et al. (226)	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Cumberland et al. (227)	+	+	+	+	+	+	+	+	+	?	+	+	+	+	+	+	+
Day et al. (228)	+	+	+	+	?	+	+	+	?	+	+	+	+	+	+	+	+
Fraser et al. (229)	+	+	+	+	+	+	+	+	+	+	+	+	n/a	+	+	+	+
Gall et al. (75)	+	+	+	+	-	+	+	+	+	+	+	+	+	+	+	+	+
Gallagher et al. (230)	+	+	+	+	+	+	+	+	+	+	+	+	n/a	+	-	+	+

Hajat et al. (231)	+	+	+	+	?	+	+	+	+	+	+	+	n/a	+	-	+	+
Hart et al. (232)	+	+	+	+	?	+	+	+	+	+	+	+	n/a	+	-	+	+
Heuschmann et al. (233)	+	+	+	+	+	+	+	+	+	+	+	+	n/a	+	+	+	+
Jerath et al. (76)	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Kerr et al. (234)	+	+	+	+	?	+	+	+	+	+	+	+	n/a	+	+	+	+
Knight and Lindfield (235)	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Kunst et al. (84)	+	+	+	+	+	?	+	+	-	+	+	+	n/a	+	+	+	+
Lazzarino et al. (236)	+	+	+	+	+	+	+	+	+	+	+	+	n/a	+	+	+	+
McCartney et al. (237)	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
McFadden et al. (238)	+	+	+	+	+	?	+	+	+	+	+	+	n/a	+	+	+	+
McKevitt et al. (239)	+	+	+	+	+	+	+	+	+	+	+	+	n/a	+	+	+	+
Patel et al. (240)	+	-	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Power et al. (82)	+	+	+	+	+	?	+	+	+	+	+	+	+	+	+	+	+
Putman et al. (87)	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Raine et al. (241)	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Redfern et al. (242)	+	+	+	+	+	+	+	+	+	+	+	+	n/a	+	-	+	+
Rowe (21)	+	+	+	+	-	+	+	+	+	+	+	+	n/a	+	-	+	+
Rowe et al. (73)	+	+	+	+	+	+	+	+	+	+	+	+	n/a	+	+	+	+
Shickle and Farragher (90)	+	+	+	+	+	+	+	+	+	+	+	+	n/a	+	+	+	+
Smeeton et al. (243)	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+

Wang et al. (244)	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Wolfe et al. (245)	+	+	+	+	?	+	+	+	+	+	+	+	+	+	?	+	+
Wolfe et al. (246)	+	+	+	+	-	+	+	+	+	+	+	+	n/a	+	+	+	+
Yip et al. (91)	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Yip et al. (93)	+	+	+	+	+	+	+	+	+	+	+	+	+	+	-	+	+

-	=Not reported	?	=Unclear	+	=Reported

Table 3.3 Articles reporting on health inequalities associated with stroke related visual impairments

Article	Year/ duration of research	Country of research	Study type	Population (n)	Patient demographics and health inequalities investigated
Rowe (21)	2007	UK	Survey of stroke services - non validated questionnaire	134 stroke services	Access to orthoptic vision services after stroke
Rowe et al. (73)	2013	UK	Online survey	31 professional groups, 548 individuals	Access to orthoptic vision services after stroke
Gall et al. (75)	1996-1999	Australia	Population-based study	1316 first ever stroke Women=731 Men=585	Gender and presentation, severity, in-hospital treatment and early mortality after stroke
Jerath et al. (76)	2011 (data collected in 1984-1989)	USA	Population-based study	449 first ischaemic stroke Women=268 Men=181	Gender and the presenting signs and symptoms of stroke

3.3.2: Health inequalities affecting stroke survivors with visual impairment

The literature search identified just four articles reporting on health inequalities facing stroke survivors with visual impairment (Table 3.3). These discussed inequalities in service delivery and gender.

3.3.2.1: *Access to services*

Rowe (21) reported that only 45% of stroke units in the UK provide a vision service at the acute stage of stroke. This will result in many stroke survivors being mismanaged or even undiagnosed of their visual impairment. The health inequality was in the area of residence (hospital catchment area) and was dependent on where one had their stroke as to whether or not they received visual input with their stroke care.

In a more recent study, Rowe et al. (73) identified further inequalities in stroke care when visual screening is undertaken. There is significant variability across the UK as to who performs the visual assessment, which tests are used, how visual impairments are managed and when patients are referred to eye care services. Many orthoptists and occupational therapists (22%) reported using screening tools commonly based on patient reported signs and symptoms or observed signs alone. As many stroke survivors cannot report their visual impairment due to stroke related speech difficulties and many visual problems will not elicit obvious signs, it is possible that few would be identified via this screening method (73, 101). It has been suggested that national care pathways, such as the National Institute for Health and Care Excellence (NICE) pathways (247), to guide healthcare professionals would address the issue of variation in visual management and onward referral to eye services to allow all stroke survivors adequate and equitable care (73).

3.3.2.2: *Gender*

Gall et al. (75) reported that women were more likely to suffer visual field loss following stroke whilst similar numbers of men and women suffered neglect. Moreover, the females in this study had a greater 28-day mortality due to their increased age and stroke severity. However, it should be noted that the data collection period for this study significantly pre-dates the year of publication and may not be a true reflection of gender differences in the current population.

A more recent study reported that following stroke, men and women can present with very different symptoms (76) although, the findings were not significant between either genders

presenting with visual field loss, which differs from the findings by Gall et al. (75). However, men more frequently reported traditional signs and symptoms of stroke including the following visual impairments: visual hallucinations, photophobia, blurred vision, nystagmus and diplopia. Women tended to present with non-traditional stroke symptoms such as fatigue and disorientation, which often resulted in delayed diagnosis and treatment. The authors urge healthcare professionals and women to become more aware of the presenting signs to reduce this inequality (76).

3.3.3: Health inequalities affecting the general stroke population

Twenty-two articles were identified which discussed health inequalities facing stroke survivors without named visual impairments (Table 3.4). Health inequalities were reported from the following subcategories: race/ethnicity; gender; age; socioeconomic; education level; and access to stroke services.

3.3.3.1: *Socioeconomic inequalities following stroke*

A number of studies (n=4) discuss the relationship between poor socioeconomic status (SES) and increased risk of stroke (232-234, 238), with one study showing that social deprivation resulted in nearly twice the risk of stroke (232). Some studies have found that certain demographics are more affected by social status than others in relation to stroke outcomes (225, 233, 234). SES is thought to influence health through the ability to purchase health promoting resources and treatments; socialisation of early health habits and continuing socialisation of health habits differs by SES (89). Additionally, it has been suggested that, health itself influences SES: less healthy individuals complete fewer years of school, miss more work, and earn lower incomes (89).

One study compared the effect of SES and stroke mortality across a number of countries including England, Wales and Ireland, however, estimates were only possible for males aged 45-59 (84). They concluded that SES played a significant role, with males of manual-class having a significantly higher rate of stroke-mortality than those of non-manual class. However, a more recent study found that females from lower SES were twice as likely to suffer a stroke (232). After adjustment for stroke risk factors, there was no longer a significant association with the male population. Furthermore, Chen et al. (225) reported a significant association between lower SES and survival after stroke but only for those of black ethnicity.

Table 3.4: Articles reporting on stroke related health inequalities

Article	Year/duration of research	Country of research	Study type	Population (n)	Patient demographics and health inequalities investigated
Addo et al. (222)	2007-2009	UK, England	Population based stroke register	3800 with first ever ischaemic stroke or primary intracerebral haemorrhage between 1995-2009	To investigate time trends in receipt of effective stroke care and to determine factors associated with provision of care
Banjeree et al. (223)	2003-2007	UK	Prospective database	811 (stroke=736)	Ethnicity
Bhopal et al. (224)	2001-2008	UK, Scotland	Retrospective cohort study	4.65 million from census and stroke database	Ethnicity and stroke incidence
Busch et al. (86)	1995-2004	UK, England (London)	Prospective, population based study	2874 first ever strokes	Employment after stroke and health determinants
Chen et al. (225)	1995-2011	UK, England (London)	Retrospective analysis of prospectively collected data	4398 first ever stroke	SES and survival after stroke
Chen et al. (226)	1995-2011	UK, England (London)	Retrospective analysis of prospectively collected data	2104 alive at 3 months post-stroke	SES and functional impairment post-stroke in relation to age, sex phenotype differences
Hajat et al. (231)	1995-1998	UK, England	Prospective population based study	1254 first ever stroke	Ethnicity and cardiovascular risk factors in patients with first ever stroke
Hart et al. (232)	Had been screened in 1972-1976	UK, Scotland	Prospective questionnaire	467 men and 535 women	Stroke differentials by SES
Heuschmann et al. (233)	1995-2004	UK, England	Prospective population based study	2874 first time stroke	Stroke incidence and modifiable risk factors between different ethnic groups
Kerr et al. (234)	2007-2008	UK, Scotland	Prospective multi-centred observational study	467 stroke and TIA (stroke=313)	SES and access to health services

Article	Year/duration of research	Country of research	Study type	Population (n)	Patient demographics and health inequalities investigated
Kunst et al. (84)	1980's	England, Wales, Ireland, Finland, Sweden, Norway, Denmark, France, Switzerland, Italy, Spain, Portugal, US	Retrospective review of national longitudinal and cross-sectional studies	Number of participants not stated Men aged 30-64 with stroke	SES and stroke mortality
Lazzarino et al. (236)	2006-2009	UK, England	Not clear if data collected retrospectively or prospectively	209,174 emergency admissions for stroke	Patient groups being excluded from brain imaging
McCartney et al. (237)	1995-2003	UK, England and Scotland	Retrospective review of 18 cohort studies (15 English and 3 Scottish)	193,873 Pooled data from 18 cohorts	SES, behaviour and mortality after stroke in Scotland compared to England
McFadden et al. (238)	1993-1997 and followed up until 2007	UK, England	Prospective population study	22,488 Followed up for stroke 39-79 years old	SES and stroke incidence
McKevitt et al. (239)	1995-2000	UK, England	Population based stroke register	1635 first ever stroke	SES and provision of acute and long term stroke care
Power et al. (82)	Over 45 year period	UK	Prospective study (follow-up of 45 years)	11,855 Women aged 14-49 (stroke=217 participants but discussed separately)	Gender, SES and risk of mortality after stroke
Putman et al. (87)	Not stated	6 stroke rehab units in Europe: UK, Germany, Switzerland, Belgium	Prospective, multicentre population based	419 first ever stroke aged 40-85	Education, income and recovery after stroke

Article	Year/duration of research	Country of research	Study type	Population (n)	Patient demographics and health inequalities investigated
Raine et al. (241)	1995-2005	UK, England	Cohort study using data from primary care database	12,830 aged 50+ who suffered a stroke between 1995-2005 and survived for the first 30 days	Sex, age, SES and access to secondary drug prevention after stroke
Redfern et al. (242)	1995-1998	UK, England (London)	Prospective population based study	717 first ever stroke	Access to healthcare follow-up after stroke
Smeeton et al. (243)	1995-2004	UK, England (London)	Prospective population based study	566 first ever stroke	Ethnicity and incidence of intracerebral haemorrhage or subarachnoid haemorrhage
Wang et al. (244)	1995-2010	UK, England (London)	Prospective population based study	4245 first ever stroke	Age, ethnicity and stroke incidence
Wolfe et al. (245)	1995-1998	UK, England (London)	Population based stroke register	1254 first ever stroke	Age, Sex, SES, ethnicity and incidence of stroke
Wolfe et al. (246)	1995-2002	UK, England (London)	Population based stroke register with follow-up	2321 first ever stroke	Age, Sex, SES, ethnicity and survival after stroke

Various articles revealed that those from lower socioeconomic status were less likely to receive adequate hospital care following stroke. It has been reported that persons of lower SES are less likely to receive brain imaging at the acute stage of stroke (222, 234). Additionally, stroke survivors from lower SES were less likely to attend their hospital appointments (234). A further study investigating functional recovery post-stroke revealed those from socioeconomically deprived areas had significant functional impairment at three months post-stroke compared to those of higher SES (226).

However, a number of articles reported little or no relationship between social class and stroke-related health inequalities. McCartney et al. (237) found a 42% increased rate of stroke mortality in Scotland compared to England but reported that socioeconomic characteristics accounted for only a quarter of this difference. They identified risk factors such as smoking as the main cause for the high stroke mortality rate in Scotland. Furthermore, Busch et al. (86) found that socioeconomic status did not impact on UK individuals' chances of returning to work after stroke, whilst Redfern et al. (242) found no socioeconomic inequalities relating to access of healthcare follow-up after stroke. Although the primary factor affecting stroke outcome is likely related to risk factors such as smoking, as opposed to social position or area of residence, these risk factors are more commonly found in lower socioeconomic groups (232, 234) and as such, infers a health inequality within this group.

3.3.3.2: *Ethnicity inequalities following stroke*

Ethnicity was identified as a key demographic variable in health inequality analysis after stroke. Particular ethnicities were identified as having genetic-predispositions to stroke, which are distinctly separate from health inequalities, as these are not considered unfair and preventable (3). However, particular ethnicities have been significantly associated with a lack of education/awareness of stroke and a significantly higher association to damaging health behaviours that could cause or exacerbate stroke, and worsen recovery of stroke impairments. Therefore, an inequality exists where any group of people are partaking in damaging health behaviours with a lack of understanding regarding the outcome of such actions. If these associations between health-risk and ethnicity are found to be preventable through education and knowledge exchange then they would be considered health inequalities (86).

Stroke incidence is shown to be higher in some ethnic groups compared to others. Overall, the black population appears to be at a higher risk of stroke than white, Asian or Hispanic populations (245). From 1995-2010 there was a significant decrease in stroke incidence in the white population but not in blacks (244). Black persons are more likely to be admitted to acute stroke units (222, 239, 246), although the reason behind this is unclear. McKevitt et al. (239) suggested one reason for this is that black minorities are more often admitted as a precaution because of their typical younger age compared to white populations, or because clinicians are now sensitised to the stroke risk profile in the black African and Caribbean populations.

Heuschmann et al. (233) noted a decrease in stoke incidence for white males and females but not for black males. Furthermore, Busch et al. (86) found the odds of black males returning to work following stroke were significantly less. Postulated reasons for this include an increased association with risk factors such as smoking and hypertension in the black population (231). It has been recommended that improved use of medication to control risk factors could address this, although, further research into compliance and dose assessment is required (246).

Some articles reported no association of race/ethnicity after stroke, or conversely, that whites were more at risk of health inequalities. Wolfe et al. (246) found the white population to have poorer survival outcomes following stroke, whilst the black population over the age of 65 were more likely to survive a first-time stroke (57% survival rate at 5 years post-stroke compared to 36% in the white population). They suggest that the heightened risk factors in the UK white population of heart disease, transient ischaemic attacks (TIA) and atrial fibrillation outweighed the risk of hypertension and diabetes in the older UK black population. Moreover, Smeeton et al. (243) identified only black Caribbean and Africans under the age of 65 to have higher rates of hypertension (246) indicating that the distinction between white and black ethnicities and risk of stroke is less than previously suggested.

Redfern et al. (242) found no association of any race in access to healthcare following stroke. The authors initially observed higher rates of lacunar strokes and infarcts were in the Asian population, although this finding was not significant (223). Likewise, Chen et al. (225) found an initial increase in risk of mortality after stroke within black Caribbean and Africans but this was deemed insignificant after adjustment for acute stroke care provisions.

3.3.3.3: *Gender inequalities following stroke*

Overall, there has been an equal decline in stroke incidence between both genders in the last ten years (244). However, one study has reported a higher incidence of stroke within the female UK population (232). What is more, Chen et al. (226) has identified females to have poorer functional recovery after stroke compared to men due to an increased risk of factors associated with social deprivation (226). Therefore, this finding seems only relevant to females residing in more deprived areas. Females were further found to have a lower chance of returning to work following a stroke (86). Hart et al. (232) was unable to explain their finding of higher stroke risk in females from the most deprived groups but speculate alcohol consumption, poor diet and lack of physical exercise as possible reasons.

Conversely, McFadden et al. (238) found that social class played a significant role in increasing stroke incidence between both genders equally, although their smaller population size could limit the validity of their findings when compared to other studies. Others found no significant differences between gender in respect to stroke incidence (223), access of stroke services (242) or access to secondary drug prevention for patients (241). One study has shown evidence of an inequality within the male population in relation to stroke care provision, whereby men are less likely to receive an electrocardiogram (ECG) following stroke (234). However, the authors indicated that this group of male patients were offered an ECG but did not attend the necessary hospital appointments, alluding to access or travel difficulties (234). Another study reported no difference between genders in relation to hospital admission or likelihood of receiving a scan (239). A more recent study reported that men were significantly more likely than women to be selected for brain scanning after a stroke, however the authors termed this a “chance-finding” and offered no further explanation for the result (236).

3.3.3.4: *Age inequalities following stroke*

Four of the fifteen articles discussing age-related health inequalities found that older persons are at higher risk of stroke (223, 244-246). Hajat et al. (231) reported that increasing age correlated significantly with increased risk of infarction but not with haemorrhagic stroke, whilst a study investigating risk of stroke in females found that age was a significant factor of stroke mortality (82).

Redfern et al. (242) found stroke survivors over the age of 65 were less likely to be offered followed-up appointments. Although they could not provide an explanation for their findings, the authors speculate that health professionals may find it difficult to discuss lifestyle issues

and behavioural risk factors with patients meaning those most at risk do not receive follow-up (242). Moreover, functional recovery after stroke is shown to be significantly worse in the older population (>65 years old) (226, 239). One study showed that the chances of returning to work decreased as age increased (86).

An inequality was identified in relation to access to stroke services as older patients (≥75) were less likely to receive brain imaging following stroke (222). This concurs with the findings from Lazzarino et al. (236) that younger patients were more likely to be selected for brain imaging. Moreover, Raine et al. (241) found that increasing age was significantly associated with reduced odds of receiving secondary preventative drugs after stroke. The odds increased from 26.4% for 50-59 year olds to 15.6% in 80-89 year olds, and just 4.2% for those aged >90. However, a study by Banjeree et al. (223) found that south Asians living in London were at an increased risk of stroke if aged ≤55 years. This is due to higher risk of diabetes in this younger population. This concurs with the findings by Wang et al. (244) who noted a 40% reduction in stroke incidence from 1995-2010 in those >45 years old. However, there was no significant change in the 15-44 year olds due to an increased rate of diabetes over this period. Additionally, Smeeton et al. (243) found that the rate of hypertension in black populations <65 years old reportedly increased between 1995 and 2004, subsequently increasing the incidence of stroke.

It was further suggested that socioeconomic factors play a role in the association between age and stroke incidence. It was found that stroke survivors in lower socioeconomic groups were of younger age (234), which could indicate poorer health outcomes from a younger age for those living in more deprived areas of the UK.

3.3.3.5: *Education inequalities following stroke*

Only one article discussed education attainment and stroke-related health inequalities, concurring that a lower educational level is associated with poorer stroke recovery whilst in hospital (87). However, this was not significant for recovery following discharge. Additionally, a high level of education correlated with a higher Rivermead motor assessment score, which may suggest that those with a higher education will have a better functional outcome after stroke (87).

3.3.4: Health inequalities affecting the visually impaired population

Thirty-eight articles reported on health inequalities associated with non-stroke related visual impairments (Table 3.5). Visual impairments can arise from a wide range of possible diagnoses including glaucoma, age-related macular degeneration (AMD) and cataracts, the symptoms of which can be compared to those caused by stroke. Potential health inequalities facing this population include gender, age, occupation, socioeconomic, education level, and transport.

3.3.4.1: *Socioeconomic inequalities following visual impairment*

Patel et al. (240) reported that British women from lower socioeconomic groups are less likely to have an optometry eye examination. The reason for this inequality is uncertain, but the authors postulate the cost of this service as the potential cause. Concurrently, Shickle and Farragher (90) found eye examinations were 71% more likely in the least deprived areas than in the most deprived areas, despite equal entitlement between groups.

A review investigating inequalities accessing eye services (private and NHS opticians) in the UK found an association between poor SES and poor attendance of eye health services (248-266). Additionally, late stage of eye disease at presentation to eye services (228, 229, 267-272); uncorrected refractive error (273, 274); increased waiting times for treatment (275, 276) and poor treatment compliance (272, 277) were identified. Articles meeting the inclusion criteria were extracted and evaluated in Tables 3.2 and 3.5. There was an equal split between articles reporting no association and those reporting a significant association between poor SES and access to eye services. The authors suggest that this is due to a number of the articles investigating access to eye services as a secondary research question (235). Two further studies remarked that as eye care is the only fee paying service in the UK, the cost of using this service could explain this possible health inequality (90, 240). One study proposed free universal public provision to tackle income effects in up taking healthcare (264).

One article reported an association between poor SES and reduced vision, which was not significant (91). They concluded that the true reason for this association was the higher rate of uncorrected refractive error within the manual working-class groups. They recommended that targeting uncorrected refractive error within deprived areas might have the potential to reduce this inequality. An additional study concurred with these findings and reported uncorrected refractive error was associated with younger age, male sex, increased deprivation and non-white ethnicities (227).

As noted previously with age-related inequalities, some ocular conditions are more prevalent in lower socioeconomic groups; namely glaucoma and AMD (93, 229). Those from lower SES groups have been reported to present with glaucoma at significantly later stages than those of higher SES (228, 229). Although Fraser et al. (229) added that family history and time since last optometry visit also played a key role in this statistic. As mentioned previously, these impairments place more deprived individuals at a significant disadvantage and at high risk of irreversible visual loss. Poor diet, increased rates of smoking and stress associated with lower SES are reportedly the cause of this progression of glaucoma (229).

Table 3.5: Articles reporting on vision impairment health inequalities

Article	Year of research	Country of research	Study type	Population (n)	Patient demographics and health inequalities investigated
Cumberland et al. (227)	2009-2010	UK	Cross-section epidemiological study	112314 Adults with low vision	SES, sex, ethnicity, age, employment and visual function
Day et al. (228)	2002-2007	UK, England (Leeds)	Equity profile mapping It is not a formal epidemiological survey	Estimate between 5963 and 6700 people with glaucoma in Leeds	Unclear. To map an equity profile for glaucoma in Leeds but can be reused for other ophthalmic conditions in other UK locations
Gallagher et al. (230)	Not stated	Ireland and Northern Ireland	14 Focus groups	121 Urban and rural dwellers with visual impairment	Mobility and transport issues of people with visual impairment (urban and rural areas)
Fraser et al. (229)	1996-1997	UK	Prospective hospital based Case-control study	220 glaucoma	SES and risk factors associated with glaucomatous VF
Knight and Lindfield (235)	Literature search was done in 2013 Included papers=1990-2013	UK	Review	37 papers	SES and access to eye health services in the UK
Patel et al. (240)	1998-2001	UK	Questionnaire	3652 (23 towns) Older Women aged 62-83	SES and self-reported use of 6 preventative and therapeutic services including eye services
Shickle and Farragher (90)	2011	UK, England (Leeds)	Population based	17,680 eye examinations taken from general ophthalmic services claim forms	The geographical differences in the uptake of general ophthalmic services
Yip et al. (91)	2004-2011	UK, England	Multicentre prospective study	8467 Persons with completed eye examinations	Area deprivation and poor vision
Yip et al. (93)	2004-2011	UK	Cross sectional study within a longitudinal cohort study	5344 pairs of fundus photos AMD patients	Area deprivation, SES and AMD

Day et al. (228) concluded that it is not acceptable to rely on high-street opticians to detect glaucoma in these areas of high deprivation and recommended the development of outreach services to tackle this concerning issue.

Furthermore, Yip et al. (93) reported higher levels of deprivation with AMD patients due to associated increased rates of smoking and lower levels of physical and academic education within this group. As smoking is a significant risk factor of AMD, they propose the potential lack of understanding regarding the risks of smoking suggested by the lower levels of education as the cause of this inequality.

3.3.4.2: *Gender inequalities following visual impairment*

Three articles discussing gender-related health inequalities and visual impairment reported that women were at a higher risk of visual impairment (91, 93, 227) potentially due to the higher prevalence of particular ocular diseases within females. Yip et al. (93) found a significant association of AMD prevalence within the female population only. The authors found that this risk was indirectly influenced by SES due to a mutual association of risk factors such as smoking and poor diet (93). Another study reported that more women were taking up eye examinations in Leeds (UK), indicating an increased prevalence of visual impairment within the female population (90), although this was not found to be statistically significant when compared to the male population utilising ophthalmic services.

3.3.4.3: *Age inequalities following visual impairment*

All of the articles reporting age-related health inequalities and visual impairment (n=6) concluded that older age was significantly associated with greater health inequalities (90, 93, 227, 228, 240). Older persons with visual impairment living in deprived areas are significantly less likely to take up eye examinations, suggesting an association between inequalities of older age and low SES (90). Moreover, a study of solely female participants reported that women >65 years old and of manual social class were less likely to take up eye examinations in the UK (240). The authors postulate that the “confusing” and “inconsistent” cost of having an eye assessment may be a determining factor for this group. Despite free eye tests for those aged ≥65years old (240), “hidden costs” in the form of eye-glass frames, prismatic lenses,

tinted lenses, bifocal or varifocal lenses, and lens thinning can incur large costs for the individual.

Gender did not appear to be a significant contributor to age-related eye conditions, as both genders in this same age group were three times more likely to be visually impaired than those under 65 years old (91).

The prevalence of various ocular diseases has shown to increase with age (93, 228). Day et al. (228) conducted a study to map the profile of glaucoma in Leeds and found that older persons are accessing glaucoma services at a later stage. This highlights a potentially significant inequality as late presentation of glaucoma can result in irreversible loss of the patients' visual acuity.

3.3.4.4: *Education inequalities following visual impairment*

Four articles reported an association between lower levels of education attainment and higher rates of visual impairment (91, 93, 229). Two articles reported a connection between lower levels of education and lower SES, which has further been associated with reduced vision in these deprived groups (91, 93). Yip et al. (93) reported that those with A-level qualifications were significantly less likely to develop AMD compared to those without O-levels, as lower education attainment is likely to result in subsequent lack of understanding of the health risk factors.

Fraser et al. (229) found that those who left fulltime education by age 14 were more likely to present to an optician with glaucoma at a later stage than those who carried on in full time education, however this association was not statistically significant.

3.3.4.5: *Occupation inequalities following visual impairment*

One study found an association with increased risk of unemployment in individuals with reduced vision, even in those with mildly reduced vision in one eye (227). Those with the most severe grade of visual impairment had three times the risk of unemployment. Visually impaired individuals who can work are more likely to have a lower grade job and are associated with living in sheltered accommodation as a result of their visual impairment (227).

3.3.4.6: *Transport inequalities following visual impairment*

One article was identified in the literature search which discussed transport issues for the visually impaired population (230). The authors identified a number of

inequalities relating to mobility and access to transport services through focus groups. They discussed the difficulty of using buses, as wheelchairs were often not admitted on board whilst many sight impaired persons required this service (230). Furthermore, the high cost of frequent taxis when transport by bus or train was not possible posed a further inequality. Moreover, when it is possible to use public transport, many visually impaired patients found this to be very stressful due to lack of confidence as a result of their sight impairment (230).

Those living in rural areas are at a further disadvantage as night buses are less available in those areas. When transport options are restricted, this results in increased dependency on family or friends to take them to appointments, which limits the patients' access to medical, social and rehabilitative services (230).

3.4: Summary

Only two articles aimed to investigate health inequalities affecting stroke survivors in the UK with visual impairment. These identified significant inconsistency in eye care provision nationally, along with variability in the assessment and management of visual disorders. Additional, international studies discussed health inequalities due to post-stroke visual impairment, although the findings should be interpreted cautiously as differences in ethnicity, lifestyle factors and private healthcare systems in these countries could yield inequalities unlikely to be experienced in the UK. These additional two articles discussed gender inequalities in visually impaired stroke survivors; women are more likely to present with visual field loss, men more likely to present with ocular motility defects and both have equal risk of neglect (75, 76).

This review further identified the following subgroups as most at risk of health inequalities in the UK and Ireland: lower SES, older age, females and those with lower education attainment. Black ethnic groups have poorer stroke outcomes than Whites and Asians, and Asians have poorer outcomes than Whites do. Health inequalities facing these populations range from likelihood of having a stroke or vision problem to limited access to healthcare resources. These findings highlight a requirement for

further research in which to develop strategies to overcome these established inequalities. Many of the subcategories named are associated with one another, for example, increased risk of stroke association with socioeconomic deprivation, which in turn is related to the increased rates of risk factors found in socially deprived areas (e.g. smoking). Therefore, the full trajectories of these inequalities should be considered when addressing these issues. Arguably, however, too much ownership is placed on modifying unhealthy risk factors in population groups as a means of tackling health inequalities, when behaviours are, in fact, related to social context and cannot be controlled in isolation (51). Wilkinson (51) postulated that the true cause of health inequalities in conditions such as stroke, is still unknown, but cannot be explained categorically by unhealthy behaviours alone.

There is a specific gap in the literature in relation to health inequalities facing this population. Due to this lack of research, it has often only been possible to speculate the potential inequalities and so, further research must be conducted in order to establish whether or not this population are at risk of the aforementioned sociodemographic and economic inequalities. Therefore, to address the suggested inequalities identified through this review, Chapter 6 will explore the demographics of the stroke survivors found to have visual impairments, and the recovery rates of these impairments to better inform patients, carers and stroke services, whilst Chapter 9 will explore the inequalities in accessing services after stroke.

This research has been published elsewhere; see:
Hanna KL, Rowe F. The health inequalities associated with post-stroke visual impairment in the United Kingdom and Ireland: a systematic review. 2017 Neuro ophthalmology, 41(3): 117-136.

The search methods described in 2.1.4 were further performed in December 2017 and no further articles were identified that met the search criteria for this chapter.

Chapter 4: Assessment for post-stroke visual impairment

Post-stroke visual impairments are wide ranging affecting approximately 65% of stroke survivors and includes reduced visual acuity, ocular motility deficits, visual field loss and perceptual deficits including visual neglect (6, 32, 122). Partial or complete recovery is possible, but often these patients suffer permanent visual disability (278). Therefore, it is imperative that all elements of visual impairment are screened for so that these patients are identified and managed as soon as possible. It is well documented that the effects of reduced visual function can have a significant negative effect on the patients' quality of life, general stroke rehabilitation, and can lead to social isolation and depression (4, 279-281).

MacIntosh (122) proposed that Orthoptic visual screening in a stroke population using validated assessments could be accurately and easily undertaken. Despite this, a survey of Orthoptic practice reported 45% of stroke services did not include a formal vision assessment. Furthermore, when screening is undertaken, there is considerable inconsistency as to how the screening is conducted and which assessments are used (2).

The purpose of this systematic review is to consider the available screening methods and vision assessments used for identifying post stoke visual impairments. A further comparison between the screening tools used in the IVIS study and those identified through this review will be made to identify inequalities of screening methods (see Chapter 7).

4.1: Methods

A systematic review was planned, aiming to collate evidence relating to screening tools for stroke-related visual problems. For the full methodology of this systematic review, see section 2.2: Methods. The MeSH (Medical Subject Headings) terms used for this review are displayed in Table 4.1.This review is conducted according to the PRISMA guidelines (153).

4.1.1: Quality assessment

The quality of the included articles was assessed using the following three checklists based on the study type. An adapted version of the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) statement was used to assess the quality of cross-sectional, cohort and control studies. The STROBE statement covers 22 items from introduction, methods, results and discussion (157). The adapted version of the STROBE statement used in this review included 18 items.

The GRACE (Good Research for Comparative Effectiveness) statement was used for observational studies with comparative effectiveness. This statement covers 11 items within the domains of data and methods. There is no formal scoring system used in this checklist, but it is suggested that if a paper addresses the majority of the checklist items, then it is deemed reliable (158).

Finally, the PRISMA (Preferred Reporting for Systematic reviews and Meta-Analyses) statement was used to assess quality of evidence in review articles. This covers 27 items within title, abstract, introduction, methods, results, discussion and funding (153).

All domains covered in these checklists are important factors to consider when evaluating the quality of evidence and risk of bias in the aforementioned articles. These domains were graded 'high risk', 'low risk' or 'unclear risk'. If it was clear the domain was performed, then this was described as "reported" and recorded as having a low risk of bias. If it appeared the domain was not included, this was described as "not reported" and deemed a high risk of bias. Insufficient evidence was labelled as an "unclear" risk.

Table 4.1 Search terms for systematic review of post-stroke assessment methods

Cerebrovascular disorders/ Brain ischaemia/ Intracranial Arterial Disease Intracranial Arteriovenous Malformations/ "Intracranial Embolism and Thrombosis*/ Stroke/	Eye Movements/ Eye/ Eye Disease/ Visually Impaired Persons/ Vision Disorders/ Blindness/ Diplopia/ Vision, Binocular/ Vision, Monocular/ Visual Acuity/ Visual Fields/ Vision, Low/ Ocular Motility Disorders/ Blindness, Cortical/ Hemianopsia/ Abducens Nerve Diseases/ Abducens Nerve/ Oculomotor Nerve/ Trochlear Nerve/ Visual Perception/ Nystagmus strabismus smooth pursuits saccades depth perception stereopsis gaze disorder internuclear opthalmoplegia Parinaud's syndrome Weber's syndrome skew deviation conjugate deviation oscillopsia visual tracking agnosia hallucinations
OR	OR
AND	

4.2: Results

Figure 4.1 illustrates the results of the search. English translation was obtained for five abstracts, which were then deemed unsuitable for the review. Twenty-four articles identified in the electronic and manual search met the inclusion criteria for this review. From the 26 studies appraised, two were review articles, fifteen were observational studies, and eight were observational studies with comparative effectiveness. Nine screening tools identified combined visual screening assessment alongside screening for general stroke disabilities. Of these, two screened for all visual impairment; four screened for visual acuity (VA); four screened for visual field (VF) loss; four screened for ocular motility (OM) defects and all screened for visual neglect (VN). A further eighteen articles were found which reported on individual vision screening tests in stroke populations; two for VF loss; six for visual perceptual defects and 11 for VN.

4.2.1: Quality of the evidence

A total of 26 articles were identified through the review and a quality of evidence assessment was undertaken for each (Tables 4.2-4.4). Evidence was defined as good quality if the article reported ≥75% of the items on the relevant assessment checklist. Two of the reported articles scored 100% in the quality of evidence assessment (282, 283). Seventeen articles reported ≥75% of the checklist items assessed and are deemed to have good quality. Four reported ≥50% of the items (284-287) and the three remaining articles failed to reach 50% (119, 288, 289).

Figure 4.1: Flowchart for the pathway of included articles for systematic review of post-stroke assessment methods

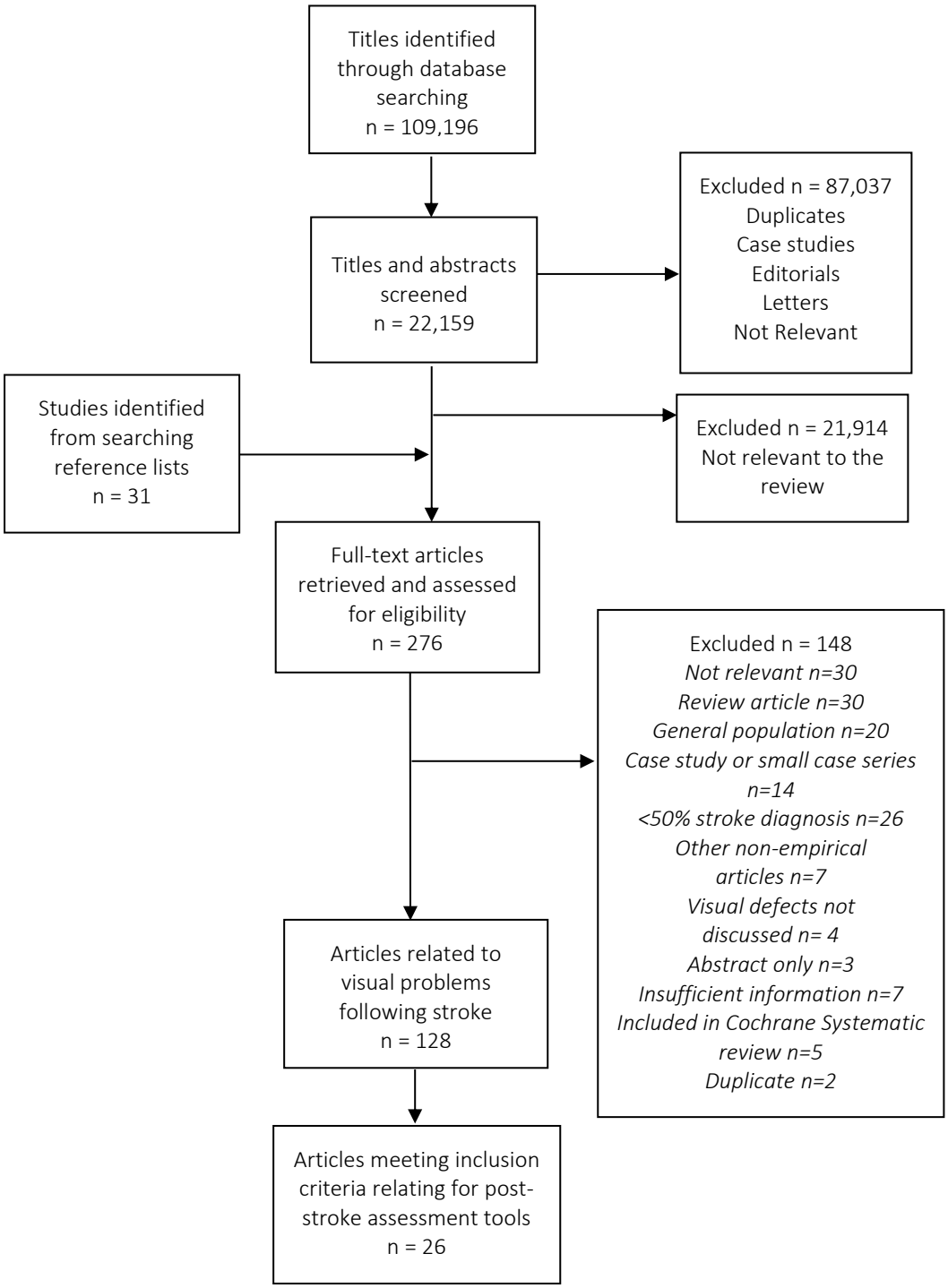


Table 4.2: Quality appraisal of articles using the STROBE checklist for systematic review of post-stroke assessment methods

	Methods									**Results**					**Discussion**		
	Study design	Participants	Variables	Data source	Bias	Study size	Quantitative variables	Statistical methods	Participants	Descriptive data	Outcome data	Main results	Other analyses	Key results	Limitations	Interpretation	Generalisability
	4	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21
Adams et al. (107)	+	+	+	-	+	+	+	+	-	+	-	n/a	+	+	+	+	+
Agrell et al. (290)	+	?	+	-	+	+	+	+	+	+	+	-	n/a	+	+	+	+
Caplan (284)	+	+	-	+	-	-	?	-	+	+	+	-	n/a	+	-	+	+
Cassidy et al. (285)	+	+	+	-	+	+	-	-	?	+	+	-	n/a	+	+	+	+
Chiu et al. (291)	+	+	+	+	+	+	+	+	+	+	-	+	+	+	+	+	+
Cooke et al. (292)	+	+	+	+	+	+	+	+	+	+	+	+	n/a	+	+	+	+
Demeyere et al. (283)	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Dong et al. (116)	?	+	-	+	+	+	+	+	+	+	+	-	+	+	-	+	+
Edwards et al. (15)	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Ferber and Karnath (118)	+	+	+	+	+	-	-	+	-	+	+	+	n/a	+	+	+	+
Fordell et al. (293)	+	+	+	+	+	+	+	+	+	+	+	+	n/a	+	+	+	+
Godefroy et al. (282)	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Jolly et al. (102)	+	n/a	+	+	+	+	+	+	+	-	+	+	n/a	+	+	+	+
Luukkainen-Markkula et al. (286)	+	+	+	-	-	+	+	+	?	+	+	-	+	+	-	+	+
Rowe and the VIS Group UK (101)	+	+	+	+	+	+	+	+	+	-	+	+	+	+	+	+	+
Townsend et al. (108)	+	+	+	+	+	+	+	+	?	+	+	+	n/a	+	+	+	+

[-] =Not reported [?] =Unclear [+] =Reported

	Data						Methods				
	D1	D2	D3	D4	D5	D6	M1	M2	M3	M4	M5
Azouvi et al. (120)	+	+	+	+	?	+	n/a	-	+	?	+
Azouvi et al. (117)	+	+	+	+	+	+	n/a	-	+	-	+
Cooke et al. (294)	+	+	+	+	+	+	n/a	+	+	-	+
Della Sala et al. (287)	+	+	+	?	+	-	-	?	+	-	-
Leibovitch et al. (114)	+	+	+	+	-	+	n/a	+	+	?	+
Lincoln and Adams (289)	+	+	?	-	?	?	+	-	?	n/a	n/a
Lindell et al. (121)	+	+	+	+	+	+	n/a	?	+	-	+
Vossel et al. (31)	+	+	+	-	+	+	+	+	+	n/a	n/a

Table 4.3: Quality appraisal of articles using the GRACE checklist for systematic review of post-stroke assessment methods

[-] =Not reported [?] =Unclear [+] =Reported

Table 4.4: Quality appraisal of articles using the PRISMA checklist for systematic review of post-stroke assessment methods

		Cermak and Lin (288)	Cooke et al. (119)
Title	1	-	-
Abstract	2	-	+
Introduction	3	+	+
	4	-	+
Methods	5	-	-
	6	+	+
	7	-	-
	8	-	-
	9	-	-
	10	-	-
	11	-	-
	12	-	-
	13	-	-
	14	-	-
	15	-	-
	16	-	-
Results	17	-	+
	18	-	+
	19	-	-
	20	-	+
	21	n/a	n/a
	22	-	-
	23	n/a	n/a
	24	+	+
Discussion	25	-	+
	26	-	+
Funding	27	-	+

-	=Not reported	?	=Unclear
+	=Reported		

4.2.2: Vision screening tools

Two tools were identified which screened for all potential stroke-related visual impairments; see Table 4.5 (101, 102).

4.2.2.1: *Vision in Stroke (VIS) Standardised Screening Form*

Rowe and the VIS Group UK (101) developed a standardised visual screening form for use with stroke survivors. The form includes documentation of ocular symptoms reported by the patient, ocular signs noticed by the examining health professional, ocular history and comment on any known cognition impairments. The high sensitivity reported was due primarily to inclusion of patient-reported visual symptoms. Sensitivity dropped to 42% in cases where the patient was unable to report symptoms such as with aphasia. Furthermore, only those patients referred with a suspected visual impairment were formally examined by the Orthoptist, and thus, it is unknown how many patients were missed by the screening form. The author suggested training/education as one option to improve the accuracy of referrals made by the multidisciplinary team when screening patients with communicative issues.

4.2.2.2: *Checklist for Vision Problems Post-Stroke*

Jolly et al. (102) described the development and evaluation of a screening tool for stroke related vision problems, which aims to allow its use by any healthcare professional because of the limited availability of Orthoptic input on Australian stroke units. Similar to the VIS tool, it involves questioning the patient regarding ocular history and current symptoms, which aids the examiner to identify specific ocular signs of impairment. A non-Orthoptist was considerably less sensitive using the test compared with an Orthoptist however, this was still significantly more sensitive when compared to the non-Orthoptists without use of the tool (102).

This tool does not involve any clinical assessment of a patient but instead relies solely on the patient being able to answer the checklist of questions. This creates a limitation for many sub-groups of the stroke population, especially those with aphasia or cognitive problems, and likely explains why Orthoptists were unable to identify all visually impaired patients when using this tool.

Table 4.5: Screening tools for visual impairment following stroke

Screening tool	Study	Study design	Visual impairment (s) screened	Time/duration of tool	Accuracy of tool
Hemispheric stroke scale	Adams et al. (107)	multicentre observational study	Neglect • line Bisection test with a single 20cm line Visual perception • figure-copying Gaze/eye movement assessment Visual field assessment by confrontation and asking the patient if they are aware of all of their limbs	30 minutes	90% of aphasic patients could undergo screening *"high sensitivity as it correlates well with Barthel index"*
Chessington OT neurological assessment battery (COTNAB)	Cooke et al. (119)	Review	12 tests in 4 sections: • Visual perception • Constructional ability • Sensory motor ability • Ability to follow instructions	60-80 minutes	No reliability or validity documented in the literature
Lowenstein OT cognitive assessment (LOTCA)	Cooke et al. (119)	Review	26 tests assessing: • orientation • visual perception • spatial perception • praxis • visuo-motor organisation • thinking operations the geriatric version includes memory testing instead of spatial perception (23 tests in total)	45 minutes Geriatric version=30-45 minutes	Not stated

Screening tool	Study	Study design	Visual impairment (s) screened	Time/duration of tool	Accuracy of tool
Ontario's society of OT's perceptual evaluation	Cooke et al. (119)	Review	28 tests assessing: • Sensation • Scanning • Apraxia • Body awareness • Spatial relations • Visual agnosia	not stated	Limited validity documentation
Rivermead Perceptual Assessment Battery (RPAB)	Cooke et al. (119)	Review	16 tests assessing: • colour, • sequencing, • object completion, • figure ground discrimination, • body image, • inattention • spatial awareness	60-120m minutes (52-58 minutes Lincoln 1989)	
The functional impairment battery	Edwards et al. (15)	Prospective clinical study	Near VA • MIS pocket vision guide Neglect: • star cancellation test	All participants could complete the tool in less than 1 hour None of the study measures are timed in this tool	70% sensitivity for VA assessment 52% sensitivity with star cancellation test
The Checklist for Vision Problems Post Stroke	Jolly et al. (102)	retrospective study from 100 patient case histories	• Reduced visual acuity • Visual field loss • Visual neglect • Ocular motility defects	Not specified	69% sensitivity with an Orthoptist 17% sensitivity with a non-Orthoptist using the tool

Screening tool	Study	Study design	Visual impairment (s) screened	Time/duration of tool	Accuracy of tool
Shortened RPAB	Lincoln and Adams (289)	controlled trial	Three shortened versions: tests in each are not specified	30-35 minutes	81% sensitivity and 100% specificity 19% patients were missed compared to the full version
VIS Standardised Screening Form	Rowe and the VIS Group UK (101)	large prospective multicentre observational study	• Reduced visual acuity • Visual field loss • Visual neglect • Ocular motility defects	Not specified	92% sensitivity However, without patient reported symptoms, sensitivity was 42% and specificity was 52%

Both the VIS and Checklist for Vision Problems tools were partly successful in their aims to improve detection of visual impairment in stroke survivors but clearly illustrate the need for added assessment of visual function to accurately capture the presence of visual impairment in this population.

4.2.3: Stroke screening tools

Five tools were identified that include some measures of visual function among measures of other motor and sensory functions: see Table 4.5.

4.2.3.1: *The National Institute of Health Stroke Scale (NIHSS)*

This screening tool describes 15 items, which are scored by their level of severity and include level of consciousness, motor and sensory deficits, speech and vision. In relation to visual impairment, it only assesses hemianopic visual field loss, visual neglect and horizontal gaze disorders (123). This excludes screening for a wide range of ocular disorders that may occur following stroke. Therefore, it can be argued that the NIHSS cannot be used solely to screen for visual impairment in stroke patients, as it will miss impairment of central vision, other eye movement disorders and further forms of visual field loss. No articles were identified from the review that evaluated the efficacy of this tool in screening for visual impairment.

4.2.3.2: *The Functional Impairment Battery*

Developed and described by Edwards et al. (15), this tool contains specific tests which the authors proposed had most potential to indicate impact on patients' independence. They included visual screening assessments amongst other functional tests but, similarly to the NIHSS, only screen for a small number of ocular deficits; specifically, visual acuity and neglect. Ocular motility and visual field assessments are excluded.

4.2.3.3: *The Rivermead Perceptual Assessment Battery (RPAB)*

One of the major concerns reported is the lack of time for completing the test as it is considered too lengthy (295). This is addressed, however, in developing the shortened battery as described below. The RPAB cannot be used solely for the detection of post-stroke visual impairment: it does not assess visual acuity, ocular motility defects and visual fields. Other issues have been identified which may hinder the reliability of the test findings; the test may

be influenced by cognitive skills and concentration, which is a common symptom in acute stroke cohorts.

4.2.3.4: *The Shortened Rivermead Perceptual Assessment Battery*

The shortened RPAB battery takes approximately 40% less time than the full version (289). Three variations of the shortened tool were developed, although it is unclear as to which visual assessments are included in each. Moreover, 19% of patients with perceptual problems were missed with the shortened battery compared to the full RPAB (289). Further investigation and development of the tool is required in order to address both the need for time effective and accurate visual assessment.

4.2.3.5: *The Hemispheric Stroke Scale*

This tool tests motor, sensory, perceptual and speech impairments, and includes the Glasgow coma scale (107). Visual field, eye movements, and visual perception including neglect are assessed with this tool. However, the gaze/eye movement assessment only seeks to identify gaze palsies or conjugately deviated gaze. Further difficulties may include potential stroke-related cognitive impairments, including aphasia, as the tool requires patients to respond to questioning of their neglect. However, most aphasic patients were able to undergo the screening. The authors postulate this to be the reason why the tool is performed quicker than the RPAB.

Many of the tools mentioned lack full assessment of potential ocular impairments, meaning various problematic visual conditions may still go undetected. A comparison of the tools with a formal visual assessment is required to validate their accuracy of identifying stroke related visual impairments.

4.2.4: Visual acuity screening tools

Very little literature was identified regarding the testing of vision and visual acuity specifically following a stroke. Edwards et al. (15) discuss the MIS[1] Pocket Vision Guide as an effective

[1] It was not possible to locate a description of the abbreviation for the MIS pocket guide. There was no direct reference to this in the literature and it has not been possible to contact the authors (Edwards et al. 2006).

means of screening near visual acuity within a battery of tests in a stroke population and their findings are shown in Table 4.5. Although the test detected significantly more cases of reduced vision, it should be noted that 20 of the 37 patients assessed did not have their refractive correction with them in the hospital, which potentially exaggerated the overall proportion of patients with reduced vision after stroke. The authors strongly advise health professionals to ask family or carers to bring glasses into the hospital.

Further tools exist, which identify reduced visual acuity, but have not been documented as a screening assessment in stroke populations. A recent review highlighted that, in the presence of aphasia, the assessment of visual problems becomes more challenging (278). However, there are assessments available for testing pre-verbal children, which could be used to overcome this problem. The Cardiff Acuity Test (CAT) is one example that estimates visual acuity by testing the principle of preferential looking. It relies on the examiner observing the eye movements of the patient to determine if their eyes are directed towards the picture presented rather than at the blank space (296). Although this study found the CAT to be a practical screening tool in older patients with dysphasia or cognition impairment, there is no reported literature considering the effectiveness of this method in a stroke population specifically. Evidently, there is a strong requirement for further research to evaluate which assessment tools are appropriate and valid for screening vision in stroke survivors.

4.2.5: Visual field screening tools

Visual field defects are common following a stroke. However, it is often not possible to assess patients using quantitative perimetry methods at the acute stage of stroke due to co-existent general stroke disabilities (297, 298). Therefore, confrontation field assessment remains the test of choice on acute stroke wards despite the higher risk of bias particularly in defects that are partial (108, 297).

One study compared the accuracy of visual field assessment by confrontation with automated perimetry assessment on the Humphrey visual field analyser (108). This technique of confrontation field assessment is described by Goldstein and Samsa (110) and involves the trained examiner moving a finger in the four quadrants and observing the patient's response. Only two of ten patients with confirmed field defects using the automated perimetry assessment were identified using the confrontation technique (108). The authors speculate that an alternative method of confrontational assessment, using red or white coloured

hatpins, is likely to provide a more effective evaluation of visual fields. This alternative method was previously described by Elliot et al. (111). However, further research is required to establish the effectiveness of this method in a stroke population specifically. The NIHSS confrontation method of finger counting is perhaps the most widely used. However due to its low sensitivity in detecting a visual field defect, it is possible that an alternative method would be more effective in the screening assessment of stroke patients (108).

A further method of confrontational field assessment has been reported by Cassidy et al. (285), which looked at the reliability of the Oculokinetic Perimetry method (OKP): see Table 4.6. This method was described by Damato (112) and consists of a white, hand-held board containing 100 numbers around a central stimulus. Where the finger counting method used in the NIHSS can only detect hemianopic or quadrantic field defects, the OKP method allows for the detection of arcuate, quadrantic, hemianopic, altitudinal and nasal step defects.

The results of the study showed that, although OKP is portable and easy to use at the patients' bedsides, as well as being extremely sensitive, it requires a normal level of language, cognition and attention, which is not reflective of an acute stroke demographic. Only 19 of their 75 participants were able to undergo the assessment, indicating that this method of confrontation field assessment is impractical for visual screening post-stroke field deficits. Additional methods of confrontational visual field assessment exist but have not been utilised in the assessment of stroke patients (299, 300). Further research is warranted to ascertain the most effective confrontation method for bedside assessment of acute stroke survivors.

Table 4.6: Screening methods for visual field loss following stroke

Study	Study design	Population (*n*)	Screening tool	Time/duration of assessment	Accuracy of tool
Cassidy et al. (285)	Prospective study (1/2 of the examiners was blinded)	Stroke *n*=19 (7 died by end of the 12 week follow-up) Seen within one week of stroke	Oculokinetic perimetry confrontation method (OKP)	Not specified	Sensitivity 94.4% *(N.B. requires a normal level of language, cognition and attention)*
Townsend et al. (108)	Prospective single blinded study	*n*=61 Post-stroke with homonymous visual field defect	NIHSS confrontation method	Not specified	sensitivity=20%, specificity=98%

4.2.6: Visual perception screening tools

Perceptual deficits can include visual neglect/inattention, visual hallucinations, agnosia, alexia, depth interpretation and colour vision disturbance amongst many others (32). Careful questioning by healthcare professionals is required to ascertain the presence of perceptual deficits in this stroke population, as patients may be unwilling to declare such problems due to fear of their mental state being questioned (32). Moreover, screening for these problems is of great importance as advice and reassurance can provide considerable relief to both the patient and families (32). This review identified five screening tools for visual perception and a further three that screen solely for visual neglect, which have been discussed below (see Table 4.7).

One article was found which reported on an individual screening tool for defective object recognition; the Poppelreuter-Ghent's overlapping figures test. Although it was only tested on 24 stroke participants, the results showed a stronger tendency for right hemispheric stroke patients (n=12) to present with object recognition deficits compared to left hemispheric stroke patients (n=1) (287). The tool was validated against healthy control participants however; the stroke patients were not assessed further for object recognition with an alternative perceptual tool to accurately determine the effectiveness of this screening method.

Table 4.7: Screening tools for visual perception following stroke

Study	Study design	Population (*n*)	Screening tool	Time/duration of tool (mins)	Accuracy of tool
Chiu et al. (291)	Prospective repeated measures design	Stroke *n*=50	<u>TVPS-3</u> 7 subscales (2 practice items and 16 test items): • Visual discrimination • Visual memory • Spatial relations • Form constancy • Sequential memory • Visual figure-ground • Visual closure	40	Overall intraclass correlation coefficient=0.92 Visual discrimination=0.64 Visual memory=0.53 Spatial relations=0.82 Form constancy=0.55 Sequential memory=0.66 Visual figure-ground=0.67 Visual closure=0.77
Cullen et al. (113)	Review	-	Various <u>MMSE</u> 30 items *This was the only tool identified which was deemed suitable for post-stroke screening and contained a visual perception domain*	10-15	0.82 internal consistency *McDowell et al1997 (56)* 0.85 test-retest *Correa et al 2001 (57)*
Cooke et al. (119)	Review	-	<u>OT-APST</u> 25 items: • Agnosia (5 items) • Visuospatial relations including neglect (5 items) • Body scheme (4items) • Constructional skills (3 items) • Apraxia (6 items) • Alcalculia (1 item) • Functional skills (5 items)	20-25	-

Study	Study design	Population (*n*)	Screening tool	Time/duration of tool (mins)	Accuracy of tool
Cooke et al. (292)	Prospective observational study	Stroke *n*=25 *n*=15 for interrater and intrarater reliability study *n*=10 for test-retest study	OT- APST (as above)	30	Interrater reliability=0.66-1.0 Intrarater reliability=0.64-1.0 Test-retest reliability= 0.76-0.95
Cooke et al. (294)	Series of observation studies, compared with control group	Stroke admissions over one year *n*=208 (healthy controls *n*=356)	OT-APST (as above)	30	Intraclass correlation coefficient range=0.6-1.0
Della Sala et al. (287)	Observational study of comparative effectiveness	Stroke *n*=24 (discussed separately) Alzheimer's n=12 (discussed separately) Healthy controls *n*=237 (discussed separately)	Poppelreuter-Ghent's overlapping figures test	10 seconds per picture: Entire test=20mins max	Correctly identified defective object recognition in 10 RH stroke patients and 1 LH stroke patient

Study	Study design	Population (*n*)	Screening tool	Time/duration of tool (mins)	Accuracy of tool
Demeyere et al. (283)	Control trial	Stroke *n*=208 Neurologically healthy controls *n*=140	OCS: • Picture naming • Semantics • Orientation free • Orientation MCQ • Visual field • Sentence reading • Number writing • Calculation • Broken hearts • Space asymmetry • Object asymmetry • Imitation • Verbal recall • Verbal recognition • Episodic Recognition • Executive task	15-20	Sensitivity and specificity values when validated against other tools: Picture naming: 59.32% sensitivity and 72.92% specificity Semantics: 27.59% 98.31% Orientation free: 68.00% 87.38% Orientation MCQ: 52.00% 92.23% Sentence reading 62.97% sensitivity and 81.94% specificity Number writing 52.63% sensitivity and 70.10% specificity Calculation 45.45% sensitivity and 91.14% specificity Broken hearts 94.12% sensitivity and 69.01% specificity Space asymmetry 65.63% sensitivity and 75.00% specificity Object asymmetry 46.88% sensitivity and 91.07% specificity Imitation 72.20% sensitivity and 90.70% specificity

Study	Study design	Population (*n*)	Screening tool	Time/duration of tool (mins)	Accuracy of tool
					Verbal recall: no cut offs Verbal recognition: no cut offs Episodic Recognition 75.00% sensitivity and 73.53% specificity Executive task 66.67% 74.19% Visual field: was not compared to other measure for validation. Test-retest reliability=83.3% sensitivity and 93.48% specificity
Dong et al. (116)	Prospective observational study	Stroke *n*=100	MMSE (as above) MoCA: 7 subtests • Visuospatial/executive functions • Naming • Memory • Attention • Language-sentence repetition • Language-verbal fluency	Not specified	MMSE identified 43 patients with impaired cognition MoCA identified 59 patients with impaired cognition
Godefroy et al. (282)	Prospective observational study	Stroke *n*=95	MMSE (as above) MoCA (as above)	Not specified	MMSE: 66% sensitivity and 97% specificity MoCA: 94% sensitivity and 42% specificity

4.2.6.1: *Mini Mental State Examination (MMSE)*

A review of the available screening tools for cognitive impairment identified only the MMSE to include a domain for visual construction as well as being deemed suitable for post-stroke screening (113). This domain consists of copying/drawing two intersecting pentagons (301). Since the publication of this study, however, several other tools have been developed and compared for validity (283).

When compared to the Montreal Cognitive Assessment (MoCA), the MMSE was unable to identify as many stroke survivors with impaired cognition (116). The authors suggest one reason for this is the inability of the tool to screen for complex impairments including visuospatial deficits following stroke. Conversely, the MMSE was found to have a significantly higher specificity score than the MoCA, increasing the reliability of this tool (282).

4.2.6.2: *Montreal Cognitive Assessment (MoCA)*

The MoCA can be performed quickly at bedside to assess post-stroke cognition following stroke. This tool includes three additional visual tasks alongside the copying task of the MMSE; the trail-making task, drawing a clock from memory, and naming pictures of animals (302). The overall sensitivity is deemed to be high but has just 42% specificity (282). It is suggested that the MoCA and MMSE have equal sensitivity providing similar cut off scores are used for both.

4.2.6.3: *Oxford Cognitive Screen (OCS)*

This tool screens for post-stroke cognitive impairments and includes some testing of visual perception (283). Domains assessed include numbers, calculations, memory, attention and praxis, with sensitivity scores ranging from 27.59-94.12% when validated against other measures. It takes slightly longer to administer at bedside and the authors note infrequent reasons when subtests could not be included; problems with vision, motor impairment, comprehension, fatigue, expressive aphasia and time. The heart cancellation test was validated against the BIT star cancellation test and yielded a score of 94% sensitivity for detecting visual neglect (see Table 4.8).

4.2.6.4: *Occupational Therapy Perceptual Screening Test (OT-APST)*

This 13-itemed tool screens for visual perception impairment and apraxia in patients following stroke and has proven to be a reliable assessment method (292). However, a separate assessment of visual acuity, tracking, visual fields and taking a visual history is first required to provide information required for the screening assessment (119). The tool is then modified

if a visual defect is present in order to keep the assessment within the patient's field of view (292, 294). Limitations of the tool include the requirements of adequate hearing and comprehension, as well as the use of either hand for writing, which is frequently not possible in stroke populations (119).

4.2.6.5: *The Leuven Perceptual Organisation Screening Test (L-POST)*

This recently developed tool has been deemed suitable for use with stroke survivors with cognitive and physical disabilities, although it is yet to be trialled with this specific population (115). It is freely available online for all clinicians to use and can be easily performed at bedside using a tablet or laptop. Furthermore, the computed result provides an indication of the presence and type of visual perceptual deficit. There is a "neglect-friendly version". However, the authors emphasise that the patient must first be pre-diagnosed with visual neglect. Further research is required to ascertain the validity of this tool in screening for perceptual disorders in stroke survivors.

4.2.6.6: *The Test of Visual Perceptual Skills – third edition (TVPS-3)*

This tool has the benefits of enabling stroke patients to respond without the need for motor or verbal expression and can further be used in those with reading difficulties as it involves only pictures (291). However, the authors suggest enlarging the pictures and eliminating timing of the memory test to address the insufficient test-retest reliability for each subscale: see Table 4.8 (303).

The majority of screening tools discussed in the literature for detecting visual impairment following stroke refer mostly to the assessment of visual neglect/inattention. Cooke et al. (119) provide an evaluation of the tools available, many of which they record as being too lengthy: the Rivermead Perceptual assessment battery (RPAB), the Lowenstein occupational therapy (OT) cognitive assessment, Ontario's society of OTs perceptual evaluation, and the Chessington OT neurological assessment battery. These tools are outlined in Table 4.5. Furthermore, validation and normative data were missing from the following tools and as such, they have not been included in this review: Ontario's society of OTs perceptual evaluation, the cerebrovascular accident (CVA) evaluation battery of St Mary's Hospital, Chessington OT neurological assessment battery and Baylor adult visual perceptual assessment.

The majority of articles identified through the literature search reported on screening methods solely for visual neglect/inattention. Cooke et al. (119) provide an evaluation of the tools available, many of which they record as being too lengthy: see Table 4.5. Furthermore, validation and normative data were missing from the following tools and as such, they have not been included in this review: Ontario's society of OTs perceptual evaluation, the cerebrovascular accident (CVA) evaluation battery of St Mary's Hospital, Chessington OT neurological assessment battery and Baylor adult visual perceptual assessment.

Various tests have been developed to screen for unilateral visual neglect such as the Line Bisection test, Cancellation Tests, Figure and Shape Copying, Text Reading, and Drawing Tasks (286, 303). When combined, these tests make up the 15-item Rivermead Behavioural Inattention Test (BIT) (304). Moreover, several shorter test batteries have been developed more recently for testing neglect, which contain various subtests taken from the BIT and claim a more concise assessment in significantly shorter time (114, 293).

It is widely postulated that a combination of neglect tests is more effective in detecting visual neglect than any one test alone (117, 120, 121, 288, 290, 293). All tests have individual merits; however, a collective battery of tests assesses a broader range of visual functions for a more accurate assessment of visual neglect.

Table 4.8: Screening methods for visual neglect following stroke

Study	Study design	Population (*n*)	Screening tool	Time/duration of tool (mins)	Accuracy of tool(s)
Agrell et al. (290)	Observational	Stroke *n*=57	Various: • Line bisection, • star cancellation, • Draw a clock, • copy a cross, • line crossing	Not specified	Line bisection test was most sensitive (55%) Followed by star cancellation (46%), Draw a clock (42%), copy a cross (27%, And line crossing was the least sensitive (14%).
Azouvi et al. (120)	Observational study (compared with previously reported control group)	Stroke patients with right hemispheric lesions *n*=206 Controls *n*=69	French test battery: • Line bisection, • Bells test, • Text reading, • figure copying, • clock drawing, • overlapping figures, • Writing	No time limit given. Only Bells test was timed. Average time to complete all tasks not specified	Line bisection: 19% sensitivity with 5cm line. 37.7% sensitivity with 20cm line Text reading: 46.8% Figure copying: 42.7% Clock drawing: 27.8% Bells test: 50.5% overlapping figures:30.7% writing: 34.35 Whole battery together=85.9% sensitivity
Azouvi et al. (117)	Prospective Observational study (compared with control group)	Stroke *n*=295 Right *n* =206 Left *n*=89 Healthy individuals (*n*=456-576 depending on the task)	French test battery: • Line bisection, • Bells test, • Text reading, • figure copying, • clock drawing • overlapping figures • writing	Not specified	Sensitivity results unclear in articles. 20cm line nearly twice as effective as 5cm line. Shape cancellation =41% sensitivity Combination of shape cancellation, complex line bisection and star cancellation=88% sensitivity Adding two part picture, articles reading and object finding=100% sensitivity
Caplan (284)	Prospective observational study	*n*=66 Stroke *n* =64 non-stroke *n*=2	Modified text reading	3 mins Time to complete task was deemed of little use as this depended on the degree of	identified mild neglect in 46.5% of patients, and severe neglect in 25.6%

Study	Study design	Population (*n*)	Screening tool	Time/duration of tool (mins)	Accuracy of tool(s)
				neglect and not a reflection on the test	
Cermak and Lin (288)	Review	Right cerebral vascular accident *n*= not specified: method of review not included	• Copying or drawing tests, • Line bisection, • Cancellation tests, • Reading tests, • The BIT	Cancellation tasks can be completed in less than 2 mins	Line bisection=76% sensitivity *Black et al 1990* (55)
Ferber and Karnath (118)	prospective observational study	Right sided stroke *n*=35	• Line bisection • Line crossing • Bells test • Letter cancellation • Star cancellation • clock drawing • copying task • baking tray task	not specified	Line bisection failed to detect 40% of neglect cases. The exact sensitivity unclear as mean values were not calculated Line crossing: 29.6% omissions detected bells test: 61% omissions detected Letter cancellation: 62% omissions detected Star cancellation: 40% omissions detected
Fordell et al. (293)	prospective observational study	Stroke *n*=31	<u>V-DiSTRO</u> • Line bisection, • star cancellation, • visual extinction, • baking tray test	Mean assessment time for entire tool was 15 mins Reported 50 mins for BIT, therefore VR-DiSTRO was 3x quicker than BIT	• Overall, 100% sensitivity and 82% specificity. • Star cancellation: 54% sensitivity and 96% specificity. • Line bisection: 33% sensitivity and 100% specificity. • baking tray task: 100% sensitivity and 86% specificity • Extinction: 100% sensitivity and 95% specificity

Study	Study design	Population (*n*)	Screening tool	Time/duration of tool (mins)	Accuracy of tool(s)
Leibovitch et al. (114)	Prospective observational	Stroke *n*=224 (right sided *n*=125, left sided *n*=99)	<u>SNAP</u> • Spontaneous drawing of clock and daisy • Line cancellation • Line bisection (15cm and 20cm) • Copying of clock and daisy • Shape cancellation	*"speed of administration is a key strength to the SNAP"* Average length of time to complete the tool not specified	Overall sensitivity of the SNAP=68% and specificity=76% Shape cancellation=most sensitive test (70%) Drawing/copying=most specific (99%)
Lindell et al. (121)	Prospective observational	Stroke *n*=30	<u>Various</u>: • Line crossing • Letter cancellation • Star cancellation • Line bisection (3xlines) • Complex line bisection (12x lines) • Figure and shape copying • Sentence copying • Representational drawing • Object finding • Picture scanning • Two part picture • Slide • Article reading • Personal neglect		Sensitivity: • Line crossing=26% • Letter cancellation=32% • Star cancellation=41% • Line bisection=38% • Complex line bisection=48% • Figure and shape copying=29% • Sentence copying=18% • Representational drawing=6% • Object finding=21% • Picture scanning=21% • Two part picture=32% • Slide=13% • Article reading=36% • Personal neglect=29% All had 100% specificity apart from shape cancellation, star cancellation, two-part picture which had 89%, 90% and 90% respectively The three most sensitive tests (Random Shape cancellation, Complex Line bisection, Star cancellation) together had 88% sensitivity

Study	Study design	Population (*n*)	Screening tool	Time/duration of tool (mins)	Accuracy of tool(s)
Luukkainen-Markkula et al. (286)	Prospective Observational	Right hemispheric stroke patients with hemi spatial neglect *n*=17	• Line cancellation • Letter cancellation • Star cancellation • figure and shape copying • line bisection • drawing	Not specified	Only the line bisection test correlated significantly with the Catherine Bergego scale
Vossel et al. (31)	Control study	Right hemispheric stroke *n*=56	• Line bisection • line cancellation • star cancellation • figure copying • text reading • clock drawing A “novel computerised task” was used to test for extinction and neglect	180 ”trials” in total but length of each trial is not specified	Positive correlation found between line bisection test only and extinction

4.2.6.7: *The Sunnybrook Neglect Assessment (SNAP)*

This battery includes four tests for neglect taken from a previously larger battery, which were deemed the most complementary to each other; copying and drawing of a clock and daisy, line cancellation, line bisection and shape cancellation (114). The SNAP is quicker to administer than the BIT and the results are reported to reflect good internal consistency, high reliability and validity. Furthermore, the authors claim to address previously identified limitations of neglect test for aphasic patients by eliminating language-based tasks. However, their pencil-and-paper tasks require handwriting and a level of cognition that may not always be possible in stroke populations.

4.2.6.8: *The French Test Battery for Unilateral Neglect*

Azouvi et al. (117) found that combining their three most sensitive tests (random shape cancellation, complex line bisection and the star cancellation test) gave a high sensitivity of visual neglect detection. However, to increase the detection rate to 100% the following tests were necessary additions to the battery; two-part picture, articles reading and object finding. A further four tests were added to enable a severity classification, resulting in a total of ten individual elements in the battery. This battery identified an additional 28% of patients with neglect, and highlights the requirement of more than one screening test due to the multi-factorial nature of neglect. However, there is no indication of the length of time for the whole battery. This is an important factor to consider as, particularly in the acute phase following stroke, concentration and attention are frequently reduced (283). The benefit of adding further tests needs to be weighed against clinical practicalities.

4.2.6.9: *Virtual Reality Diagnostic Test (VR-DiSTRO)*

Fordell et al. (293) developed a computer-based battery of four modified neglect tests and found that most patients felt able to focus and understand the instructions. Furthermore, this method is reported to be around three-times quicker to administer than the BIT. However, the computer set up indicated by the instructions would not allow assessment to be performed at the bedside and would require sufficient sitting balance, which may not possible for stroke survivors. The authors state they carried out the assessment on average within 2 weeks of the stroke onset. The concept of a technological form of visual screening tool is positive but would require some

modification to encompass usage by the majority of stroke survivors, such as making it more accessible in the form of portable, bedside equipment.

Conversely, pencil-and-paper tests are easily administered at bedside deeming them more suitable for this population. Sensitivity varies greatly between the various available neglect tests as seen in Table 4.8 (118, 120, 290). The following section describes individual paper-and-pencil tasks identified to screen for visual neglect following stroke.

4.2.6.10: *The Line Bisection Test*

The typical method of the Line Bisection test requires the patient to draw a line or cross where they interpret the middle of a given horizontal line to be. The length of the test line has differed in various studies, ranging from 50mm to 200mm, which has shown to greatly affect the accuracy of the test (120, 121).

One study found the line bisection test to be one of the least reliable methods, especially when tested with the shorter 50mm line (120). A more recent study by the same authors concurrently found a 200mm line proved almost twice as effective as a 50mm line at detecting neglect (117).

Lindell et al. (121) modified the line bisection test to include 12 lines, six on either side of the page, which varied between three lengths: 63mm, 123mm and 185mm. This increases the sensitivity from 38% with the conventional method, to 48% with the modified method, further indicating that larger lines should be used on the test sheet to make the assessment as sensitive as possible.

Additional studies have found the line bisection test to have a poor predictive value at detecting neglect in a stroke population (118). It is suggested that patients with only mild symptoms of neglect would be missed when using this test. Azouvi et al. (117) found the line bisection test to be the least sensitive measure. Even when compared to their healthy control group, they found that this test was the only assessment from their battery to be significantly affected when patients used their left hand to write. However, this was only significant in the smaller 50mm line, further supporting the previous recommendation that longer lines should be used in this assessment. A separate study addresses this issue by altering the length of the line depending on which hand the patient uses (114). Although they report that this

method proved effective, they do not specify which length they used for which hand, making it difficult for health professionals to translate this method into practice.

The line bisection test has been deemed reliable in a number of studies at detecting visual neglect, particularly in association with other attentional tasks. Luukkainen-Markkula et al. (286) found the line bisection subtest to be especially sensitive in detecting a combination of both hemispatial neglect and visual field deficits. Agrell et al. (290) reported the line bisection was the most sensitive neglect test in their comparative study. However, they postulate that performance on the line bisection test further expresses motor neglect, skewing the accuracy of the test.

The line bisection test has further been proven useful in detecting both visual neglect and extinction. Extinction is described as the ability to respond to stimuli on either side, but failing to respond to a contralesional stimulus when an ipsilesional stimulus is presented simultaneously (305). Visual neglect is the general failure to respond to stimuli on the contralesional side, with or without stimuli presented in the ipsilesional side (120). Vossel et al. (31) observed the effectiveness of the line bisection test in the detection of extinction using a computerised form of testing. They found a significant correlation in the increased number of errors on the line bisection test in the presence of extinction. Conversely, they found no significant relationship between the cancellation inattention tests and extinction. Therefore, the line bisection test was the only inattention test reported to effectively detect both visual neglect and extinction. Unfortunately, lack of description of the computerised method of assessment does not allow for confirmation that this is a suitable bedside screening tool for visual neglect.

4.2.6.11: *Cancellation Tests*

Cancellation tasks are the most widely used pencil-and-paper assessments to investigate the presence of neglect (306) and are broadly similar in method. They require the patient to scan a page of various images, and cross out the specific target stimuli (120).

Various studies have highlighted the star cancellation tests and shape cancellation test for their accuracy in detecting visual neglect after stroke (15, 117). Both tests are similar in that they involve distractor items amongst target items (114).

Comparatively, Ferber and Karnath (118) found the Bells test and the letter cancellation test to be equally effective and both significantly more sensitive than the star cancellation test. By calculating an omission score of unseen items, they could accurately compare the different cancellation tests. They postulate that the distractor items of the star cancellation test are easily discriminated and could yield a "pop-out" effect making it easier for the patient to detect the intended targets. Whereas, all items in the letter cancellation and Bells tests resemble each other, and so, can detect visual exploratory deficits more sensitively. They recommend the Bells test and letter cancellation test, above all other tests, to robustly diagnose visual neglect of all levels.

A more recent study identified the shape cancellation test to be the most sensitive cancellation test in screening for visual neglect (114), which contradicts previous findings that distractor items reduce the sensitivity of these tests. No direct comparison has been made between the Bells test and the letter cancellation test, thus further research is indicated in order to determine whether or not distractor items have a negative effect on cancellation tests.

One concern raised with undertaking the Bells Test is that performance is affected significantly in certain patient demographics (117). Higher numbers of omissions occur with older patients and less educated patients. The authors encourage consideration of these factors where possible when assessing neglect with the Bells Test. Furthermore, the patient's spontaneous starting point on the page is the most sensitive measure at detecting neglect, particularly when they begin to cancel the targets in the direction of right to left (117, 120). Taking the starting point into consideration increased the sensitivity of the Bells test from 41.3%, when based on number of omissions only, to 50.5% (120).

4.2.6.12: *Text Reading*

Azouvi et al. (120) described the method of text reading, which considers variables such as the number of words omitted, and the difference between omissions on the left and right side. They found it had the second highest sensitivity of all the inattention tests, after the Bells test.

Caplan (284) described an alternate form of test reading, which specifically assesses left-sided neglect, such that the left-sided margin was indented randomly, requiring additional scanning to re-fixate from the end of one line to the beginning of the line below. The test identified an additional ten patients with neglect who had previously been missed with OT tasks. Where other assessment methods have been criticised for failing to detect mild cases of visual neglect (118), the text reading task effectively identified mild neglect in 46.5% of patients (284).

4.2.6.13: *Figure copying and Drawing tasks*

The methods of figure copying and drawing a clock from memory are described by Azouvi et al. (117). It has been suggested that copying an image relies more on visual input compared to drawing from memory and therefore, copying tasks are more sensitive at picking up visual neglect (307). Azouvi et al. (120) described their copying task to include a range of images that they considered to make the test more sensitive. This is supported in their findings, as the figure-copying task was one of the more effective tests at detecting neglect, whilst the clock-drawing test scored poorly. Moreover, Cooke et al. (292) noted variability in the scoring of the clock drawing test, as subtle errors made interpretation of the scoring criteria unclear. However, the authors fail to state the nature of these errors. They indicate a requirement for future research in order to re-evaluate this test and take into account the interpretation of minor errors, which could subsequently increase the reliability of this screening method.

4.3: Summary

The results of this systematic review showed that there is currently no single tool that can effectively screen for all potential post-stroke visual impairments when the patient's cognitive and communicative disabilities are taken into account. The results of this review should not be interpreted as a requirement for creating new orthoptic assessments for use in stroke patients, as a multitude of orthoptic tests have been identified, which can be adapted for use in neurological patients. However, the need to select the appropriate tests (which have not been recommended in national

guidelines (124)), dependent on the differing needs of the patient, is required for consistent and equitable post-stroke vision screening. For example, linear visual acuity screening using Snellen or LogMAR charts is preferred, although the addition of a matching card may be required for use in patients with speech impairment, or the use of fading optotypes may be required following cognitive impairment.

Furthermore, as many functional deficits after stroke are not always apparent immediately, and with many patients unable to report their symptoms due to these difficulties, standardised screening protocols are needed to accurately identify individuals with visual impairments. Additionally, the use of tools to screen for ocular motility, ocular alignment, binocular vision and central vision are largely unreported after stroke, meaning many patients could potentially be missed or misdiagnosed of these conditions.

Moreover, when used by non-eye care specialists, the efficacy of various screening methods is significantly reduced. This highlights an urgent demand for the development of a tool that can be used by any healthcare professional at the acute stage of stroke to identify all potential visual impairments. If identified, these patients can be referred for more thorough investigation of visual function, which will further aid planning of their general rehabilitation.

The findings from Chapter 3 presented variability in the screening of vision problems after stroke. The results of this review (Chapter 4) highlight a lack of high-quality comparative studies to ascertain the validity of individual screening methods as well as overall assessment tools. Further work is needed to inform national guidelines of the necessary screening methods that ensure equitable screening nationally. Chapter 7 will continue this investigation into the full range of appropriate visual screening methods after stroke to address this inequality.

This research has been published elsewhere; see:

Hanna K, Rowe F and Hepworth L. The screening methods for post-stroke visual impairment: a systematic review. 2016 Disability and rehabilitation, 39(25): 2531-2543.

The search methods described in 3.1.4 were further performed in December 2017 and no further articles were identified that met the search criteria for this chapter.

Chapter 5: The rehabilitation options for post-stroke visual impairment.

5.1: Background

Visual impairment is a "non-correctable deficit of visual function", meaning the deficit cannot be remedied with a prescription of eye-glasses (308). Following stroke, this includes abnormalities of central and/or peripheral vision, eye movements and a variety of visual perception problems such as inattention and agnosia. The visual problems (types of visual impairment) can be complex including ocular as well as cortical damage (4, 32). Visual impairments can have wide reaching implications on daily living, independence and quality of life. Links with depression have also been documented in the literature (10-14). The estimation of the overall prevalence of visual impairment is approximately 60% (2, 7-9, 32, 139, 309).

In order to manage visual impairments caused by stroke it is important to establish the range and effectiveness of the available rehabilitation options. The aim of this systematic review is to provide a comprehensive synthesis of the evidence relating to visual problems after stroke, with specific attention given to intervention options.

5.2: Methods

For the full methodology for this systematic review, see 2.2. The MeSH (Medical Subject Headings) terms used for this review are displayed in Table 5.1.

5.2.1: Quality assessment

Assessment of the quality of the studies included in this review consisted of the use of the following four checklists. For the evaluation of the quality of evidence in randomised control and control trials, an adapted version of the CONSORT (Consolidated Standards of Reporting Trials) statement was used. The CONSORT

statement covers 25 items within the following domains; title/abstract, introduction, methods, results, discussion and other information (156). An adapted version of the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) statement was used to assess the quality of cross-sectional, cohort and control studies. The STROBE statement covers 22 items from introduction, methods, results and discussion (157). An adapted version of the PRISMA (Preferred Reporting for Systematic reviews and Meta-Analyses) statement was used to assess quality of evidence in review articles, including the three Cochrane review papers used. This covers 27 items within title, abstract, introduction, methods, results, discussion and funding (153). Finally, an adapted version of the GRACE (Good Research for Comparative Effectiveness) statement was used for observational studies with comparative effectiveness. This statement covers 11 items within the domains of data and methods. There is no formal scoring system used in this checklist, but it is suggested that if a paper addresses the majority of the checklist items, then it is deemed reliable (158).

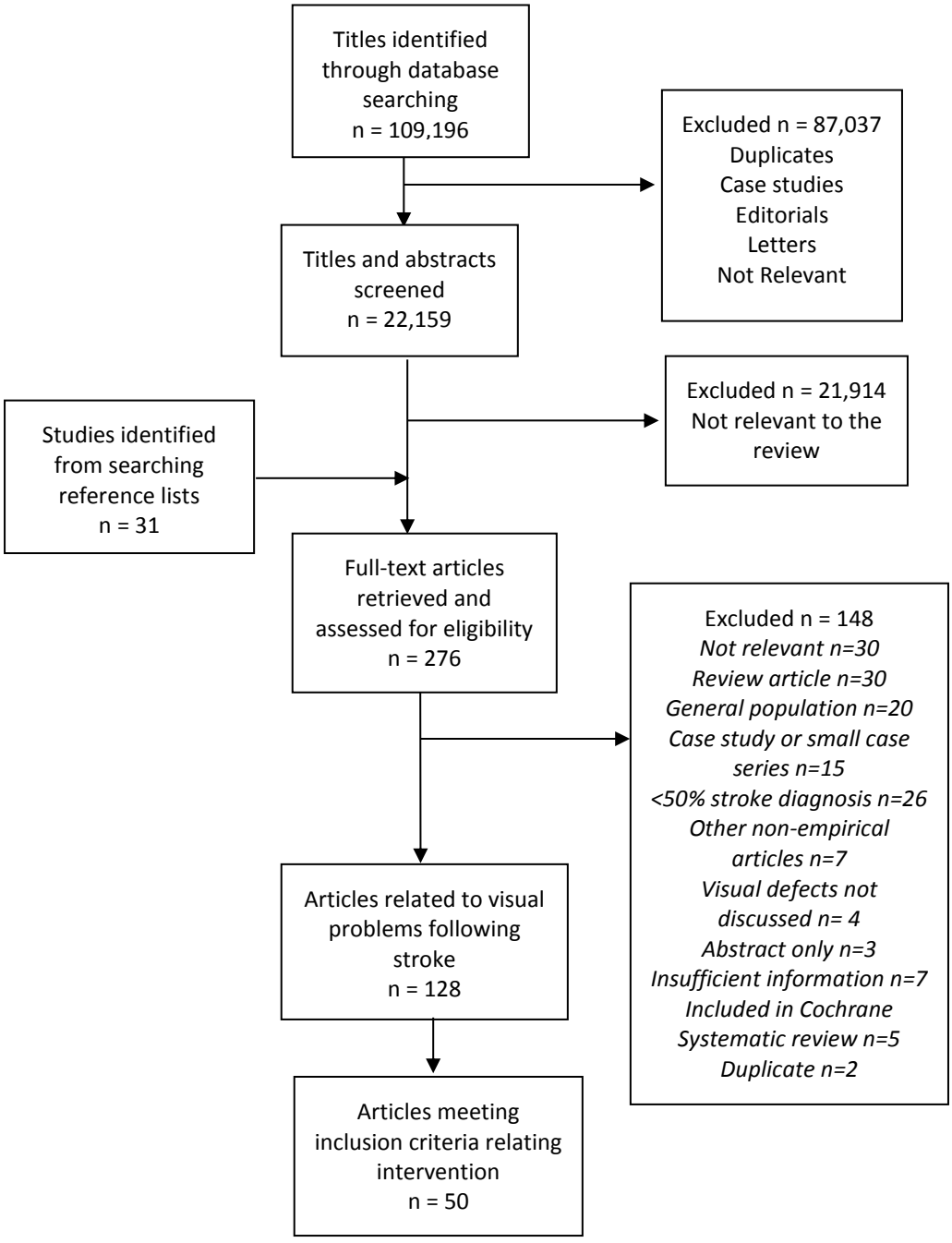
The adapted version of the STROBE statement used in this review included 18 items. Only the information pertinent to quality appraisal of the studies was included. The items excluded were not considered relevant information i.e. the title/abstract, background, setting and funding. The adapted version of the CONSORT statement included 31 items of relevance.

All domains covered in these checklists were considered important factors when the quality of evidence and risk of bias in the reported articles was evaluated. These domains were graded ‘high risk’, ‘low risk’ or ‘unclear risk’. If it was clear that the domain was performed, then this was described as “reported” and was recorded as having a low risk of bias. If the domain was not included, this was described as “not reported” and deemed a high risk of bias. Insufficient evidence was labelled as an “unclear” risk.

Table 5.1: Search terms for systematic review of post-stroke treatment methods

Cerebrovascular disorders/ Brain ischaemia/ Intracranial Arterial Disease Intracranial Arteriovenous Malformations/ "Intracranial Embolism and Thrombosis*/ Stroke/	Eye Movements/ Eye/ Eye Disease/ Visually Impaired Persons/ Vision Disorders/ Blindness/ Diplopia/ Vision, Binocular/ Vision, Monocular/ Visual Acuity/ Visual Fields/ Vision, Low/ Ocular Motility Disorders/ Blindness, Cortical/ Hemianopsia/ Abducens Nerve Diseases/ Abducens Nerve/ Oculomotor Nerve/ Trochlear Nerve/ Visual Perception/ Nystagmus strabismus smooth pursuits saccades depth perception stereopsis gaze disorder internuclear opthalmoplegia Parinaud's syndrome Weber's syndrome skew deviation conjugate deviation oscillopsia visual tracking agnosia hallucinations
OR	OR
AND	

Figure 5.1 Flowchart of pathway to inclusion of articles for systematic review of post-stroke treatment methods



5.3: Results

Figure 5.1 illustrates the results of the search. Fifty articles (3700 participants and 529 healthcare professionals) were included. This number includes four Cochrane reviews relating to interventions available for visual problems following stroke. In view of the high standard and rigorous methods of Cochrane reviews, the findings of these four papers are summarised as an overview, followed by a review of trials and studies not included in the Cochrane reviews. The 50 included studies consisted of four Cochrane systematic reviews, eight randomised trials, one randomised crossover trial, two non-randomised controlled trials, 27 prospective observational studies, three retrospective analyses, four prospective surveys/questionnaires and one prospective observational study with a questionnaire. One study only used a control group for the pre-treatment data and so was treated as a prospective observational study and not a controlled trial (20).

The included articles reported on interventions for one or a combination of two or more visual impairments. Thirty-four studies (2320 participants and 69 healthcare professionals) reported on interventions for visual field loss; nine reported on interventions for visual inattention/neglect (227 participants and 732 healthcare professionals); seven of the studies (1029 participants and 529 healthcare professionals) reported on intervention for ocular motility or alignment defects; six studies (1085 participants and 55 healthcare professionals) reported on intervention for reduction of central vision and two (187 participants) reported on interventions for visual perceptual defects.

5.3.1: Quality of the evidence

A total of 50 articles were included in this review paper and the quality of evidence was assessed for each (Tables 5.2-5.5). Evidence was deemed to be of good quality if the article reported ≥75% of the items on the relevant assessment checklist. Overall, ten of the reported articles scored 100% in the quality of evidence assessment. Thirty-four out of the 49 articles included in this review reported between 75 and 99% of the checklist items assessed and were deemed to have good quality. Five reported between 50 and 74% of the items. The remaining one article failed to reach 50%, achieving 26% respectively (310).

Table 5.2: Quality appraisal of papers using the CONSORT checklist for systematic review of post-stroke treatment methods

			Aimola et al. (127)	*Beasley and Davies (133)*
Introduction	Objectives	2b	+	+
Methods	Trial design	3a	+	+
	Changes to methods	3b	-	-
	Eligibility	4a	+	+
	Interventions for each group	5	+	+
	Outcome measures	6a	+	+
	Changes to trail outcomes	6b	+	+
	Sample size	7a	+	+
	Interim analysis	7b	n/a	n/a
	Method of random allocation	8a	+	+
	Randomisation	8b	+	+
	Implementation of random allocation	9	+	-
	Generation of random allocation	10	-	-
	Blinding	11a	+	+
	Similarity of interventions	11b	n/a	n/a
	Statistical methods	12a	+	+
	Additional analyses	12b	+	+
Results	No. of participants	13a	+	+
	Losses and exclusions	13b	+	?.
	Dates of recruitment - follow-up	14a	+	+
	Reason trial ended	14b	-	-
	baseline demographic	15	+	?.
	Analysis of original assigned groups	16	+	+
	Results with precision	17a	+	+
	Binary outcomes	17b	n/a	+
	Additional analysis	18	+	+
	Harms	19	-	-
Discussion	Limitations	20	+	+
	Generalisability	21	+	+
	Consistent interpretation	22	+	+
Other Info	Access to full protocol	24	+	-

	Beis et al. (136)	*Bowers et al. (311)*	*Kerkhoff et al. (312)*	*Machner et al. (135)*
2b	+	+	+	+
3a	+	+	+	+
3b	-	-	-	n/a
4a	+	+	+	+
5	+	+	+	+
6a	+	+	+	+
6b	-	-	-	-
7a	-	+	+	+
7b	n/a	n/a	n/a	n/a
8a	-	+	+	+
8b	+	+	+	+
9	-	+	+	+
10	-	+	+	+
11a	-	+	-	n/a
11b	n/a	+	-	+
12a	+	+	+	+
12b	+	+	+	+
13a	+	+	+	+
13b	?	+	+	+
14a	+	+	+	+
14b	-	-	-	-
15	-	-	+	+
16	-	+	+	+
17a	-	+	+	+
17b	-	+	+	+
18	+	+	+	+
19	-	-	-	-
20	+	+	+	+
21	+	+	+	+
22	+	+	+	+
24	-	+	-	-

	Mazer et al. (313)	*Plow et al. (314)*	*Rowe et al. (315)*
2b	+	+	+
3a	+	+	+
3b	+	-	+
4a	+	+	+
5	+	+	+
6a	+	+	+
6b	n/a	-	+
7a	+	+	+
7b	+	n/a	n/a
8a	+	-	+
8b	+	-	+
9	-	-	+
10	?	-	+
11a	+	+	+
11b	+	+	+
12a	+	+	+
12b	+	+	+
13a	+	+	+
13b	+	+	+
14a	+	?	+
14b	-	-	+
15	-	+	+
16	+	+	+
17a	+	+	+
17b	+	+	+
18	+	+	+
19	+	+	+
20	+	+	+
21	+	-	+
22	+	+	+
24	+	-	+

[-] =Not reported [?] =Unclear [+] =Reported

Table 5.3: Quality appraisal of papers using the STROBE checklist for systematic review of post-stroke treatment methods

	Methods									Results					Discussion		
	Study design	Participants	Variables	Data source	Bias	Study size	Quantitative variables	Statistical methods	Participants	Descriptive data	Outcome data	Main results	Other analyses	Key results	Limitations	Interpretation	Generalisability
	4	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21
Bergsma et al. (316)	-	+	+	+	+	+	+	-	+	+	+	-	n/a	+	+	+	+
Choudhuri et al. (132)	+	+	+	+	-	+	-	-	+	+	+	+	+	+	-	+	n/a
Freeman and Rudge (8)	+	+	+	+	-	+	-	-	+	+	+	-	n/a	+	-	+	-
Gall and Sabel (317)	+	+	+	+	+	+	+	+	+	+	+	+	n/a	+	+	+	+
Giorgi et al. (129)	+	+	+	+	+	+	+	+	+	+	+	+	-	+	-	-	-
Hayes et al. (318)	+	+	+	+	+	-	-	-	+	+	+	n/a	n/a	+	+	+	+
Lane et al. (319)	+	+	+	+	+	-	+	+	+	+	+	+	+	+	-	+	+
Lotery et al. (18)	+	+	?	+	-	+	-	-	+	+	+	+	n/a	+	-	+	+
Mannan et al. (320)	+	+	+	+	+	-	+	+	+	+	+	+	n/a	+	-	+	+
Marshall et al. (321)	+	+	+	+	+	-	+	+	+	+	+	-	n/a	+	+	+	+
Menon-Nair et al. (322)	+	+	+	+	+	+	+	+	+	+	+	+	n/a	+	+	+	+
Mueller et al. (323)	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	-	-
Nelles et al. (324)	+	+	+	+	+	-	+	+	-	+	+	-	n/a	+	-	+	-
Ong et al. (325)	+	+	+	+	+	+	+	+	+	+	+	+	n/a	+	+	+	+
Ong et al. (326)	+	+	+	+	-	+	+	+	+	+	+	+	n/a	+	+	+	+

Pambakian et al. (327)	+	+	+	+	-	+	-	+	+	+	+	+	n/a	+	-	+	+
Poggel et al. (144)	+	+	+	+	+	+	+	+	+	+	+	+	n/a	+	+	+	+
Pollock et al. (134)	+	+	+	+	+	+	+	n/a	+	+	+	+	n/a	+	-	+	+
Pollock et al. (328)	+	+	+	+	+	+	+	n/a	+	+	+	+	n/a	+	+	+	+
Reinhard et al. (329)	+	+	+	+	+	-	+	+	+	+	+	+	n/a	+	+	+	+
Romano et al. (330)	+	+	+	+	+	+	+	+	+	+	+	+	n/a	+	+	+	+
Rowe et al. (32)	+	+	+	+	+	+	+	+	+	+	+	+	n/a	+	-	+	+
Rowe and VIS Group UK (141)	+	+	+	+	+	+	+	+	+	+	+	+	n/a	+	+	+	+
Rowe et al. (16)	+	+	+	+	+	+	+	+	+	+	+	+	n/a	+	+	+	+
Pollock et al. (126)	+	+	+	+	+	+	+	+	+	+	+	+	n/a	+	+	+	+
Pollock et al. (27)	+	+	+	+	+	+	+	+	+	+	+	+	n/a	+	+	+	+
Sabel et al. (331)	+	+	+	+	+	+	+	+	+	+	+	+	+	+	-	+	+
Sabel et al. (332)	+	+	+	+	+	+	-	+	+	+	+	+	n/a	+	-	+	+
Schmielau and Wong Jr (333)	+	+	+	+	+	+	+	+	+	+	+	+	+	+	?	+	+
Woodhead et al. (138)	+	+	+	+	+	-	+	+	?	+	+	+	n/a	+	-	+	+
Zihl (334)	+	+	+	+	+	-	+	+	?	+	+	+	n/a	+	-	+	-
Zihl and von Cramon (310)	-	+	+	+	-	-	-	-	-	+	+	+	n/a	+	-	-	-
Zihl and von Cramon (335)	-	?	+	+	+	-	-	-	?	+	+	+	n/a	?	-	+	+
Zihl and von Cramon (336)	+	+	+	+	+	+	-	-	?	+	+	+	n/a	+	+	+	+

[-] =Not reported [?] =Unclear [+] =Reported

Table 5.4: Quality appraisal of papers using the PRISMA checklist for systematic review of post-stroke treatment methods

	Title	Abstract	Introduction		Methods												Results								Discussion		Funding
			Rational	Questions	Existing review protocol	Study Characteristics	Sources	Search strategy	Study selection	Data extraction	Variables	Risk of Bias	Summary measures	Data handling	Risk of Bias (cumulative)	Additional analyses	No. of studies	Characteristics data extraction	Risk of Bias (individual)	Benefits or Harms	Meta-analyses	Risk of Bias (across studies)	Additional analyses	Summary	Limitations	Generalisability	
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27
Bowen et al. (337)	+	+	+	+	-	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	n/a	+	+	+	-	+	+
Pollock et al. (126)	+	+	+	+	-	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	-
Pollock et al. (27)	+	+	+	+	-	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	n/a	+	n/a	+	+	+	-
Pollock et al. (338)	+	+	+	+	-	+	+	+	+	+	+	+	+	+	+	+	+	n/a	n/a	n/a	n/a	n/a	n/a	+	+	+	-

[-] =Not reported [?] =Unclear [+] =Reported

Table 5.5: Quality appraisal of papers using the GRACE checklist for systematic review of post-stroke treatment methods

Study	Data						Methods				
	Treatment	Primary outcomes	Primary clinical outcome	Validation	Outcome	Both groups measured equally	Population restriction	Comparison groups	Confounding variables	Immortal-time bias	Analyses
	D1	D2	D3	D4	D5	D6	M1	M2	M3	M4	M5
Datié et al. (137)	+	+	+	+	+	+	?	+	+	-	+
Jacquin-Courtois et al. (339)	+	+	+	+	+	+	?	+	+	-	+
Nelles et al. (11)	+	+	+	+	+	+	?	-	+	-	+

[-] =Not reported [?] =Unclear [+] =Reported

5.3.2: Visual field loss

Visual field loss can affect the peripheral and/or central field of vision following stroke although, less frequently, the central visual field may present as an isolated defect. Visual field defects can often present with visual perceptual disorders, such as visual inattention and/or agnosia, further complicating the management of the visual field loss. One Cochrane review relating to visual field loss following stroke focused on three types of interventions: restitutive, compensatory and substitutive (338). Functional ability in performing activities of daily living was used as a primary outcome measure. Thirteen trials were identified as meeting the inclusion criteria (128, 340-351). Limited meta-analyses were possible and were only completed for compensatory interventions. A key finding was the limited evidence for all interventions related to visual field loss following stroke. It was not possible to comment on the effectiveness of restitutive or substitutive interventions. Pollock et al. (134) reported that at least half of Orthoptists in Scotland provided typoscopes, Peli prisms, reading aids and scanning therapy to stroke patients with field loss, with advice on head postures and general information being the most frequently reported strategy. Concurrently, Rowe et al. (23) reported that advice and raising awareness of the field loss were the most common forms of rehabilitation (52.7%). Advice included reading strategies, scanning eye and head movements, use of lighting, compensatory head posture, and registration for visual impairment. Further rehabilitation of field loss included typoscopes (43.9%) and Peli prisms (28.6%) (23).

Table 5.6: Results for rehabilitation of visual field defects

Study	Study design	Aim/objective	Sample size (*n*)	Population	Intervention	Time/duration of intervention
Aimola et al. (127)	RCT Parallel design	Evaluate the efficacy and feasibility of an unsupervised reading and exploration computer training	52 Intervention: 28 Control: 24	Mixed Ischaemic stroke *n*=39, haemorrhage *n*=6, TBI *n*=6, tumour *n*=1 At least 3months post-stroke	*Compensatory*: Computer-based reading and visual exploration training vs. sham exploration task	Experimental group=14blocks of training per day. Control group=10 blocks per day. One hour sessions for up to 10 weeks
Bainbridge and Reding (346) *Article taken from Cochrane review Pollock et al. (338)*	RCT	To assess the effect of full field prisms for hemi-field visual impairments	18	stroke	*Substitutive:* 15 dioptre prism vs. hemifield prisms	Prism wear while awake for 4 weeks
Bergsma et al. (316)	Cohort study	Determine whether peripheral training also causes improvement in colour and shape perception and reading speed	12	Chronic stroke (6-102 months post-stroke)	*Restitutive*: VRT	40x 1hour sessions of training, For 10 weeks.
Bowers et al. (311)	Double masked, multi-centre,	Evaluate efficacy of real relative to sham	61	Stroke	*Subsitutive*: 57^{Δ} prism placed above and below the visual axis	Each set of prisms were worn for 4 weeks.

Study	Study design	Aim/objective	Sample size (*n*)	Population	Intervention	Time/duration of intervention
	randomised crossover trial	peripheral prism glasses		At least 3 months post-stroke	vs. sham (5^{Δ}). Horizontal vs. oblique positioning	Measured at 6 months
Carter et al. (128) *Article taken from Cochrane review Pollock et al. (338)*	RCT	To test the effect of cognitive skill remediation training vs. control/standard care	33	Stroke With or without visual field defect or neglect	*Compensatory:* Cognitive skill remediation training	30-40mins 3x weekly for 3-4 weeks
Freeman and Rudge (8)	Prospective observational study	Identify the Orthoptists' role in stroke management	76	Stroke	Advice (for field defect and inattention, n=4) Occlusion (n=10), prisms (n=7), registered blind (n=2), observation (n=20), glasses (n=5)	Within 1 week post-stroke. Follow-up ranged from 1 week to 4 years
Gall and Sabel (317)	Prospective non-controlled trial	Examine whether increased visual functioning after VRT coincides with improved reading abilities	11	Mixed Infarct *n*=7, haemorrhage *n*=1, AVM *n*=1, subarachnoid haemorrhage *n*=1, encephalitis *n*=1	*Restitutive*: VRT	30mins 2x daily, 6 days a week, for 6 months
Giorgi et al. (129)	Cohort study	Evaluate Peli prisms as a low vision optical device for hemianopia in an extended wearing trial	23	Mixed Stroke *n*=16, surgery *n*=4, TBI *n*=2, congenital *n*=1	*Subsitutive*: 40^{Δ} prism placed above and below the visual axis	Peli prisms worn for 6 weeks, 3 months and long-term. "Long-term" follow-up not specified

Study	Study design	Aim/objective	Sample size (*n*)	Population	Intervention	Time/duration of intervention
Hayes et al. (318)	Interventional case series	Evaluate functional changes following the NVT program for homonymous hemianopia after stroke	13	Stroke Within 2weeks – 6months post-stroke	*Compensatory*: NVT	One hour per session, 3x per week for 7 weeks
Jacquin-Courtois et al. (339)	Prospective observational study	Test the effect of a compensatory eye movement training	7	Mixed Stroke *n*=5 Tumour *n*=2 Chronic field loss, approx. 2.9 years post-stroke	*Compensatory*: Visual search	1x 30 min session
Jobke et al. (345) *Article taken from Cochrane review Pollock et al. (338)*	Randomised, double blinded, crossover study	To compare extrastriate vs. conventional VRT in patients with visual field loss	21	Mixed Stroke/ischaemia *n*=10, cranio-cerebral injury *n*=3, brain surgery *n*=3, tumour *n*=1, meningitis *n*=1	*Restitutive:* Extrastriate VRT vs. Conventional VRT	Extrastriate 30mins daily for 90 days. Then crossover of conventional VRT for 90 days
Kasten et al. (351) *Article taken from Cochrane review Pollock et al. (338)*	RCT, double blinded	to assess the effect of computer-based training to treat partial blindness	19	Mixed Stroke *n*=10, trauma *n*=4, other *n*=5	*Restitutive:* VRT	1 hour per day, 6 days per week for 6 months (total=150 hours)
Kasten et al. (344) *Article taken from Cochrane review Pollock et al. (338)*	RCT	to test the hypothesis that VRT does not benefit from co-stimulation	23	Mixed stroke, ischaemia, cerebral haemorrhage, vascular disease (*n*=14	*Resititutive:* Parallel co-stimulation, moving co-stimulation or single stimulus	all groups had 30mins 2x daily for 3 months

Study	Study design	Aim/objective	Sample size (*n*)	Population	Intervention	Time/duration of intervention
				combined), trauma (*n*=8),inflammation (*n*=1)		
Lane et al. (319)	Non-randomised controlled trial	Explore the efficacy of a visual exploration training	42	Mixed Ischaemic *n*=28, haemorrhage *n*=10, TBI *n*=4	*Compensatory*: Visual exploration training Visual attention training	Exploration training=40min sessions, over 2-9 weeks. Attention raining=30min sessions, over 2-7 weeks.
Mannan et al. (320)	Prospective observational study	Characterise changes in eye movements resulting from training	29	Mixed Infarct *n*=22, haemorrhage *n*=6, surgery *n*=1, tumour *n*=2 At least 3months post-stroke	*Compensatory*: Visual search training	20x 40min sessions for 1 month
Marshall et al. (321)	Longitudinal cohort	Determine whether visual field expansion occurs with VRT	7	Stroke	*Restitutive*: VRT using microperimetry	20-30 mins 2x daily, 6 days a week, For 3 months
Mazer et al. (313)	RCT	To compare driving performance after useful field of view retraining (UFOV) compared to traditional visuoperceptual retraining	84	Stroke	*Compensatory* UFOV vs. commercially available computer-based visuoperceptual retraining (control)	Both received 20 sessions (each session 30-60mins long) at a rate of 2-4 sessions per week

Study	Study design	Aim/objective	Sample size (*n*)	Population	Intervention	Time/duration of intervention
Mueller et al. (323)	Prospective observational study	Evaluate the outcome of VRT in a larger sample	302	Mixed Stroke *n*=214, trauma *n*=43, tumour *n*=34, AION *n*=5	*Restitutive*: VRT	1hour of training, 6 days a week, For 6 months
Nelles et al. (11)	Prospective observational study	Investigate whether training eye movements would induce change in the neural activity of cortical visual areas	21 Controls: 23 health participants	Stroke Infarct *n*=16 Haemorrhage *n*=5	*Compensatory*: Eyes fixating vs. exploratory eye movements	30mins per session, 2x daily, for 4 weeks
Nelles et al. (324)	Prospective observational study	Can the internet be used as a resource so that suitable patients can build up practice to improve	8	Ischaemic stroke	*Compensatory*: Eye movement training	30 min session 1x daily for 4 weeks
Ong et al. (325)	Longitudinal cohort study	To see if Eye-search web based hemifield search training improves patients search time and "real world" outcomes	33	Stroke participants with right homonymous hemianopia Infarct *n*=14, haemorrhage *n*=3, AVM *n*=1, unknown *n*=15	*Compensatory*: OKN therapy - "Read right"	20mins of therapy per day (suggested). Patients prompted to test reading speed after 5 hours of therapy accrued.
Ong et al. (326)	Prospective observational study	Evaluate efficiency of eye movements following visual search training	78	Hemianopic patients with no neglect	*Compensatory*: Eye-search scanning exercises online	11 days of therapy (length of each session not specified)

Study	Study design	Aim/objective	Sample size (*n*)	Population	Intervention	Time/duration of intervention
				77%=stroke patients (8%= tumour, 3% TBI, 13%= other)		
Pambakian et al. (327)	Prospective observational study	Examine whether directing attention to ARV using a visuospatial cue also increases long-term neural plasticity	31 (29 completed training)	Mixed Infarct *n*=22, haemorrhage *n*=6, surgery *n*=1, tumour *n*=2 At least 3months post-stroke.	*Compensatory*: Visual search training	20x 40min sessions, In 1 month
Plow et al. (350) *Article taken from Cochrane review Pollock et al. (338)*	RCT	to test the effect of transcranial direct current stimulation to enhance VRT	8	Stroke	*Restitutive:* VRT with active tDCS vs. VRT with sham tDCS	VRT=30min 2x daily for 3 months Active tDCS=2mA/ min along with VRT sham tDCS=30 seconds ramped down to 0 then turned off, along with VRT
Plow et al. (314)	Pilot, double blinded RCT	Investigate whether training eye movements would induce change in the neural activity of cortical visual areas	12 (8 included in final analysis)	Mixed Stroke *n*=10, surgical trauma *n*=2 At least 3 months post-stroke	*Restitutive*: VRT compared with active tDCS (control group received sham tDCS)	30mins of training, 3x a week, For 3 months.
Poggel et al. (343)	RCT	to assess whether or not attentional	20	Mixed post-genicular lesions	*Restitutive*:	30-35mins 2x daily, for 56 sessions lasting approx. 1 month

Study	Study design	Aim/objective	Sample size (*n*)	Population	Intervention	Time/duration of intervention
Article taken from Cochrane review Pollock et al. (338)		cueing improves VRT			VRT with attentional cueing vs. VRT with no attentional cueing	
Poggel et al. (144)	Retrospective analysis of a prospective clinical trial. Retrospective analysis of questionnaire	Assess the possible efficacy of tDCS combined with VRT	trial=19 questionnaire=121	Mixed Infarct *n*=15, vascular *n*=3, TBI *n*=1	*Restitutive*: VRT	30-35mins of training, 2x daily, For 6 months.
Pollock et al. (328)	Survey	To explore the current assessments, protocols, referrals and treatments of visual problems after stroke by OTs	55	Occupational therapists	Visual field, eye movement disorders and visual neglect (scanning training, patching/prisms, ADL training, reading aids/ magnifiers, information, environment modification)	45% of OTs said they would treat within 2 weeks of stroke. 75% said they would treat patients within 6 weeks of stroke. 38% said they would continue treatment up to 3months
Pollock et al. (134)	Survey	To explore the current assessments, protocols, referrals and treatments of visual problems after stroke by Orthoptists	14	Orthoptists	Visual field, eye movement disorders and visual neglect (scanning training, patching/prisms, ADL training, reading aids/ magnifiers, information, environment modification)	Time of intervention not stated. 86% did not have a protocol/management plan for visual treatment of stroke patients
Pollock et al. (338)	Cochrane systematic review	To determine the effects of interventions for visual field defects after stroke	13 studies *n*=344	Mixed Stroke *n*=285	Various (studies listed individually)	Restitutive n=5, compensatory n=5, substitutive n=3.

Study	Study design	Aim/objective	Sample size (*n*)	Population	Intervention	Time/duration of intervention
Reinhard et al. (329)	Prospective observational study	Examine if VRT is able to change absolute homonymous field defects	17	Mixed Ischaemia *n*=11, trauma/surgery *n*=4, haemorrhage *n*=2	*Restitutive*: VRT using scanning laser ophthalmoscope	1hour of training, 6x per week, For 6 months.
Romano et al. (330)	Retrospective analysis	Determine the effect of a visual rehabilitation intervention on visual field defects	161	Mixed stroke 84%, TBI 9%, surgery 3%, other/unknown 4%	*Restitutive*: VRT	30mins of training, 6 days per week, For 26-30 weeks.
Rossi et al. (342) *Article taken from Cochrane review Pollock et al. (338)*	RCT	to see if Fresnel prisms improve visual perception	30	Stroke	*Substitutive:* 15 dioptre hemi-circular Fresnel prisms applied to glasses along with standard rehabilitation	worn all day for 4 weeks
Roth et al. (349) *Article taken from Cochrane review Pollock et al. (338)*	RCT	comparing explorative saccade and flicker training	30	Mixed stroke/haemorrhage *n*=26, other *n*=4	*Compensatory: exploratory eye scanning training* *Restitutive: flicker-stimulation training*	Both=30mins 2x daily, 5 days a week for 6 weeks
Rowe et al. (315)	Prospective, multicentre, single-blinded RCT	To compare prism therapy and visual search training to standard care (information only) for homonymous hemianopia	87	Stroke	*Compensatory* Visual scanning training and standard care (information provision) *Substitutive* Peli prisms	Scanning training=30mins, 5 days a week for 6 weeks. Peli prisms=wear for a min of 2 hours a day, 5 days a week for 6 weeks
Rowe et al. (32)	Prospective multicentre cohort trial	to profile the site of stroke, type and extent	915	Stroke	*Compensatory:* typoscope, orthoptic exercises, advice	follow-up between 2 weeks and 3 months

Study	Study design	Aim/objective	Sample size (*n*)	Population	Intervention	Time/duration of intervention
		of field loss, treatment and outcome	*n*=479 with field loss *n*=151 with field loss as only complaint		(awareness of visual field loss, reading strategies, scanning eye and head movements, use of lighting, compensatory head posture, and registration for visual impairment) *Substitutive:* Peli prisms, diplopia prisms, occlusion, low vision aids	Duration of individual treatments not specified
Sabel et al. (331)	Prospective observational study	Evaluate the efficacy of VRT using different perimetry methods	16	Mixed Ischemia n=11 Surgery n=3 Haemorrhage n=2 At least 15 months post-stroke	*Restitutive*: VRT measured with different methods of perimetry: Tubinger, automated and scanner laser ophthalmoscope	between 30-60mins per session, and performed between daily- 6 weeks
Sabel et al. (332)	Prospective observational study	Investigate the role of residual vision in recovery	23	Stroke - at least 1 month post-stroke	*Restitutive*: VRT	6 months of training (length and duration of training sessions not explained)
Schmielau and Wong Jr (333)	Cohort study	To evaluate whether restoration of VF in patients with homonymous hemianopia is possible using the LRP	20	Mixed Infarction *n*=11, haemorrhage *n*=7, trauma *n*=2	*Restitutive*: VRT using the Lubeck reaction perimeter	45mins of training, 2x a week. Average length of training=8.2months (range=2 - 27 months)

Study	Study design	Aim/objective	Sample size (*n*)	Population	Intervention	Time/duration of intervention
Spitzyna et al. (348) *Article taken from Cochrane review Pollock et al. (338)*	RCT	To see if optokinetic therapy improves test reading for hemianopic dyslexia	22	Mixed	*Compensatory:* optokinetic nystagmus inducing reading therapy	4 weeks of training (minimum of 400 minutes of rehabilitation) 20x 20min sessions
Szlyk et al. (347) *Article taken from Cochrane review Pollock et al. (338)*	Randomised crossover design	To assess the use of prisms for navigation and driving for patients with hemianopia	10	Mixed population injury involving occipital lobe only	*Substitutive:* Gottlieb visual field awareness system 18.5 dioptre lens vs. 20 dioptre Fresnel prisms	VFAS=training of 4x 2-3hour indoor sessions with LVA specialist and 8x 2hour outdoor sessions behind the wheel Prisms were worn for 3 months
Weinberg et al. (341) *Article taken from Cochrane review Pollock et al. (338)*	RCT	to test the effect of visual scanning training on reading related tasks	57	stroke	*Compensatory:* visual scanning training	1 hour a day for 4 weeks (20 hours of training)
Weinberg et al. (340) *Article taken from Cochrane review Pollock et al. (338)*	RCT	to test the effect of visual scanning training on reading related tasks	53	stroke	*Compensatory:* visual scanning training	1 hour a day for 4 weeks (20 hours of training)
Zihl and von Cramon (310)	Prospective observational study	Present evidence that diminished visual function can be improved by systematic	12	Mixed Infarct *n*=6, haemorrhage *n*=2, tumour *n*=3, hypoxia *n*=1	*Restitutive*: VRT	1hour of training per day. Total length of treatment not specified

Study	Study design	Aim/objective	Sample size (*n*)	Population	Intervention	Time/duration of intervention
		stimulation of impaired areas of the visual field.				
Zihl and von Cramon (335)	Prospective observational study	to test the hypothesise that recovery takes place at the level of the striate cortex	30	Mixed Vascular *n*=24, surgery *n*=6	Comparing *restitutive* VRT and *compensatory* eye movement training: Light detection vs. Saccadic localisation	Treatment started between 1-6months of onset of field defect. Total length of treatment not specified.
Zihl and von Cramon (336)	Retrospective case series (from a larger study)	To assess the recovery of visual field loss with VRT vs. compensatory eye movement training	55 post hoc sample from *n*=125	Mixed 80% Infarct 20% TBI At least 4weeks post-stroke	*Compensatory*: Exploratory visual search	Training performed between daily- 3x weekly. Total length of treatment not specified. Followed up for at least 4months post treatment
Zihl (334)	Retrospective analysis	Investigate eye movement patterns in patients with hemianopic dyslexia	*n*=50 before treatment assessment *n*=20 after treatment assessment	Stroke 3-12 weeks post-stroke	*Compensatory* Optokinetic therapy	Not specified

Articles taken from Cochrane reviews are included in this table for information only and are not included in the overall review

5.3.2.1: *Compensatory therapies*

A variety of different visual scanning and search training methods have been reported in the literature. These include computer- and paper-based search and scanning training programmes and use of word search games. They aim to facilitate the patient in learning to compensate for difficulties by improving the speed and accuracy of eye movements made into the visual field defect side. A number of studies have explored the effect of scanning eye movements into the affected visual field. In a study attempting to regain driving ability in hemianopic stroke survivors (313), there were no significant differences in improved driving performance between those undertaking the useful field of view attention retraining programme (UFOV) and those receiving general computer-based training.

In the Cochrane review on interventions for visual field loss (126), a recommendation was reached for compensatory interventions only. The authors reported that compensatory interventions were more favourable than a placebo or control at improving specific tasks but not at aiding recovery of the visual field.

Expansion of the field by 1-48 degrees has been reported (336). However, expansion of the visual field due to natural recovery early after stroke onset cannot be ruled out. Specific improvements, however, relate more to speed and accuracy of eye movements into the affected visual field after training with increased reaction times (127, 319, 325-327, 339) and increased number of saccades into the blind field (320) with some training available freely e.g. Eye-search (www.eyesearch.ucl.ac.uk) and Read-right (www.readright.ucl.ac.uk) (326). Subjective improvements in ADL, such as reading speed and accuracy, have also been reported by participants (11, 127, 318, 326, 339).

Nelles et al. (324) reported that such training was associated with increased activity in the ipsilateral cortex to the insult after training with reports that training is task specific. Eye search training improves eye scanning into the affected side with little objective improvement in reading, whilst reading training improves reading ability with little objective improvement on visual search (325, 334). In a recent trial, combined training resulted in an improvement in both eye search and reading (127).

Other compensatory interventions listed in the literature are the use of typoscopes, rulers and vertical reading. Vertical reading was initially mentioned in the literature as an anecdotal report by a patient describing this as helpful with their hemianopia (352). It has since been

stated as a rehabilitation option in review articles but no empirical evidence has been published (353-355).

A trial compared compensatory intervention (visual search training), substitutive intervention (Peli prisms) and standard care in the form of verbal and written advice, for the rehabilitation of hemianopia following stroke (315). The results found scanning therapy to be most effective when compared to Fresnel prisms and standard care by the patient reported outcome measure (VFQ 25-10), although there was no significant expansion of the visual field area (315). Adverse events were mild, consisting mainly of fatigue and headache. Thus, the authors recommend a greater, cumulative number of shorter training periods as opposed to a single, longer training session to avoid these adverse events.

5.3.2.2: *Substitutive management options*

Peli prisms use one or two high strength prisms, placed above and/or below the pupil, with the prism base out on the spectacle lens to the side of visual field loss (356). These prisms create a shift of images on the side of the visual field loss so they move to overlay on the seeing field. This in turn acts as a cue for the patient to look towards the affected side.

In a study of Peli prisms Giorgi et al. (129) found that the majority (74%) of participants wearing Peli prisms reported a positive difference over six weeks. Of these, 93% continued to wear the prisms for up to three months and 42% at an unspecified 'long-term follow-up'. However, there were no changes to participant responses in the quality of life questionnaire (NEI VFQ-25) completed over the initial six-week period. In a subsequent trial Bowers et al. (311) investigated the efficacy of real Peli prisms (57^{Δ}) versus sham Peli prisms (5^{Δ}), and further compared horizontal versus oblique positioning of the prisms. Sixty-one percent continued prism wear with an equal number from the oblique and horizontal position groups. A significantly higher proportion wished to continue wearing the real prisms with the most common reason being that prisms helped when walking (92%). However, the analysis of this study demonstrated a possible period effect, as the participants were aware they would switch to a second prism. As a result, only 12% reported that they would continue to wear the first prism until they had made a comparison with the second, rather than a comparison against no prisms. Forty-four percent continued wear after trialling the second prism (311).

The VISION trial found Peli prisms to be less favourable when compared to compensatory scanning therapy, as these typically resulted in more adverse events (69.25%), namely in the

form of headaches, double vision, navigation difficulties and optical glare/aberrations (315). Subsequently, the authors encouraged caution to be taken when prescribing prism glasses as a rehabilitation option for visual field loss following stroke.

5.3.2.3: *Visual restoration treatment*

Visual restoration therapy (VRT) involves presenting light stimuli at the border area of visual field loss (126). One key difference between reported studies is the amount of training prescribed. Some studies (*n*=7) prescribed a set amount of training for the whole cohort and others had allowed a range in the amount of training completed by their participants (*n*=6). Not one of the studies prescribed exactly the same amount of training, rendering it difficult to make direct comparisons.

Three studies prescribed specific session length and number per week but did not specify the total length of treatment (310, 333, 335). Across these studies, the mean reported expansion of the visual field border ranged from 1-11.3 degrees. Eye movement recordings were not undertaken and thus improvement in the visual field due to eye movements could not be excluded.

The majority of studies (*n*=7) prescribed variable session lengths and numbers. The length of session varied from 30 minutes to one hour for around six months of training (144, 317, 323, 329-332). The shorter sessions were repeated more than once per day, adding up to a possible maximum per day commitment of 70 minutes. The frequency of training varied between six times per week and daily.

A number of studies reported expansion of the visual field following treatment (316, 323, 330). However, for studies in which fixation was controlled and assessed using the scanning laser ophthalmoscope, little or no change in the visual field area was noted (321, 329, 331). Despite little or no improvement in the visual field area, patients reported an improvement in quality of life and ADL, such as mobility and reading (314, 316, 317, 323, 331). Although not statistically significant, reports of visual hallucination or less dense areas of visual field loss were also more likely to show improvement (144, 332). The majority of studies recruited patients with chronic homonymous hemianopia (longer than six months post onset). Recruitment within three to six months could not rule out an element of natural recovery where visual field improvement was reported (323). Thus, subjective improvements noted by patients are more likely to represent adaptation to the visual field defect.

5.3.3: Strabismus and ocular motility

Strabismus pertains to misalignment of the two eyes such that one eye does not point in the same direction as the fellow eye. Ocular motility abnormalities can relate to ocular cranial nerve palsies, gaze palsies, nystagmus and vergence disorders. There are several extensively used interventions for the management of various ocular motility problems in mixed aetiology populations such as prisms and occlusion/patching. Many interventions have been tested on non-stroke populations, as the ocular motility defects that arise as a result of stroke can also be caused by other neurological conditions.

5.3.3.1: *Pharmacological management*

A Cochrane review relating to eye movement defects following stroke focused solely on pharmacologic interventions for nystagmus, as no trials relating to restitutive, compensatory or substitutive methods were found specifically for stroke populations with other ocular motility disorders (27). Functional ability in performing activities of daily living was used as a primary outcome measure. Two trials were identified as meeting the inclusion criteria, which included a limited number of stroke patients (*n*=5) (357, 358). In view of the limited number of trials identified and the limited number of stroke patients included, the authors recommended a wider review of interventions in acquired brain injury (ABI) populations.

A further temporary intervention for ocular misalignment is botulinum toxin (BT) which has been reported widely in the literature for its use with strabismus (338). Its effects are reported to last for around three months. BT can also be helpful when planning a more permanent intervention such as ocular muscle surgery.

Table 5.7: Results for rehabilitation of ocular motility defects

Study	Study design	Aim/objective	Number of participants	Type of population	Intervention	Time/duration of intervention
Choudhuri et al. (132)	Survey	Determine current management of acquired nystagmus by ophthalmologists and neurologists	n=312 ophthalmologists n= 148 neurologists	Ophthalmologists and neurologists	Pharmacological Surgical	Not specified
Freeman and Rudge (8)	Prospective observational study	Identify the orthoptic problems associated with stroke	n=76 Excluded=TIA and other medical conditions	Stroke	Advice (for field defect and inattention, n=4) Occlusion (n=10), prisms (n=7), registered blind (n=2), observation (n=20), glasses (n=5)	Within 1 week post-stroke. Follow-up ranged from 1 week to 4 years
Leigh et al. (357) *Article taken from Cochrane review Pollock et al. (27)*	Randomised double blinded crossover trial	To compare the effect of trihexyphenidyl 5mg vs. tridihexethyl chloride 25mg on acquired nystagmus	n=10	Mixed (stroke n=2)	Trihexyphenidyl 5mg (Drug A) vs. tridihexethyl chloride 25mg (Drug B)	Both drugs=1 capsule per day. Drug dosage increased by 1 tablet per week until patient is taking 4 tablets per day. 1-2 week washout, then drug crossover
Pollock et al. (328)	Survey	To explore the current assessments, protocols, referrals and treatments of visual problems after stroke by OTs	n=55	Occupational therapists	Visual field, eye movement disorders and visual neglect (scanning training, patching/prisms, ADL training, reading aids/ magnifiers, information,	45% of OTs said they would treat within 2 weeks of stroke. 75% said they would treat patients within 6 weeks of stroke.

Study	Study design	Aim/objective	Number of participants	Type of population	Intervention	Time/duration of intervention
					environment modification)	38% said they would continue treatment up to 3months
Pollock et al. (134)	Survey	To explore the current assessments, protocols, referrals and treatments of visual problems after stroke by Orthoptists	n=14	Orthoptists	Visual field, eye movement disorders and visual neglect (scanning training, patching/prisms, ADL training, reading aids/ magnifiers, information, environment modification)	Time of intervention not stated. 86% did not have a protocol/management plan for visual treatment of stroke patients
Pollock et al. (27)	Cochrane systematic review	Determine the effects of interventions for eye movement disorders	2 studies n=28	2 studies with mixed population n=28 (Stroke n=5)	Pharmacological	Not specified
Rowe and VIS Group UK (141)	Prospective observational cohort	Determine prevalence of ocular motor cranial nerve palsies	n=915 (n=89 with cranial nerve palsy)	Stroke	Occlusion (n=30), Prisms (n=30), Advice (n=59), compensatory mechanisms	Treatment offered after approx. 22 days (0-2543 days) Duration of individual treatments not specified Only half followed up for review

Study	Study design	Aim/objective	Number of participants	Type of population	Intervention	Time/duration of intervention
Rowe et al. (5)	Prospective observational cohort	To evaluate the profile of ocular gaze abnormalities occurring following stroke	n= 915 (n=207 with gaze abnormalities)	Stroke	Occlusion (n=40), prisms (n= 27), refraction (n=22), orthoptic exercises (n=1), advice (n=69)	37 discharged after initial assessment and treatment. 29 referred onto ophthalmology service. 141 offered review appointments (28 did not attend). Follow-up lasted 2weeks – 6 months Duration of individual treatments not specified
Strupp et al. (358) *Article taken from Cochrane review Pollock et al. (27)*	Prospective RCT, double blinded, crossover.	assessing the effect of 3,4 diaminopyridine (DAP) on downbeat nystagmus	n=18	Mixed (stroke n=3)	3,4 diaminopyridine (DAP) and lactose 20mg vs. placebo lactose capsule	1 capsule taken Eye movements measured 30mins after taking capsule. Questionnaire undertaken 30 and 60 mins after taking capsule.

Articles taken from Cochrane reviews are included in this table for information only and are not included in the overall review.

Choudhuri et al. (132) conducted a survey of neurologists and ophthalmologists across the UK regarding the preferred choice of management for nystagmus, although response rate was viewed as low (34% of neurologists and 37% of ophthalmologists returned the survey). Both physicians reported prescribing pharmaceutical agents most commonly when managing nystagmus: Gabapentin and Baclofen were used most often.

5.3.3.2: *Substitutive management options*

Prisms are commonly used in clinical practice for the amelioration of the symptom of diplopia. Prisms may take the form of a temporary Fresnel prism or with a permanent prism ground into a spectacle lens. The theory of prisms is that the image of the object is shifted by a magnitude proportional to the strength of the prism, thus compensating for the eye misalignment (130). The images are moved such that they overlap and allow the brain to fuse the images back to one image, in cases where the patient has potential for binocular single vision. Alternatively, the images are moved so they are separated to place the second image into a pre-existing visual suppression area or, separated to an extent so that the second image can be ignored and/or is less troublesome for the patient.

Surveys of treatment provision for stroke survivors, (134) reported prisms to be the most common management provided (93%) followed by advice on head postures (64%) and convergence exercises (50%). Concurrently, Rowe et al. (5) reported prisms and/or occlusion to be the most commonly prescribed intervention with the purpose to alleviate diplopia. A number of observational studies report the positive benefit of prisms and occlusion for relief of diplopia in stroke survivors (141). Furthermore, advice is frequently provided, primarily consisting of adaptive alternative head postures (AHPs) to avoid the direction of gaze associated with diplopia (5, 141).

5.3.3.3: *Compensatory therapies*

There are occasions when the use of prisms is not suitable, such as the deviation being too large and the presence of torsion or variable deviations (130). In these circumstances occlusion can be used, which is frequently in the form of an opaque patch to eradicate the second image. Other options for occlusion include Bangerter foils or frosted tape which aim to blur the second image so it may be ignored (359). It is also possible to provide partial sector

occlusion for patients where diplopia is only bothersome in one direction of gaze (360). Furthermore, advice on compensatory strategies include adaptive head postures, reading options and the use of appropriate task lighting to optimise visual function (5).

5.3.3.4: *Restitutive treatment*

Conservative treatment options for specific ocular motility problems, such as convergence insufficiency, include vergence exercises (16). Improving ocular convergence with exercises can eliminate the symptom of diplopia and asthenopia in the near position (361). Previous research reported reduced convergence of <10cm was present in one third of stroke survivors, which frequently contributed to reading difficulty (32).

Once recovery has ceased and if a deviation persists, a more permanent intervention may be considered, such as ocular muscle surgery. There are a variety of procedures for the many types of ocular motility conditions, which are detailed in the literature but are not specific to stroke populations. For example, one trial (131) reported surgical success in 92.7% of adult participants receiving surgery for horizontal strabismus compared to 50.6% of those receiving BT after 6 months.

For cases of acquired nystagmus, relatively few ophthalmologists reported the use of surgical management (132). For an overview of management options for nystagmus, including pharmacological, optical, surgical and botulinum toxin, see Thurtell and Leigh (362).

5.3.4: Central vision

Impaired central vision includes reduced visual acuity and contrast sensitivity. Pollock et al. (338) completed a Cochrane review investigating whether interventions used to treat other visual problems that are age related, also improved the functional outcome following stroke. In addition to stroke related visual problems, the authors also included patients with cataracts, glaucoma, age-related macular degeneration or diabetic retinopathy. They used functional ability as the primary outcome measure. Twenty-four potential trials were found. However, it was not clear if these trials included stroke as a sub-group. In view of this, the authors took the decision to exclude these trials as age-related visual problems are already well covered by other Cochrane systematic reviews: age-related macular degeneration (338, 363-377), cataracts (378-390), diabetic retinopathy (391-395), and glaucoma (396-409). They recommended signposting readers to these Cochrane reviews covering different aspects of the specific conditions.

It is well recognised that many stroke survivors wore glasses prior to their stroke and it is important that they have access to their glasses, or receive a retest for glasses after their stroke (18). For those patients who still have reduced central vision even with glasses correction, low visual aids (LVAs) such as magnifiers may be helpful (16). LVAs have been shown to be effective amongst patients suffering visual impairment for a variety of reasons, such as cataracts and macular degeneration. Information on reading aids such as electronic and non-electronic optical aids, magnifiers and coloured filters is available (133, 410).

The use of spectral filters after stroke, however, showed no improvement in reduction of errors in either the experimental or control group (133). Possible reasons for this may be due to the study design, such that it lacked masking, or the questionable inclusion of the grey filter, which is widely accepted in orthoptic practice as a placebo filter during screening.

Table 5.8: Results for treatment of central visual impairment

Study	Study design	Aim/objective	Number of participants	Type of population	Intervention	Time/duration of intervention
Beasley and Davies (133)	Randomised crossover study	Consider the use of spectral filters on visual search in stroke patients	n=17	Stroke	Spectral filters and visual search training	2 weeks using the filters. 2 weeks washout. 2 weeks of using placebo filters
Freeman and Rudge (8)	Prospective observational study	Identify the orthoptic problems associated with stroke	n=76 Excluded=TIA and other medical conditions	Stroke	registered blind (n=2), observation (n=20), glasses (n=5)	Within 1 week post-stroke. Follow-up ranged from 1 week to 4 years
Lotery et al. (18)	Prospective Observational	Examine visual status of patients after stroke	n=77	Stroke	Glasses	Within 2 weeks of admission with stroke
Pollock et al. (328)	Survey	To explore the current assessments, protocols, referrals and treatments of visual problems after stroke by OTs	n=55	Occupational therapists	Visual field, eye movement disorders and visual neglect (scanning training, patching/ prisms, ADL training, reading aids/magnifiers, information, environment modification)	45% of OTs said they would treat within 2 weeks of stroke. 75% said they would treat patients within 6 weeks of stroke. 38% said they would continue treatment up to 3months
Pollock et al. (338)	Cochrane systematic review	Determine if interventions for age-related visual problems improve functional ability following stroke	0 studies found	-	-	-
Rowe et al. (16)	Prospective multicentre cohort	To identify all patients referred with suspected visual impairment who had reported reading difficulty to establish the prevalence of ocular and non ocular causes	n=915 (n=177 with reading difficulty)	Stroke	Advice, reading strategies, typoscopes, low vision aids, occlusion, prisms, exercises, CVI registration.	Review appointments within 3 months. Duration of individual treatments not specified

A further systematic review addresses the use of low vision services, such as standard hospital-based services, multidisciplinary services and services with an emphasis on the psychological needs of the patient (411). Further modifications to light and environment to aid visually impaired people at home include the use of colour and contrast, avoiding clutter and using accessible appliances (412, 413). However, these have yet to be validated in the literature for their use in a stroke population.

5.3.5: Visual inattention/neglect

Unilateral visual inattention is the difficulty attending to one side of space (337). A Cochrane review relating to spatial neglect following stroke focused on cognitive rehabilitation programs, encompassing a variety of bottom-up and top-down interventions (337). Measures of functional ability/disability as a primary outcome measure were used. Twenty-three trials were identified as meeting the inclusion criteria, eleven of which were new to this update (143, 341, 342, 414-433). Meta-analyses showed no significant persistent effect either on standardised assessments or for functional ability.

5.3.5.1: *Substitutive management options*

Menon-Nair et al. (322) conducted a survey of occupational therapists in Canada asking what rehabilitation they perform for unilateral spatial neglect. The most commonly used interventions were perceptual retraining (33.2%) and visual scanning training (16.2%). No details were collected on how these interventions were performed.

Table 5.9: Results for rehabilitation of visual neglect/inattention

Study	Study design	Aim/objective	Number of participants	Type of population	Intervention	Time/duration of intervention
Beis et al. (136)	RCT	Compare control with occlusion	n=22	Right sided vascular lesion. 42-56 days post-stroke.	Half eye patches vs. Full eye patches	Glasses with occlusion were worn 12 hours a day for 3months
Bowen et al. (337)	Cochrane systematic review	Assess whether cognitive rehabilitation improved neglect	23 studies n=628	Stroke	Top-down approaches Bottom-up approaches Mixed approaches	Various dependant on intervention type (4days- 2months)
Cherney et al. (430) *Article taken from Cochrane review Bowen et al. (337)*	RCT	A comparison of two approaches to treat unilateral neglect (top down approach)	n=4	Stroke Right hemisphere	Visual scanning, practising letter and word cancellation tasks vs. repetitive practise of functional task/oral reading	Both groups=20 sessions Frequency of sessions unknown
Cottam (429) *Article taken from Cochrane review Bowen et al. (337)*	RCT	Assessing visual scanning training for left hemispatial neglect (Top down approach)	n=12	Stroke	Visual scanning in 3 separate phases: Scanning a light board when stationary, while self-propelling, and naming objects present on both sides	Each phase= 5x 5hour sessions (5days)
Datié et al. (137)	Prospective observational study	Investigate the use of prisms for neglect	n=20 patients n= 15 healthy volunteers	Unilateral vascular lesion wit left sided neglect	Prisms	15 mins of prism adaptation

Study	Study design	Aim/objective	Number of participants	Type of population	Intervention	Time/duration of intervention
Edmans et al. (431) *Article taken from Cochrane review Bowen et al. (337)*	RCT	To compare the effectiveness of the transfer of training and functional approaches in improving perceptual and functional abilities after stroke (top down approach)	n=42	Stroke	Cueing and feedback teach compensation vs. functional approaches	Both groups=2.5 hours of training per week for 6 weeks
Fanthome et al. (432)	RCT	The treatment of neglect using feedback eye movements (Top down approach)	n=18	Stroke Right hemispheric	Specially adapted glasses with auditory signal vs. no treatment	2hours 40 mins per week for 4 weeks
Ferreira et al. (425) *Article taken from Cochrane review Bowen et al. (337)*	RCT	To compare mental practice vs. visual scanning to treat neglect (top down approaches)	n=10	Stroke Right hemispheric	Visual scanning vs. mental practice	10x 1-hour sessions over 5 weeks
Fong et al. (419) *Article taken from Cochrane review Bowen et al. (337)*	RCT	To assess the effect of trunk rotation with and without hemifield eye patching to treat neglect (bottom up approach)	n=60	Stroke	Voluntary trunk rotation vs. Trunk rotation with hemi field eye patching vs. conventional OT (control)	Trunk rotation=1 hour per day (15mins ADLs and 45mins trunk rotation) for 5 day per week for 30 days (30hours)
Freeman and Rudge (8)	Prospective observational study	Identify the orthoptic problems associated with stroke	n=76	Stroke	Advice (for field defect and inattention, n=4)	Within 1-week post-stroke. Follow-up

Study	Study design	Aim/objective	Number of participants	Type of population	Intervention	Time/duration of intervention
					Occlusion (n=10), prisms (n=7), registered blind (n=2), observation (n=20), glasses (n=5)	ranged from 1 week to 4 years
Kalra et al. (415) *Article taken from Cochrane review Bowen et al. (337)*	RCT	To evaluate the effectiveness of spatial cueing during motor activity on functional outcome and resource use in neglect patients (bottom up approach)	n=50	Stroke	conventional therapy vs. spatial-motor cueing	47.7 hours of conventional therapy over 64 days vs. 27.8 hours of therapy with spatial-motor cueing over 36 days
Kerkhoff et al. (428) *Article taken from Cochrane review Bowen et al. (337)*	RCT	To compare the effect of OKS (bottom up) and visual scanning training (top down) in the treatment of neglect	n=6	Stroke	Optokinetic stimulation (OKS) Vs. Visual scanning training	Both=20x treatment sessions for 50 mins, 5 sessions per week
Kerkhoff et al. (312)	RCT	Compare the effects of smooth pursuit eye movement therapy on auditory and visual neglect in chronic stroke patients	n=50	Stroke Ischemia n=37 Haemorrhage n=8 All had left-sided visual and auditory neglect. At least 1month post-stroke	Smooth pursuit eye movement training n=24 vs. Visual scanning training n=21	5x 50min sessions, over period of 7-9 days.
Luukkainen-Markkula et al. (143)	RCT	Comparing visual scanning training (top down) and arm	n=12	Stroke	visual scanning training vs.	Arm activation=20-30 hours of left arm activation

Study	Study design	Aim/objective	Number of participants	Type of population	Intervention	Time/duration of intervention
Article taken from Cochrane review Bowen et al. (337)		activation training (bottom up)			left arm activation training	Visual scanning=1hour 4x weekly (10 hours) with OT training 1-hour 2x daily both groups=48 hours of treatment in 3 weeks
Machner et al. (135)	RCT	To establish if hemifield eye patching or OKS is an effective therapy for neglect in acute stroke patients	n= 21	Acute right hemispheric stroke patients	Hemifield eye patching and optokinetic stimulation therapy	OKS=15min sessions daily for one month. Eye patch to be worn full time.
Menon-Nair et al. (322)	Survey	To obtain a response from 61 stroke inpatients	n=663	Occupational Therapists	Perceptual training, scanning training, activation treatment, cognitive therapy, eye patch, constraint-induced therapy, prisms, trans-electrical nerve stimulation	Not specified
Mizuno et al. (426) *Article taken from Cochrane review Bowen et al. (337)*	RCT, multi-centre, double blinded	Comparing search training with and without prisms (bottom up approach)	n=38	Stroke	Training=pointing at targets whilst sitting – 30x without prisms, 90x with, then 60x without Prisms shift field 12 right	2x daily 20 min sessions, 5 days a week for 2 weeks (20 sessions)
Nys et al. (420)	RCT, single blinded	To assess the effect of prism adaptation on neglect	n=16	Stroke	Prism adaptation	30min sessions for 4 days in a row vs. placebo

Study	Study design	Aim/objective	Number of participants	Type of population	Intervention	Time/duration of intervention
Article taken from Cochrane review Bowen et al. (337)		rehabilitation (bottom up)				
Polanowska et al. (422) *Article taken from Cochrane review Bowen et al. (337)*	RCT, double blinded	To assess the effectiveness of left hand stimulation bottom up) combined with scanning training (top down) to treat neglect	n=40	Stroke	Electrical somatosensory stimulation to left hand with conventional visual scanning training	45 min per sessions for 5days weekly for 1 month (20 sessions)
Pollock et al. (328)	Survey	To explore the current assessments, protocols, referrals and treatments of visual problems after stroke by OTs	n=55	Occupational therapists	Visual field, eye movement disorders and visual neglect (scanning training, patching/prisms, ADL training, reading aids/magnifiers, information, environment modification)	45% of OTs said they would treat within 2 weeks of stroke. 75% said they would treat patients within 6 weeks of stroke. 38% said they would continue treatment up to 3months
Pollock et al. (134)	Survey	To explore the current assessments, protocols, referrals and treatments of visual problems after stroke by Orthoptists	n=14	Orthoptists	Visual field, eye movement disorders and visual neglect (scanning training, patching/prisms, ADL training, reading aids/magnifiers, information, environment modification)	Time of intervention not stated. 86% did not have a protocol/management plan for visual treatment of stroke patients

Study	Study design	Aim/objective	Number of participants	Type of population	Intervention	Time/duration of intervention
Robertson (414) *Article taken from Cochrane review Bowen et al. (337)*	RCT	To assess the effect of microcomputer-based rehabilitation on left sided visual neglect (Top down)	n=30	Stroke	Computerised scanning and attention training vs. Recreational computing	14x 75 sessions, 2x weekly for 7 weeks (15 ½ hours) vs. 11.4 hours of recreational computing
Robertson et al. (417) *Article taken from Cochrane review Bowen et al. (337)*	RCT	To explore whether or not limb activation rehabilitation reduces left sided motor impairment in neglect patients (bottom up)	n=40	Stroke	Wearing a limb activation device during perceptual training vs. Perceptual training with inactive limb device	45min training per week for 12 weeks
Rossi et al. (342) *Article taken from Cochrane review Bowen et al. (337)*	RCT	To assess the use of Fresnel prisms to improve visual perception (bottom up approach)	n=39	Stroke	15 dioptre base out hemi-field prism vs. placebo	Worn for all daytime activities
Rusconi et al. (433) *Article taken from Cochrane review Bowen et al. (337)*	RCT	To investigate the effect of cueing on visual scanning therapy to treat neglect (top down)	n=24	Stroke	Visual scanning with and without verbal and visuospatial cueing	5x 1hour sessions per week for 2 consecutive months (40 sessions)
Schröder et al. (421) *Article taken from Cochrane review Bowen et al. (337)*	RCT	A comparison of visual exploration training with and without OKN in the treatment of neglect (Combined=bottom up, scanning alone=top down)	n=30	Stroke	Visual exploration vs. Visual exploration and OKS	Both=20x 25-40min sessions over 4 weeks

Study	Study design	Aim/objective	Number of participants	Type of population	Intervention	Time/duration of intervention
Tsang et al. (423) *Article taken from Cochrane review Bowen et al. (337)*	RCT	To investigate the efficacy of right half-field eye patching in treating subacute stroke patients with neglect trial.(bottom up)	N=35	Stroke	Conventional OT training with or without Half-field eye patching (right sided)	5x 60min OT sessions per week, with or without hemifield eye patching worn for an average 12 hours daily for 4 weeks
Turton et al. (424) *Article taken from Cochrane review Bowen et al. (337)*	RCT, single blinded	To assess if prism adaptation therapy helps improve self-care in stroke patients (bottom up)	n=37	Stroke	Prism adaptation training (10 dioptres) with repeated pointing movements to targets	Training once a day each working day for 2 weeks
Weinberg et al. (341) *Article taken from Cochrane review Bowen et al. (337)*	RCT	To test the effect of visual scanning training on reading related tasks (top down)	n=57 (25/57 reported on as severe data)	stroke	visual scanning training	1 hour a day for 4 weeks (20 hours of training)
Welfringer et al. (427) *Article taken from Cochrane review Bowen et al. (337)*	RCT	The use of visuomotor imagery in neglect rehabilitation (top down)	n=30	Stroke	Visuomotor-imagery therapy	2x 30min sessions daily for 3 weeks (28-30 sessions overall)
Wiart et al. (416) *Article taken from Cochrane review Bowen et al. (337)*	RCT	Trunk rotation and scanning therapy for the rehabilitation of stroke patients with neglect (top down)	n=22	Stroke	Experimental therapy with traditional rehabilitation	One hour daily for 20 days

Articles taken from Cochrane reviews are included in this table for information only and are not included in the overall review.
OKS=Oculokinetic Stimulation.

A subsequent survey engaged orthoptists working in stroke care in Scotland and reported a high proportion would provide advice or explanation of neglect (72%). Other methods included typoscopes, reading aids, non-computerised scanning therapy and onward referral to other professionals, although these methods were issued less frequently (21%) (134).

A further trial (135) examined the effect of hemifield eye patching and optokinetic stimulation (OKS). This method was described as a "forced-use" therapy comprising of sector occlusion over the non-neglecting side of plano lenses and removed when completing the OKS. The results showed that both the control group and those receiving therapy had an equal improvement in neglect-related functional disability over time.

5.3.5.2: *Compensatory therapies*

A survey of occupational therapists (328) reported a high proportion delivered therapy for visual neglect (89%) and visual field defects (69%), most commonly non-computerised scanning training, activities of daily living training and provision of aids and modifications. Other compensatory methods of rehabilitation of visual neglect/inattention include occlusion and prism adaptation (136, 137).

A Cochrane review meta-analysis initially showed cognitive rehabilitation to have a significant immediate effect on standardised assessments (337). The analysis was repeated with only high-quality trials included. This significant effect was not maintained. In addition, trials that compared cognitive rehabilitation with visual scanning therapies were too heterogeneous to enable the authors to draw conclusions. In view of these findings, the authors could not support or refute the interventions covered by the review. The recommendations were that clinicians should continue to follow national guidelines until further high-quality evidence is available.

A further trial aimed to investigate whether or not smooth pursuit therapy is superior to standard scanning therapy (312). The authors reported more improvement following smooth pursuit training in both auditory and visual outcomes. These

improvements were also seen for both mild and severe degrees of neglect with stability of improvement up to two weeks following training.

5.3.6: Other visual perceptual deficits

Visual neglect/inattention is the most frequently occurring visual perceptual disorder following stroke (6). Additional deficits include visual hallucinations, object agnosia, colour detection problems and difficulty judging depth (32). Spontaneous recovery may occur for perceptual deficits. However, patients reported a benefit from verbal advice and coping strategies, as well as the relief associated with diagnosis and recognition of the impairment, which can cause significant distress to the patient

Interventions for perceptual deficits are reported frequently as case studies or small retrospective cohorts. One prospective observational study used cross-modal word recognition training with a group of patients with pure alexia, which involved single words presented visually and via audio simultaneously. The group of patients were reported to read words from the training program quicker than untrained words, especially for the longer words. There was no transfer following training to letter or sentence reading. The improvement seen with words in the training program was not maintained at the follow-up visit at two to four weeks after training had finished (138).

Table 5.10: Results for rehabilitation of visual perceptual defects

Study	Study design	Aim/objective	Number of participants	Type of population	Intervention	Time/duration of intervention
Rowe et al. (32)	Prospective observational cohort	Evaluate prevalence of perceptual deficits post-stroke	n=178	Stroke	Advice, compensatory strategies, scanning strategies, general awareness	Average=22 days post-stroke (range=0-2543 days) Duration of individual treatments not specified
Woodhead et al. (138)	Prospective observational study - repeated measures	Test the efficacy of audio-visual reading training	n=9	Mixed Infarct n=7 Haemorrhage n=1 TBI n=1 Patients had pure alexia	Audio-visual reading training. Cross modal word recognition training	Duration of training not stated, Follow-up at 2 and 4 weeks post training

5.4: Summary

Overall, the findings from this review highlight implications for further research. There is a strong requirement for further high-quality randomised controlled trials to determine the effectiveness of interventions when treating post-stroke visual impairments. Furthermore, the majority of studies included in this review used a small number of patients in their study populations. Future research must address these issues and should consider the impact of interventions.

A variety of interventions exist for the rehabilitation of visual field loss, although, not enough high-quality research exists to decipher the true efficiency of a number of these rehabilitation options. The current recommendation is for compensatory strategies to manage post-stroke visual field loss. However, future longitudinal studies need to control for spontaneous recovery of visual field loss when determining the validity of restitutive treatments. Overall, advice and visual aids may be of benefit to stroke survivors with central visual impairment, however, these have not yet been evaluated within a specific stroke population. Further research is required to determine the benefit of these therapies following stroke. Compensatory scanning therapies appear most favourable for option of visual neglect. However, due to lack of high-quality evidence, these methods cannot be recommended in clinical guidelines at present. A range of visual perceptual disorders can occur following stroke, however very few rehabilitation options have been discussed in the current literature. It is possible that a number of options including advice are being used in practice with no clear evidence base and as such, further research is required to establish these methods.

It is important to note that some interventions have been tested on broader populations and not an isolated stroke survivor population. However, in many visual conditions, the evidence can be applied to stroke survivors; for example, prisms have been shown to be effective in a general diplopia population and are an accepted and effective option.

The focus of future research should be relevant to activities of daily living, visual function and vision-related quality of life. Studies should aim to include long-term follow-up of the stroke survivors being offered visual rehabilitation in order to accurately capture the effectiveness of these interventions and the transferability of these skills to activities of daily living. The current reported research has touched on recently developed, free web-based therapies for visual search training and improving reading speeds. However, there is limited literature on

these tools and more research, preferably with control groups and larger population sizes, are required to investigate the effectiveness of these interventions further.

The findings from Chapter 3 presented variability in the visual rehabilitation options offered to patients after stroke. The results of this review (Chapter 5) highlight a lack of high-quality comparative studies to ascertain the validity of individual methods. Various rehabilitation options currently used in clinical and social care to aid post-stroke visual impairments, such as environmental and lighting modifications, vertical reading, line guides and typoscopes, have yet to be thoroughly investigated. Reproach is required to inform clinicians of the full range and effectiveness of such rehabilitation options. Furthermore, national stroke guidelines must be explicit with the preferred visual rehabilitation options to ensure equitable care nationally. Chapter 8 will continue this investigation into the full range of appropriate rehabilitation options after stroke to address this inequality.

This work has been published elsewhere; see:

Hanna KL, Hepworth L, Rowe F. The treatment methods for post-stroke visual-impairment: a systematic review. 2017. Brain and Behavior, 7(5):1-26.

The search methods described in 2.1.4 were further performed in December 2017 and no further articles were identified that met the search criteria for this chapter.

Section 2

Chapter 6: The overall results of the IVIS study

This chapter begins to describe the results from the second phase of research. Chapters 3-5 reported the findings from phase one of the study and identified inequalities in visual service provision after stroke, and identified the key demographic factors associated with stroke and/or visual impairments. Chapters 7-8 will describe the screening assessments used and the rehabilitation offered in the study, along with an exploration of potential health inequalities associated with these methods. Chapter 9 will report the final results from this second phase of the research by reporting on inequalities in outpatient attendance.

6.1: Patient demographics: background.

The patient data collected at baseline was imported from a MACRO database to SPSS for analysis. Data were collected for patient's ethnicity, age, type of stroke, gender and postcode (for which IMD deciles were obtained). Additionally, the patients' discharge destinations and their Barthel index (measure of stroke severity) were obtained from their hospital notes and discharge letters. Each demographic has been described in more detail (see 6.1.1-6.1.7).

6.1.1: Ethnicity

It was not possible to formally document an ethnicity for 17 stroke survivors at two hospitals (Hospital 1 n=14, Hospital 3 n=3). Overall, the recruited population was overwhelmingly White British within the three hospitals (see Table 6.1). Statistical analysis could not be performed between the various ethnic groups, as there were too many categories with extremely small numbers for accurate comparisons between hospital sites. Furthermore, analysis could not be performed between the White British group and all other ethnicities as a separate cohort, due to the heterogeneity of the different ethnicities.

Table 6.1: The differences in ethnicity between the stroke survivors at Hospitals 1-3.

Ethnicity	Number of stroke survivors at each hospital					
	Hospital 1 (n)		Hospital 2 (%)		Hospital 3 (%)	
White British	536	**96.6%**	409	**93%**	468	**95.5%**
White Irish	3	**0.5%**	9	**2%**	2	**0.4%**
Any other White British	10	**1.8%**	8	**1.8%**	5	**1%**
Black British	0	**-**	0	**-**	1	**0.2%**
White and Black Caribbean	1	**0.2%**	1	**0.2%**	0	**-**
White and Black African	0	-	2	**0.5%**	1	**0.2%**
Indian	1	**0.2%**	3	**0.7%**	5	**1%**
Pakistani	0	-	3	**0.7%**	4	**0.8%**
Bangladeshi	0	-	0	**-**	1	**0.2%**
Chinese	3	**0.5%**	3	**0.7%**	1	**0.2%**
Other	0	-	2	**0.5%**	0	**-**
Total	555	37.4%	440	29.7%	488	32.5%

Where "other" was documented for two stroke survivors, this was recorded as Asian.

6.1.2: Gender

Table 6.2 shows the gender of stroke survivors recruited into the IVIS study. There were no missing values for any patient. The results showed no significant differences between the three sites in relation to gender (p=0.699, Fishers exact test). Overall, the gender difference in the entire stroke cohort of the IVIS study is 48% female vs. 52% male.

6.1.3: Type of stroke

The type of stroke was recorded at hospital admission. It was not possible to identify the type of stroke for just one patient recruited at Hospital 2. Overall, more patients suffered an ischaemic stroke than a haemorrhagic stroke (87.5% vs. 12.5%); see Table 6.3. There was no significant difference between the type of stroke at the three hospital sites (p=0.691).

6.1.4: Age at stroke onset

Age was calculated in Microsoft Excel using the equation (=DATEIF(*date of birth*, *date of stroke*)/"Y") based on the patient's date of birth and the date of their stroke. Where it was not possible to obtain the exact date of stroke for any patient, the date of their first hospital visit post-stroke was used to calculate their age, to ensure age was calculated as accurately as possible. This was only necessary for one subject recruited from Hospital 1.

The mean age of all stroke survivors recruited from the study was 73.35 (±13.68). Table 6.4 shows the mean ages of the stroke patients recruited from each site.

A one-way ANOVA test was used to compare the means across the three hospital sites and found no significant differences for age at time of stroke between the recruiting sites (p=0.247). Figure 6.1 further displays the similarity of the age at time of stroke across the three sites, indicating generalisability of the entire stroke cohort in relation to age.

Table 6.2: The gender differences of the stroke survivors at Hospitals 1-3.

Gender	**Hospital**						Total	
	Hospital 1 (n)		Hospital 2 (n)		Hospital 3 (n)			
Males	289	**50.8%**	227	**51.6%**	262	**53.4%**	778	51.9%
Females	280	**49.2%**	213	**48.4%**	229	**46.6%**	722	48.1%
Total	569	**37.9%**	440	**29.3%**	491	**32.7%**	1500	-

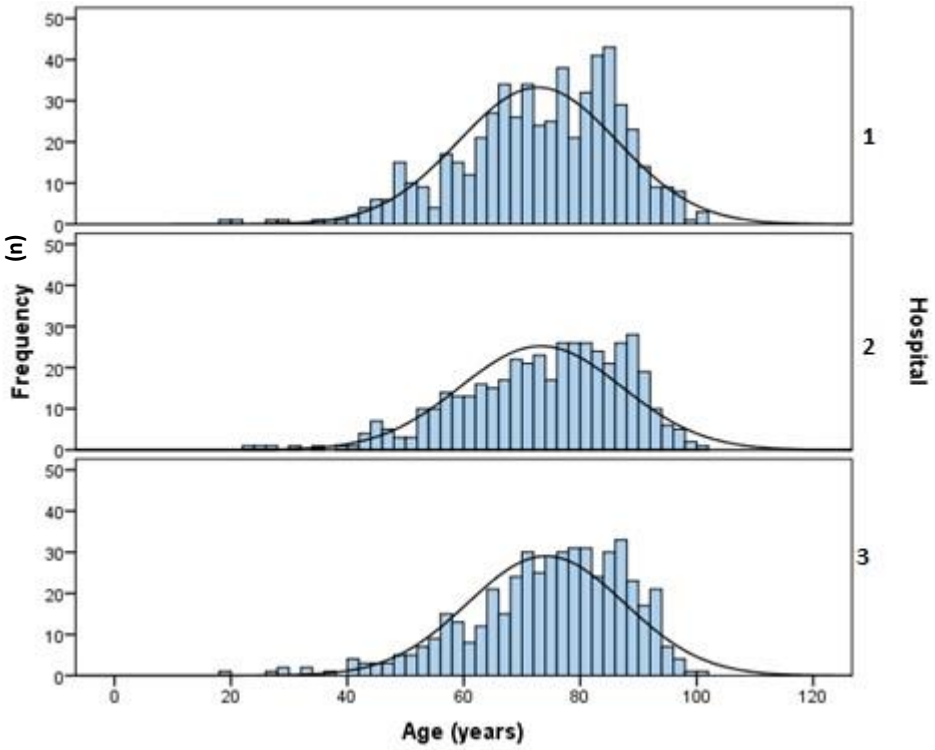
Table 6.3: The difference in stroke type at Hospitals 1-3.

Type of stroke	**Hospital**						Total	
	Hospital 1 (n)		Hospital 2 (n)		Hospital 3 (n)			
Infarction	497	**87.3%**	382	**87.0%**	433	**88.2%**	1312	**87.5%**
Haemorrhage	72	**12.7%**	57	**13.0%**	58	**11.8%**	187	**12.5%**
Total	569	40.0%	439	29.3%	491	32.8%	1499	-

Table 6.4: The age range of the stroke survivors at Hospitals 1-3.

Hospital	*Mean (M)*	*Number of patients (n)*	*Std. Deviation (SD)*	*Minimum (years)*	*Maximum (years)*
Hospital 1	72.65	569	13.65	19	99
Hospital 2	73.26	440	13.91	22	100
Hospital 3	74.13	491	13.48	19	100
Total	73.35	1500	13.67	19	100

Figure 6.1: Age at time of stroke in Hospitals 1-3.



6.1.5: Deprivation

The postcode for each stroke survivor recruited into the IVIS study was obtained from the hospital case notes. The postcodes were then used to calculate the Index of Multiple Deprivation (IMD) for each patient, which represented the level of deprivation in their residing area. It was not possible to obtain a postcode, or a valid IMD decile, for 67 stroke survivors (Hospital 1 n=22, Hospital 2 n=13, Hospital 3 n=32).

The results show a significant difference between the three hospital sites in relation to IMD (p=<0.001, chi-squared test). Table 6.5 shows a broad spread in IMD deciles assigned to the stroke survivors in Area 3, with the majority of patients residing in areas representative of an IMD decile of 8 or 9 (n=70 and n=78 respectively). Hospitals 1-2 typically observed the admission of stroke patients from the most significantly deprived parts of Areas 1-2 with an IMD decile of 1 (n=232 and n=118 respectively).

6.1.6: Severity of stroke

Severity of stroke was calculated using the Barthel index at the time of hospital admission. It was not possible to obtain a Barthel index at the time of hospital admission for 230 stroke survivors (Hospital 1 n=83, Hospital 2 n=16, Hospital 3 n=131).

The results showed a significant difference between the three hospital sites in relation to severity of stroke (p=0.006, Kruskal-Wallis test). A total of 315 patients across the three hospitals had a Barthel index of zero and therefore, suffered a highly severe stroke with subsequent stroke disabilities (see Table 6.6).

Of the 955 stroke survivors with a Barthel index >0, the results showed that Hospital 2 had more patients (62.3%) with a better stroke outcome (Barthel index ≥10) compared to Hospital 1 (52.6%) and Hospital 3 (50%): p=0.003, Kruskal-Wallis test. Furthermore, the results showed that the stroke survivors admitted to Hospitals 1 and 2 with lower IMD deciles often had lower Barthel indices showing a possible correlation between deprivation and stroke severity. Using a Spearman's rank order correlation, analyses revealed that the two are significantly associated (p=0.003) but with a weak correlation coefficient (-0.085).

Table 6.5: The Index of Multiple Deprivation (IMD) deciles of all stroke survivors at Hospitals 1-3.

Index of multiple deprivation		Hospital						Total (n)	
		Hospital 1 (n)		Hospital 2 (n)		Hospital 3 (n)			
Least deprived	10	2	**0.4%**	18	**4.2%**	32	**7.0%**	52	**3.6%**
	9	21	**3.8%**	22	**5.2%**	70	**15.3%**	113	**7.9%**
	8	30	**5.5%**	12	**2.8%**	78	**17.5%**	120	**8.4%**
	7	25	**4.6%**	20	**4.7%**	41	**8.9%**	86	**6.0%**
	6	48	**8.8%**	37	**8.7%**	31	**6.8%**	116	**8.1%**
	5	39	**7.1%**	49	**11.5%**	37	**8.1%**	125	**8.7%**
	4	40	**7.3%**	50	**11.7%**	26	**5.7%**	116	**8.1%**
	3	33	**6%**	44	**10.3%**	29	**6.3%**	106	**7.4%**
Most deprived	2	77	**14.1%**	57	**13.3%**	59	**12.9%**	193	**13.5%**
	1	232	**42.4%**	118	**27.6%**	56	**12.2%**	406	**28.3%**
Total		547	38.2%	427	29.8%	459	32.0%	1433	-

Table 6.6: The Barthel indices of all stroke survivors at Hospitals 1-3.

Barthel Index at hospital admission	Hospital			Total (n)
	Hospital 1 (n)	Hospital 2 (n)	Hospital 3 (n)	
Mean	10.60	9.63	8.75	9.75
Standard deviation	7.49	7.93	7.80	7.76

A lower Barthel index (closer to 0) represents a more severe stroke, with more post-stroke disabilities. A higher value (closer to 20) represents a less severe stroke with fewer impairments.

Accurate conclusions that stroke survivors residing in more deprived areas (with lower IMD deciles) have an increased severity of stroke cannot be taken from this result. Although the finding was statistically significant, it is possible that this was due to the large sample size (n=1270) of stroke survivors with available Barthel indices, whilst the magnitude of the correlation between deprivation and stroke severity was in fact, quite small.

6.1.7: Discharge destinations

The discharge destinations of the stroke survivors discharged from hospital were obtained from the hospital case notes or discharge summary letter. It was not possible to obtain discharge destinations for 573 stroke survivors (Hospital 1 n=255, Hospital 2 n=98, Hospital 3 n=220). A large number of these died in hospital (n=162) and therefore were not discharged. Despite this, discharge destination remained largely unreported (n=411). The reasons for this include computer system errors at Hospital 3. Moreover, discharge destination was not always recorded prior to the patient's hospital discharge. Additionally, the research orthoptists often relied on the research nurses at all sites to collect this data, which further added to the difficulty in gaining this information.

Analysis revealed a significant difference between the three hospital sites in relation to where patients were discharged to after stroke (p=<0.001, chi-squared test). Table 6.7 shows that, overall, the majority of stroke survivors were discharged to their own homes. Intermediate/respite care is described as short-term care, usually in a residential setting for patients who no longer need to be in hospital but still require extra support (434). Hospital 3 discharged more patients to intermediate/respite care than the other hospital sites, and Hospitals 1 and 2 discharged more patients to a nursing home than Hospital 3.

This may indicate a poorer stroke outcome in these hospitals (as shown in the lower Barthel indices), which subsequently required more dependent living following hospital discharge.

To test for the relationship between Barthel index and discharge destination, a univariate analysis of variance was used. A significant association was found between Barthel index and discharge destination at all three sites (p=0.003); see Table 6.8.

Table 6.7: The discharge destinations recorded for all the stroke survivors at Hospitals 1-3.

Discharge destination	Number of stroke survivors at each hospital						Total	
	Hospital 1 (n)		Hospital 2 (n)		Hospital 3 (n)			
Home	249	**69.2%**	239	**60.8%**	197	**58.6%**	685	**62.9%**
Intermediate/ respite care	3	**0.8%**	3	**0.8%**	19	**5.7%**	25	**2.3%**
Nursing home	52	**15.0%**	69	**18.1%**	35	**11.3%**	156	**15.0%**
Living with family	4	**0.6%**	4	**0.5%**	4	**0.3%**	12	**0.5%**
Never discharged/ died in hospital	46	**12.8%**	51	**13.0%**	65	**19.3%**	162	**14.9%**
Other	6	**1.7%**	27	**6.9%**	16	**4.8%**	49	**4.5%**
Total	360	38.8%	393	42.4%	271	29.2%	927	-

Where "other" was documented for the discharge destination of 49 patients, this was recorded as: Out of area (n=18), repatriated to another NHS hospital in the same area (n=17), repatriated to another NHS hospital out of area (n=5), a prison (n=3), a secure mental health unit (n=3), a hospice (n=2) and homeless (n=1).

Table 6.8: The mean Barthel indices for each discharge destination

Discharge destinations	*Mean Barthel index*	*N*	*Std. Deviation*	*Minimum (n)*	*Maximum (n)*
Home	13	616	6.67	0	20
Intermediate/ respite care	5	21	4.90	0	15
Nursing home	5	151	5.63	0	20
Living with family	10	4	6.97	2	18
Never discharged/ died in hospital	2	139	4.43	0	20
Other	8	37	7.23	0	20
Total	10	968	7.70	0	20

Those with lower Barthel indices (and subsequently, poorer consequences of stroke) are significantly more likely to be discharged to supported forms of living.

The stroke survivors found to have one or more post-stroke visual impairments have been compared against the cohort identified as having a normal visual status (6.2), in order to identify any demographic at higher risk of developing vision problems due to stroke.

6.2: Identification of stroke survivors with resultant visual impairments

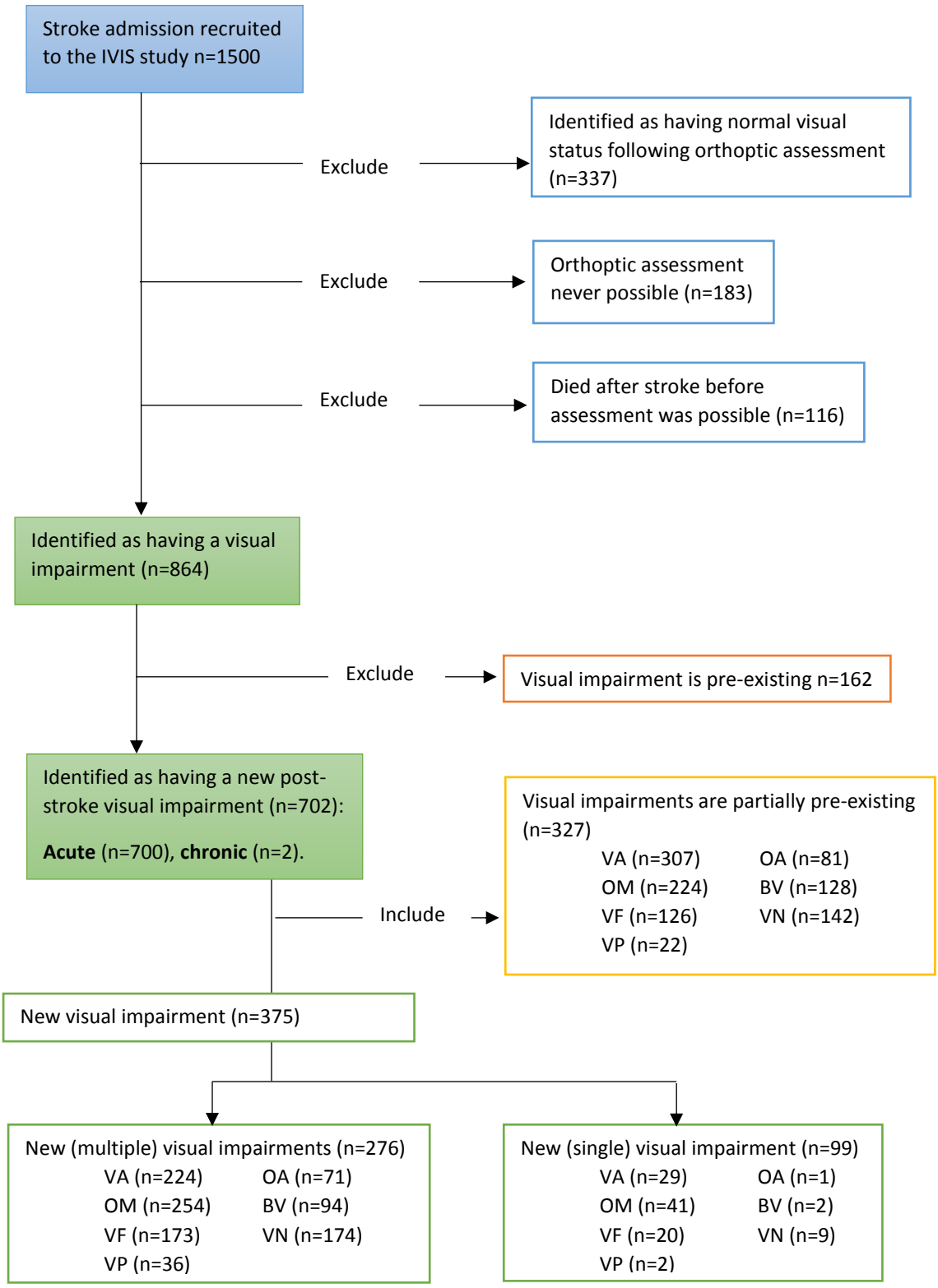
Figure 6.2 shows the identification of new post-stroke visual impairments in all stroke survivors across the three hospital sites. The individual numbers at each site and the demographics of the stroke survivors have been discussed later in 6.2.

Of the 1500 stroke participants recruited to the IVIS study across the three hospital sites, 337 were found to have normal visual status following orthoptic assessment, 116 died before assessment was possible and 183 were never able to be assessed before discharge from the acute stroke unit (and were unsuitable for outpatient follow-up). Table 6.9 later describes the reasons why full assessment was not possible for these patients.

Overall, 864 (57.6%) stroke survivors were identified as having a visual impairment following initial orthoptic assessment across the three hospital sites. However, 162 (18.7%) of the 864 stroke survivors reported having a pre-existing ocular condition or were identified as having a longstanding eye condition through history taking and concurrent medical note investigation (see 2.3.7). These patients have therefore been excluded from the overall cohort with a new diagnosis of visual impairment secondary to stroke onset (see Figure 6.2).

A further 327 (37.8%) of the 864 stroke survivors with visual impairment were found to have a partially pre-existing ocular condition (one or more impairments were pre-existing but others were due to new stroke aetiology). It should be noted that the breakdown of numbers for each type of visual impairment listed in Figure 6.2 represents the number of visual impairments identified and not number of patients; one patient could have numerous impairments.

Figure 6.2: The identification of stroke survivors with post-stroke visual impairments in the IVIS study.



Key: *VA= Visual Acuity impairment, OA= Ocular Alignment impairment, OM= Ocular motility defect, BV= Binocular vision defect, VF=Visual Field loss, VN=Visual Neglect, VP= Visual Perceptual deficit.*

Patients often had various reasons for why complete visual assessment was not possible and these varied further at each hospital visit. On average, each patient was assigned two separate codes for why a full orthoptic assessment was not possible (Mean 2.44 codes ±2.82, range 0-15 codes). Table 6.9 shows how frequently each code was assigned to the patients, with the most common reasons for non-assessment described as early discharge from the stoke unit and the patient being asleep.

After elimination of those stroke survivors with only longstanding ocular conditions unrelated to the newly acquired stroke, and including those with a partial or a completely new post-stroke visual impairment, the overall number of stroke survivors with one or more stroke-induced visual impairments during the IVIS study period was 702 (46.8%). In total, 700 patients (46.6%) were first assessed in the acute stage of stroke (<6 months post-stroke onset) and two in the chronic stage (>6 months from stroke onset).

The total number of stroke survivors with a purely new post-stroke visual impairment during the IVIS study period was 375 (25%): 99 (6.6%) with a single visual impairment and 276 (18.5%) with multiple visual impairments.

The proportion of patients with a new or partially new post-stroke visual impairment at Hospitals 1-3 were 48.7%, 41% and 50% respectively, and the difference was not statistically significant (p=0.201). This shows generalisability of the three sites and therefore, further analysis of post-stroke visual impairments has included the three hospital sites as a whole cohort; see 6.3.

Table 6.9: Reasons provided for why full assessment was not possible.

Reasons for why assessment was not possible	***Frequency (n)***	
Early discharge	575	**15.9%**
Asleep	572	**15.8%**
Lacking cognition	377	**11%**
Medically unwell	344	**9.5%**
Not on ward/stroke unit	276	**7.6%**
Fatigue	219	**6%**
DNA appointment	217	**6%**
Lacking attention	201	**5.5%**
Cancelled appointment	179	**5%**
Died	163	**4.5%**
Unwilling to assent to screen	157	**4.3%**
Care of the dying pathway	85	**2.3%**
Speech impairment	79	**2.2%**
Patient upset/confused	42	**1.2%**
Visual impairment preventing full assessment/no glasses available	29	**0.8%**
No follow-up required	27	**0.7%**
Unconscious	23	**0.6%**
Lives out of area	22	**0.6%**
Assessed by clinical orthoptist	13	**0.4%**
Foreign language barrier	10	**0.3%**
Family present	5	**0.1%**
Nursing home unable to transfer patient	5	**0.1%**
Deafness	3	**0.08%**
Seizure	1	**0.03%**
Fall (on ward)	1	**0.03%**
Contact details incorrect	1	**0.02%**
Unable to contact	1	**0.02%**

It was found that 299 stroke patients were never assessed and therefore, it was not possible to determine whether a post-stroke visual impairment was present. Moreover, it was observed that a number of stroke survivors (n=82) were discharged with a documented vision impairment at the time of hospital admission, but were later found to have normal vision when assessed as an outpatient, indicating visual recovery. These impairments included visual field loss (n=13), visual neglect (n=13), ocular motility defects (n=21) and diplopia (n=15). Additional impairments recorded as "other" at the time of hospital admission included oscillopsia (n=1), past-pointing (n=3), nystagmus (n=7), blurred vision (n=8), visual field defects (n=3), bilateral blindness (n=1) and visual perpetual defects consisting of alexia (n=1), agnosia (n=3) and hallucinations (n=1). Furthermore, a number of patients were discharged with symptoms that may have been related to an undiagnosed visual impairment, such as headaches (n=15), dizziness (n=12) and imbalance (n=7).

Therefore, it is possible that a further number of stroke survivors suffered a vision impairment but were undiagnosed during the study period. This was explored further by identifying how many stroke survivors had a reported visual impairment at time of admission, which had recovered by the time of complete orthoptic assessment, approximately three days later. It was found that 69 (13%) of the 534 stroke survivors with a suspected visual impairment at point of hospital admission were found to have normal vision post-orthoptic assessment, whilst 314 (59%) had a confirmed visual impairment. The remaining 151 (28%) were unable to be assessed, died in hospital or did not return for follow-up orthoptic assessment as an outpatient.

6.3: Did the patient demographic affect visual status after stroke?

An investigation was undertaken to identify any particular patient group that were more at risk of visual impairment following stroke. The demographics of those stroke survivors found to have a new or partially pre-existing post-stroke visual impairment (n=702) and those found to have normal visual status (n=337) were compared. Those that could never be assessed were excluded from analysis, as it was unknown as to whether or not they had a post-stroke visual impairment. Moreover, those found to have a new visual impairment but were initially screened for a visual impairment >6months post-stroke (n=2) have been excluded from later analysis, as their presenting signs and management options are not comparable to the acute cohort (74).

The Directed Acyclic Graph (DAG) shown in Figure 6.3 displays the possible confounding variables when exploring the effect of patient demographics on post-stroke visual impairment. Chapter 3 describes the health inequalities in relation to stroke and visual impairment. A relationship between ethnicity and IMD was identified, as it was found that low socioeconomic status (SES) correlated with poor survival post-stroke in Black ethnic groups only (225, 244). Additionally, ethnicity was found to affect age and type of stroke, as younger Black and Asian ethnicities have an overall increased risk of stroke (223, 239), and Black groups suffer significantly more ischaemic than haemorrhagic strokes due to a genetic predisposition of raised hypertension (243).

Furthermore, the DAG shows a biasing line between IMD and type of stroke, as lower SES typically resulted in increased stroke mortality due to associated risk factors such as smoking (237). Therefore, ischaemic strokes are likely to be more prevalent than haemorrhagic strokes in lower IMD groups. The DAG further suggests that IMD adjusts for gender, as more females from lower SES were found to have an increased risk of stroke (232). As stroke survivors from lower SES tend to be of a younger age than those of higher SES (234), age will therefore adjust for IMD.

Finally, type of stroke and Barthel index will have adjusted for patient age, as older stoke survivors suffer significantly more ischaemic strokes (231) and have shown poorer functional recovery if >65 years old (226, 258). To test for this, a Kruskal-Wallis test showed that older age was significantly associated with a lower Barthel index ($p=<0.001$), confirming this hypothesis.

The factors identified as potential confounding variables have been adjusted for in the following binary logistic regression analyses; see 6.3.1-6.3.7. Ethnicity, however, has been excluded from further regression analyses due to the extremely small numbers of ethnic minorities, which skews the overall data results.

The presence of post-stroke visual impairment was first analysed per hospital site (see Table 6.10). This did not show to be significantly different between sites (p=0.201) and therefore, further analyses of the patient demographics has included the three hospital sites as one cohort.

6.3.1: Ethnicity

It was not possible to formally document the ethnicity of one stroke survivor at Hospital 3. The vast majority of stroke survivors were White British in both groups (see Table 6.11). Statistical analysis could not be performed between the various ethnic groups, as there were too many categories with extremely small numbers for accurate comparisons between hospital sites (see 6.1.1).

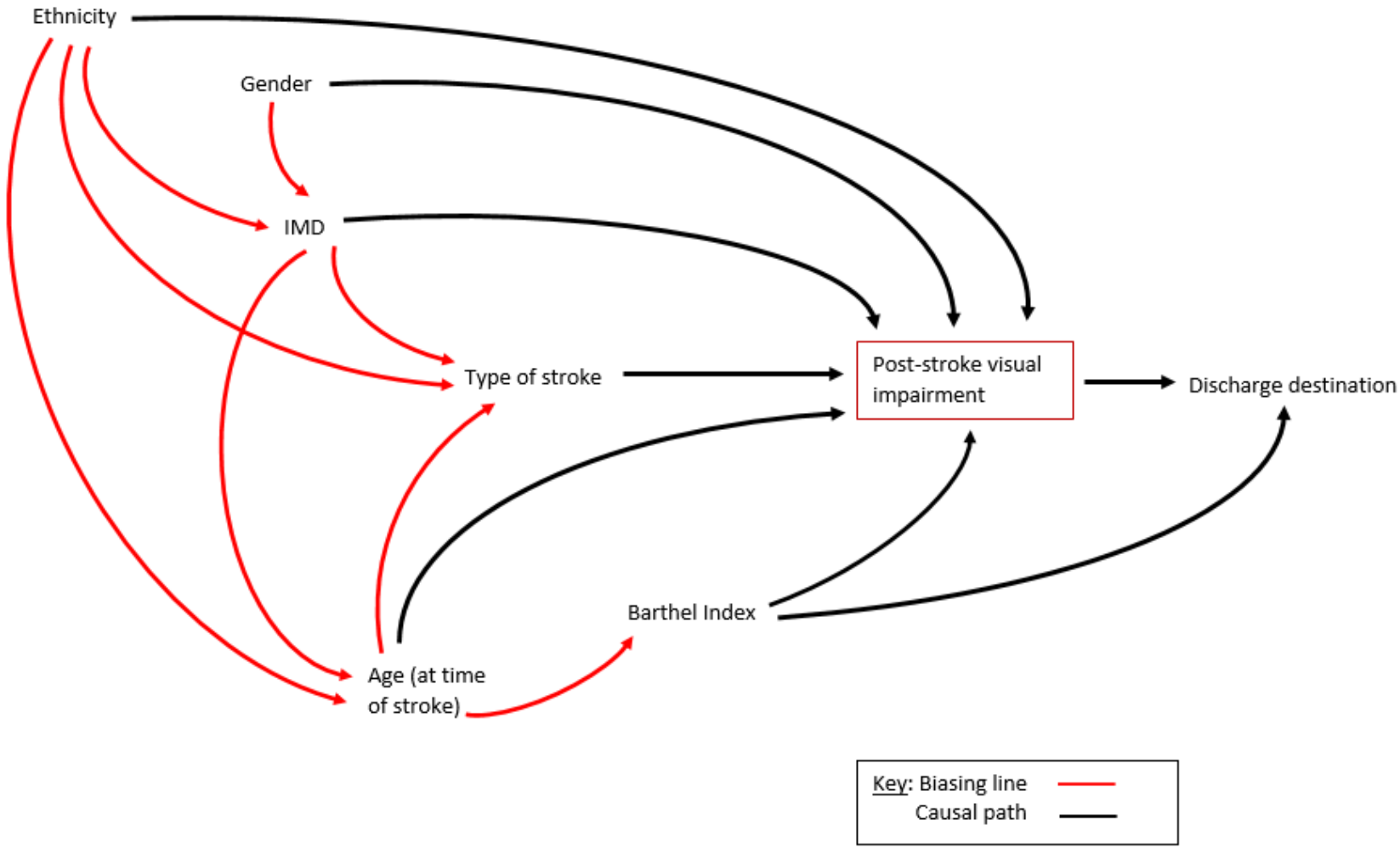
6.3.2: Gender

Overall there were more males (n=571, 55%) than females (n=468, 45%) in both the visually impaired group and the normal vision group but this was not statistically significant (p=0.387, Fisher's exact test); see Table 6.12.

6.3.3: Type of stroke

More patients suffered an ischaemic stroke than a haemorrhagic stroke in both the visually impaired and the normal vision groups (see Table 6.13). The differences between the two groups were not significant (p=0.093, Fisher's exact test). The association between type of stroke and the presence of post-stroke visual impairment was adjusted for age, gender and IMD in a binomial regression analysis, as these factors were identified as potential confounding variables (see 6.3 and Figure 6.4). Ethnicity was omitted from the overall adjusted analysis (see 6.3). This gave an adjusted p-value of 0.208 (odds ratio (OR): 0.73, CI: 0.44-1.19).

Figure 6.3: Directed acyclic graph illustrating the causal pathways of post-stroke visual impairment



Legend: A biasing line indicates a potential confounding affect from one demographic factor to another. A causal path indicates a direct affect from the demographic factor to the outcome variable (post-stroke visual impairment).

Table 6.10: The presence of post-stroke visual impairment between the three hospital sites.

Hospital	Visually impaired (n)		Normal vision (n)	
Hospital 1	277	**39.5%**	148	**43.9%**
Hospital 2	179	**25.6%**	81	**24%**
Hospital 3	244	**34.9%**	108	**32%**
Total	700	67.6%	337	32.4%

Table 6.11: The differences in ethnicity between the stroke survivors with and without post-stroke visual impairments.

Ethnicity	Visually impaired (n)		Normal vision (n)		Total	
White British	661	**95.4%**	315	**96%**	978	**95.6%**
White Irish	4	**0.6%**	4	**1.2%**	8	**0.8%**
Any other White British	11	**1.6%**	2	**0.6%**	13	**1.3%**
Black British	1	**0.1%**	0	**-**	2	**0.2%**
White and Black Caribbean	2	**0.3%**	0	**-**	3	**0.3%**
White and Black African	3	**0.4%**	0	**-**	7	**0.7%**
Indian	5	**0.7%**	2	**0.6%**	5	**0.5%**
Pakistani	3	**0.4%**	2	**0.6%**	1	**0.1%**
Bangladeshi	0	**-**	1	**0.3%**	5	**0.5%**
Chinese	3	**0.4%**	2	**0.6%**	1	**0.1%**
Total	693	68.0%	328	32.0%	1023	-

Table 6.12: The gender differences for the stroke survivors with and without post-stroke visual impairments.

Gender	Visually impaired (n)		Normal vision (n)		**Total**	
Males	378	**54%**	192	**57%**	571	**55%**
Females	322	**46%**	145	**43%**	468	**45%**
Total	700	67.6%	337	32.4%	1039	-

Table 6.13: The type of stroke recorded for the stroke survivors with and without post-stroke visual impairments; reported for all hospital sites.

Type of stroke	Visually impaired (n)		Normal vision (n)		**Total**	
Infarction	625	**89.2%**	312	**92.6%**	938	**90.3%**
Haemorrhage	75	**10.8%**	25	**7.4%**	101	**9.7%**
Total	700	67.6%	337	32.4%	1039	-

6.3.4: Age

An association was found between age (at time of stroke) and having a post-stroke visual impairment within the IVIS study population. The stroke survivors in the visually impaired cohort were significantly older (74±14 years) compared to the group with normal visual status (67±13 years); p=<0.001, one-way ANOVA (see Table 6.14). The association between age and the presence of post-stroke visual impairment was adjusted for gender and IMD, as these were identified as potential confounding variables (see 6.3 and Figure 6.4), which gave an adjusted p-value of <0.001 (OR 1.04, CI: 1.03-1.05).

6.3.5: Deprivation

It was not possible to obtain postcodes or valid IMD deciles for 44 stroke survivors (Hospital 1: n=14, Hospital 2: n=8 and Hospital 3: n=22). No significant differences in IMD were identified between those with visual impairments and those without (p=0.352, chi-squared test); see Table 6.15. The association between IMD and the presence of post-stroke visual impairment was adjusted for gender, as these were identified as potential confounding variables (see 6.3 and Figure 6.4). After adjustment for gender, IMD decile was found to be a significant predictor of visual impairment post-stroke, although this was only significant for decile 8 when compared to decile 1 as the reference category (p=0.015, OR 2.79, CI: 1.22-6.37).

Table 6.14: The ages of the stroke survivors with and without post-stroke visual impairments, reported for all hospital sites.

	Mean (M)	Number of patients (n)	Std. Deviation (SD)	Min (years)	Max (years)
Visually impaired (n=700)	74.19	76	14.12	50	99
Normal Vision (n=337)	67.12	68	13.76	25	94

Table 6.15: The IMD deciles of the stroke survivors with and without post-stroke visual impairments, reported for each hospital site.

Index of multiple deprivation		Visually impaired (n)		Normal Vision (n)		Total	
Most deprived	1	186	**27.6%**	97	**30.3%**	283	**28.4%**
	2	84	**12.4%**	47	**14.7%**	131	**13.2%**
	3	48	**7.1%**	26	**8.1%**	74	**7.4%**
	4	62	**9.2%**	22	**6.9%**	84	**8.4%**
	5	64	**9.6%**	20	**6.3%**	85	**8.5%**
	6	54	**8%**	26	**8.1%**	80	**8%**
	7	29	**4.3%**	24	**7.5%**	53	**5.3%**
	8	71	**10.7%**	17	**5.3%**	89	**8.9%**
	9	51	**7.6%**	25	**7.8%**	76	**7.6%**
Least deprived	10	24	**3.6%**	16	**5%**	40	**4%**
Total		673	67.8%	337	33.9%	995	-

A lower IMD value (closer to 1) represents a more socially deprived area. A higher value (closer to 10) represents a more affluent area of residence.

6.3.6: Severity of stroke

It was not possible to obtain a Barthel index for 164 stroke survivors (Hospital 1 n=59, Hospital 2 n=8 and Hospital 3 n=97). Differences in Barthel index varied significantly between the visually impaired cohort and those with normal visual status (p=<0.001, Kruskal-Wallis test). The visually impaired stroke population had significantly lower Barthel indices (see Table 6.16), indicating that those with a higher severity of stroke also presented with post-stroke visual impairments.

The association between severity of stroke and the presence of post-stroke visual impairment was adjusted for gender, IMD, and age, as these were identified as potential confounding variables (see 6.3 and Figure 6.4). After adjustment, Barthel index was further found to be a significant predictor of visual impairment post-stroke (p=<0.001, OR 0.85, CI: 0.83-0.88).

6.3.7: Discharge destination

There was no missing information on discharge destination within either group. Discharge destination was significantly different between those with post-stroke visual impairments and those with normal vision in each of the hospital sites (p=<0.001, chi-squared). Stroke survivors discharged to nursing homes and other forms of supported living were more likely to have a post-stroke visual impairment (see Table 6.17), whilst those with normal visual status were most likely to be discharged home. Of the 162 patients that died in hospital and were never discharged, 45 (27.7%) had a confirmed visual impairment. The remaining 117 (72.3%) could not be assessed or died before assessment was possible.

Unlike the demographic factors described previously, discharge destination does not affect the presence of post-stroke visual impairment, instead it itself may be affected by the presence of post-stroke visual impairment.

Table 6.16: The Barthel indices for stroke survivors with and without post-stroke visual impairments, per hospital site.

Barthel index at hospital admission	Visually impaired (n)	Normal Vision (n)	Total
Mean	8.60	15.90	10.94
Standard deviation	7.25	4.94	7.43

A lower Barthel index (closer to 0) represents a more severe stroke, with more post-stroke disabilities. A higher value (closer to 20) represents a less severe stroke with fewer impairments.

Table 6.17: The discharge destinations of the stroke survivors with and without post-stroke visual impairments.

Discharge destination	Visually impaired (n)		Normal vision (n)		Total	
Home	318	**60.3%**	203	**94.4%**	522	**70.2%**
Intermediate/respite care	22	**4.2%**	0	**-**	22	**3%**
Nursing home	113	**21.4%**	6	**2.8%**	119	**16%**
Living with family	4	**0.8%**	1	**0.5%**	5	**0.7%**
Never discharged/ died in hospital	44	**8.5%**	0	**-**	45	**6%**
Other	26	**4.9%**	5	**2.3%**	31	**4.2%**
Total	482	65.1%	215	28.9%	744	-

Where "other" was documented for 31 discharge destinations, these were recorded as repatriated to other NHS hospital (n=11), out of area (n=7), repatriated to other NHS hospital out of area (n=6), prison (n=3), a 24 hour care home (n=2), mental health unit (n=1) and homeless (n=1).

6.3.8: Linear regression with adjustment for potential health inequalities

A linear regression analysis was conducted for all potential health inequalities explored in this chapter. Discharge destination was not included in the regression analysis as it succeeds the stroke; see Figure 6.4. Table 6.18 shows the results of the linear regression. The variables that were found to be significant concurred with those reported in the previous analysis; age at time of stroke, Barthel index, but also found IMD decile to be significant. Although individually, IMD was only significant for deciles 1, 3-5 and 8 (compared to decile 10 as the reference category for the regression analysis). Hospital site showed no significant difference in suffering post-stroke visual impairment following analysis. This aids justification for the decision not to analyse each site individually (6.3).

Table 6.18: Linear regression analysis with adjustment for potential predictors of post-stroke visual impairment

Variables	P-Value	Likelihood of predictor (odds ratio) Exp(B)	95% CI for EXP(B)	
			Lower	Upper
Gender	0.480	0.882	0.623	1.249
Age (at stroke admission)	<0.001	1.027	1.014	1.040
Barthel index	<0.001	0.852	0.827	0.877
IMD decile (compared against decile 10)	0.032			
IMD decile 1	0.036	2.771	1.070	7.175
IMD decile 2	0.167	2.010	0.747	5.411
IMD decile 3	0.040	3.024	1.051	8.706
IMD decile 4	0.045	2.967	1.026	8.579
IMD decile 5	0.005	4.581	1.578	13.303
IMD decile 6	0.097	2.432	0.852	6.945
IMD decile 7	0.468	1.499	0.502	4.472
IMD decile 8	0.001	6.065	2.029	18.127
IMD decile 9	0.131	2.257	0.785	6.489
Hospital site (compared against Hospital 3)	0.239			
Hospital (1)	0.953	1.014	0.647	1.589
Hospital (2)	0.162	1.404	0.872	2.260

6.4: Did the patient demographic affect the recovery of post-stroke visual impairments?

Analysis using SPSS version 24.0 (185) was used to determine the recovery of the post-stroke visual impairments and whether or not this was associated with any of the patient demographics including level of area deprivation. Each of the patients' visual impairments identified through the study were coded as fully recovered, partly recovered or never recovered. See 2.3.7.1 for definitions of full, partial and no recovery of visual impairments.

Of the 700 acute stroke survivors found to have a 'new' or 'partially new' post-stroke visual impairment, it was found that overall, 182 fully recovered, 366 partially recovered and 152 stroke survivors never recovered from their post-stroke visual impairments during the study period. However, within the group that partially recovered, some of the visual impairments fully recovered and some never recovered. Table 6.20 shows the recovery of each of the post-stroke visual impairments. Many of the stroke survivors had multiple visual impairments and recovery varied between the individual impairments.

A Chi-squared test showed that the differences in full, partial or no recovery for the post-stroke visual impairments were significantly different ($p=<0.001$), with the majority of patients showing partial recovery: see Table 6.19. Furthermore, the recovery reported for each of the post-stroke visual impairments individually showed further significant variation: $p=0.018$ for reduced VA and $p=<0.001$ for OA, OM, BSV, VF loss, VN and VP.

Table 6.19 shows that most visual impairments were equally as likely to fully recover or never recover at all. Visual perceptual problems, however, were significantly more likely to completely resolve (98%).

Table 6.19: Recovery of the post-stroke visual impairments

Post-stroke visual impairments (single and multiple impairments)	Fully recovered (n)		Partially recovered (n)		Never recovered (n)	
Reduced visual acuity	129	**36.8%**	130	**37%**	90	**26.2%**
Ocular alignment	76	**57.6%**	10	**7.6%**	46	**34.8%**
Ocular motility	174	**39.5%**	102	**23.1%**	164	**37.4%**
Binocular single vision	134	**69.4%**	8	**4.1%**	51	**26.4%**
Visual field loss	110	**36.7%**	64	**21.3%**	125	**42%**
Visual neglect	146	**46.3%**	48	**15.2%**	120	**38.4%**
Visual perceptual defects	36	**98%**	4	**1.2%**	17	**0.1%**
Total (n=stroke survivors)	182	**25.9%**	366	**52.1%**	152	**21.9%**

The patient demographics that were not found to be significantly associated with recovery of the post-stroke visual impairments were ethnicity, type of stroke, gender, IMD and Barthel Index (p=0.898, 0.161, 0.340, 0.360 and 0.061 respectively); see Tables 6.20-6.24.

However, patient age at time of stroke and discharge destination were found to be significantly associated with recovery of visual impairment. A one-way ANOVA test showed that patients who had full recovery of their post-stroke visual impairments were significantly younger than those with partial or no recovery (p=0.004). Table 6.25 displays the mean age at time of stroke for those that fully recovered, partially recovered or never recovered from their post-stroke visual impairments.
Furthermore, those who showed no recovery of their visual impairments were significantly more likely to be discharged to nursing homes or intermediate respite care. The patients with full or partially recovery were more likely to be discharged home (p=0.008), chi-squared test; see Table 6.26.

Table 6.20: The ethnicities of the stroke survivors, as per the recovery of the post-stroke visual impairments.

Ethnicity	Fully recovered (n)		Partially recovered (n)		Never recovered (n)	
White British	173	**96.1%**	345	**95.3%**	143	**94.8%**
White Irish	1	**0.6%**	3	**0.8%**	0	**-**
Any other White British	3	**1.7%**	6	**1.7%**	2	**1.3%**
White and Black Caribbean	1	**0.6%**	1	**0.3%**	0	**-**
White and Black African	1	**0.6%**	1	**0.3%**	1	**0.7%**
Indian	1	**0.6%**	2	**0.6%**	2	**01.3%**
Pakistani	0	**-**	2	**0.6%**	1	**0.7%**
Bangladeshi	0	**-**	2	**0.6%**	1	**0.7%**
Chinese	0	**-**	0	**-**	1	**0.7%**
Total	180	**25.9%**	362	**52.1%**	151	**22.0%**

Table 6.21: The difference in stroke type, as per the recovery of the post-stroke visual impairments.

Type of stroke	Fully recovered (n)		Partially recovered (n)		Never recovered (n)		**Total**	
Infarction	158	**86.8%**	327	**89.3%**	140	**91.6%**	625	**89.2%**
Haemorrhage	24	**13.2%**	39	**10.7%**	12	**8.4%**	75	**10.8%**
Total	182	26.0%	366	52.1%	152	21.9%	702	-

Table 6.22: The gender differences, as per the recovery of the post-stroke visual impairments.

Gender	Fully recovered (n)		Partially recovered (n)		Never recovered (n)		**Total**	
Males	106	**58.2%**	189	**51.6%**	83	**54.5%**	378	**54%**
Females	76	**41.8%**	177	**48.4%**	69	**45.5%**	322	**46%**
Total	182	26.0%	366	52.1%	152	21.9%	702	-

Table 6.23: The IMD deciles, as per the recovery of the post-stroke visual impairments.

Index of multiple deprivation		Fully recovered (n)		Partially recovered (n)		Never recovered (n)		Total (n)	
Least deprived	10	4	**2.3%**	14	**4%**	6	**4.1%**	24	**3.6%**
	9	17	**9.8%**	27	**7.6%**	7	**4.7%**	51	**7.6%**
	8	21	**12.1%**	41	**11.6%**	9	**6.8%**	71	**10.7%**
	7	8	**4.6%**	16	**4.5%**	5	**3.4%**	29	**4.3%**
	6	12	**6.9%**	26	**7.4%**	16	**10.8%**	54	**8%**
	5	12	**6.9%**	41	**11.6%**	11	**8.1%**	64	**9.6%**
	4	14	**8%**	31	**8.8%**	17	**11.5%**	62	**9.2%**
	3	14	**8%**	23	**6.5%**	11	**7.4%**	48	**7.1%**
Most deprived	2	24	**13. 8%**	35	**9.9%**	25	**16.9%**	84	**12.4%**
	1	48	**27.6%**	99	**28%**	39	**26.4%**	186	**27.6%**
Total		174	25.8%	353	52.3%	146	21.9%	673	-

Table 6.24: The Barthel indices, as per the recovery of the post-stroke visual impairments.

Barthel index at hospital admission	Fully recovered (n)	Partially recovered (n)	Never recovered (n)	Total (n)
Mean	10.03	7.69	8.49	8.58
Standard deviation	7.12	7.08	7.67	7.25

A lower Barthel index (closer to 0) represents a more severe stroke, with more post-stroke disabilities. A higher value (closer to 20) represents a less severe stroke with fewer impairments.

Table 6.25: The patient age at time of stroke, as per the recovery of post-stroke visual impairments.

	Mean (M)	Number of patients (n)	Std. Deviation (SD)	Min (years)	Max (years)
Fully recovered	71.32	182	14.34	19	96
Partially recovered	75.30	366	12.36	32	99
Never recovered	75.58	154	13.97	19	97
Total	74.33	702	13.36	19	99

Table 6.26: The discharge destinations of the stroke survivors, as per the recovery of the post-stroke visual impairments.

Discharge destination	Fully recovered (n)		Partially recovered (n)		Never recovered (n)	
Home	93	76.9%	166	57.6%	59	50%
Intermediate/ respite care	5	4.1%	12	4.2%	5	4.2%
Nursing home	13	10.7%	75	26%	25	20.8%
Living with family	1	0.8%	1	0.3%	2	1.7%
Never discharged/ died In hospital	4	3.3%	19	6.6%	21	18.3%
Other	5	4.1%	15	5.2%	6	5%
Total	182	26.0%	366	52.1%	152	21.9%

Where "other" was documented for 31 discharge destinations, these were recorded as repatriated to other NHS hospital (n=13), out of area (n=8), repatriated to other NHS hospital out of area (n=4), prison (n=2), a 24-hour care home (n=2), mental health unit (n=1) and homeless (n=1).

6.4.1: The time to recovery of the post-stroke visual impairments

The average time to full recovery of stroke-induced visual impairment was 60.5 days (median 38.5 days), ranging from 1-391 days post-stroke. For those that partially recovered from their stroke-induced visual impairments, they were followed up for an average of 116.2 days (median 71 days), ranging from 1-530 days post-stroke. The patients that never recovered from their stroke-induced visual impairments were followed up for an average of 68.2 days (median 43.5 days), ranging from 1-446 days post-stroke. The patients that showed no recovery of vision were discharged earlier than those that showed partial recovery, as the recovery was continuously monitored until satisfied that it has ceased.

The Kaplan-Meier (Figure 6.5) curve shows that approximately half of the stroke survivors did not recover from their post-stroke visual impairments.

For the 182 stroke survivors identified as fully recovering from their post-stroke visual impairments, survival analysis using a Cox's proportional hazards regression model was used to explore whether or not particular patient demographics were associated with faster complete recovery of the visual impairments (see Figure 6.5 and Table 6.27). This analysis was then repeated for partially recovered post-stroke visual impairments (see Figure 6.6 and Table 6.28).

Kaplan-Meier curves were used to display the complete and partial recovery of gender and type of stroke due to the small number of groups within these variables (see Figures 6.6-6.9).

It was found that complete recovery of the post-stroke visual impairments could not be predicted by any particular patient demographic or by discharge destination (see Table 6.27). However, a low Barthel index, older age at time of stroke, and discharge destination (supported forms of living) were found to be predictors of partial recovery of post-stroke visual impairments (see Table 6.28).

Figure 6.4: Kaplan-Meier curve showing the rate of complete recovery of all post-stroke visual impairments

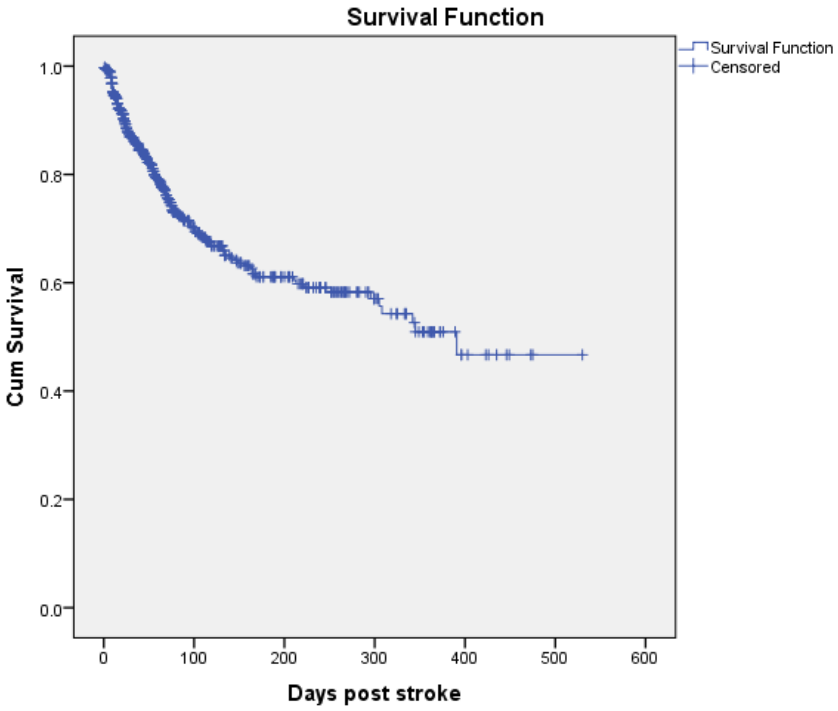


Figure 6.5: Kaplan-Meier curve showing the rate of partial recovery of all post-stroke visual impairments

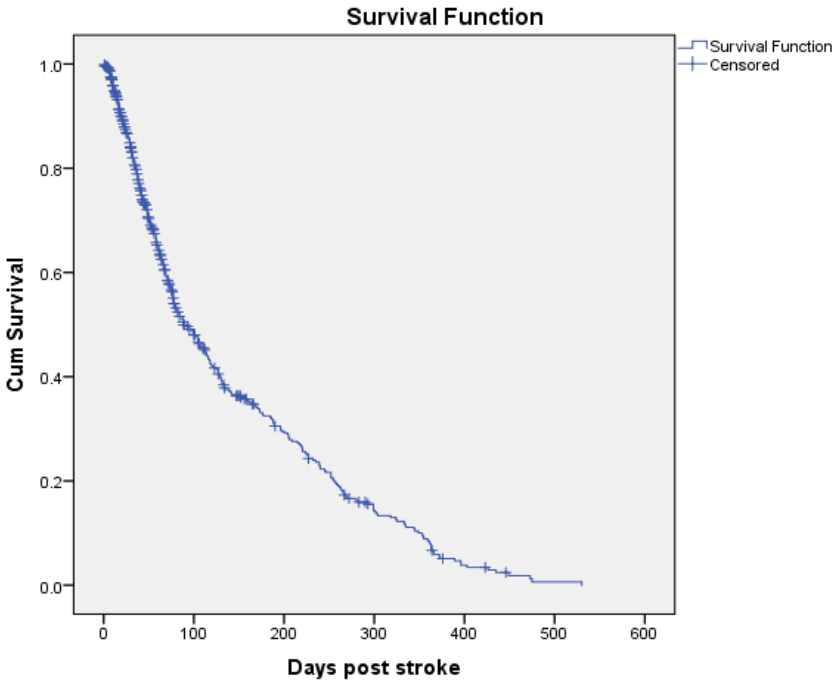


Table 6.27: Cox's proportional hazard regression analysis with adjustment for potential predictors of **complete** *recovery of post-stroke visual impairment*

Variables	P-value	Likelihood of predictor (Hazard ratio) Exp(B)	95.0% CI for Exp(B)	
			Lower	Upper
Gender	0.777	0.940	0.615	1.438
Barthel index	0.850	0.997	0.967	1.028
IMD decile (compared against decile 10)	0.829			
IMD decile 1	0.541	1.569	0.370	6.660
IMD decile 2	0.400	1.908	0.424	8.590
IMD decile 3	0.723	1.340	0.265	6.779
IMD decile 4	0.828	1.191	0.245	5.786
IMD decile 5	0.876	1.134	0.233	5.507
IMD decile 6	0.454	1.806	0.384	8.484
IMD decile 7	0.179	3.020	0.602	15.153
IMD decile 8	0.566	1.563	0.341	7.173
IMD decile 9	0.661	1.427	0.291	7.008
Type of stroke	0.460	0.788	0.418	1.483
Age at time of stroke	0.488	0.994	0.979	1.010
Discharge destination (compared against "home")	0.074			
Discharge destination (intermediate/respite care)	0.919	0.947	0.329	2.725
Discharge destination (nursing home)	0.269	0.511	0.155	1.682
Discharge destination (living with family)	0.982	0.977	0.128	7.466
Discharge destination (died in hospital/never discharged)	0.003	0.343	0.169	.696
Discharge destination ("other")	0.245	0.492	0.149	1.625

Table 6.28: Cox's proportional hazard regression analysis with adjustment for potential predictors of **partial** *recovery of post-stroke visual impairment*

Variables	P-value	Likelihood of predictor (Hazard ratio) Exp(B)	95.0% CI for Exp(B)	
			Lower	Upper
Gender	0.257	1.137	0.911	1.420
Barthel index	0.001	0.973	0.957	0.989
IMD decile (compared against decile 10)	0.701			
IMD decile 1	0.838	0.938	0.509	1.728
IMD decile 2	0.717	0.884	0.455	1.719
IMD decile 3	0.661	1.169	0.582	2.346
IMD decile 4	0.761	0.900	0.455	1.777
IMD decile 5	0.632	1.172	0.611	2.249
IMD decile 6	0.903	0.958	0.480	1.911
IMD decile 7	0.238	1.580	0.739	3.377
IMD decile 8	0.858	0.941	0.484	1.830
IMD decile 9	0.859	0.939	0.467	1.887
Type of stroke	0.830	0.963	0.686	1.353
Age at time of stroke	0.015	1.012	1.002	1.022
Discharge destination (compared against "home")	0.038			
Discharge destination (intermediate/respite care)	0.192	0.662	0.356	1.230
Discharge destination (nursing home)	0.718	1.100	0.656	1.845
Discharge destination (living with family)	0.458	0.585	0.142	2.411
Discharge destination (died in hospital/never discharged)	0.039	0.740	0.557	0.985
Discharge destination ("other")	0.006	0.452	0.255	0.800

Figure 6.7 Kaplan-Meier curve showing the difference in gender for complete recovery of post-stroke visual impairments.

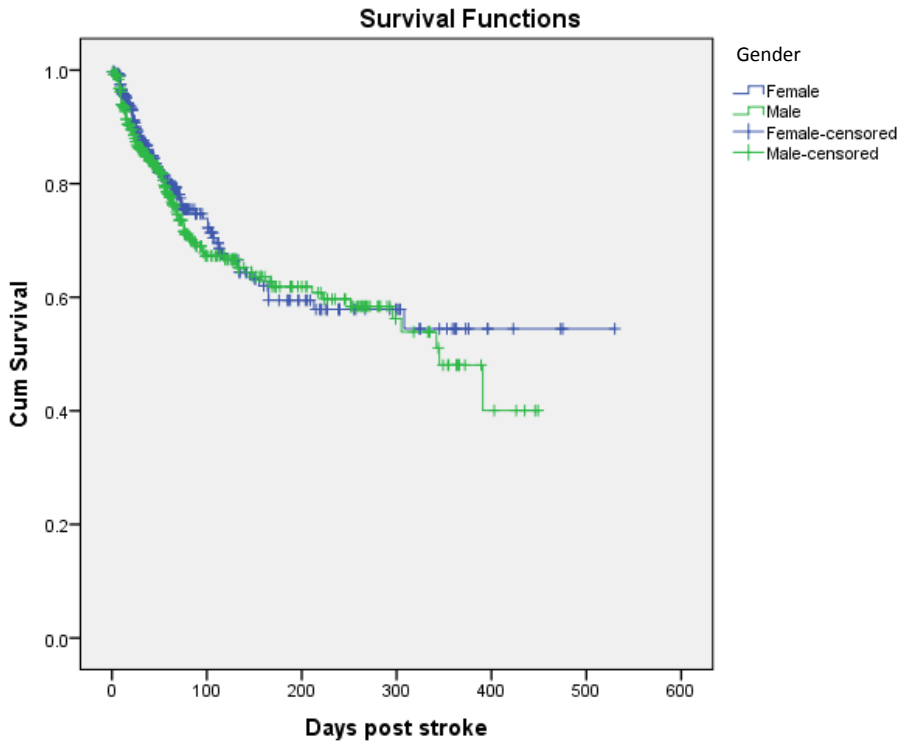


Figure 6.6: Kaplan-Meier curve showing the difference in gender for partial recovery of post-stroke visual impairments.

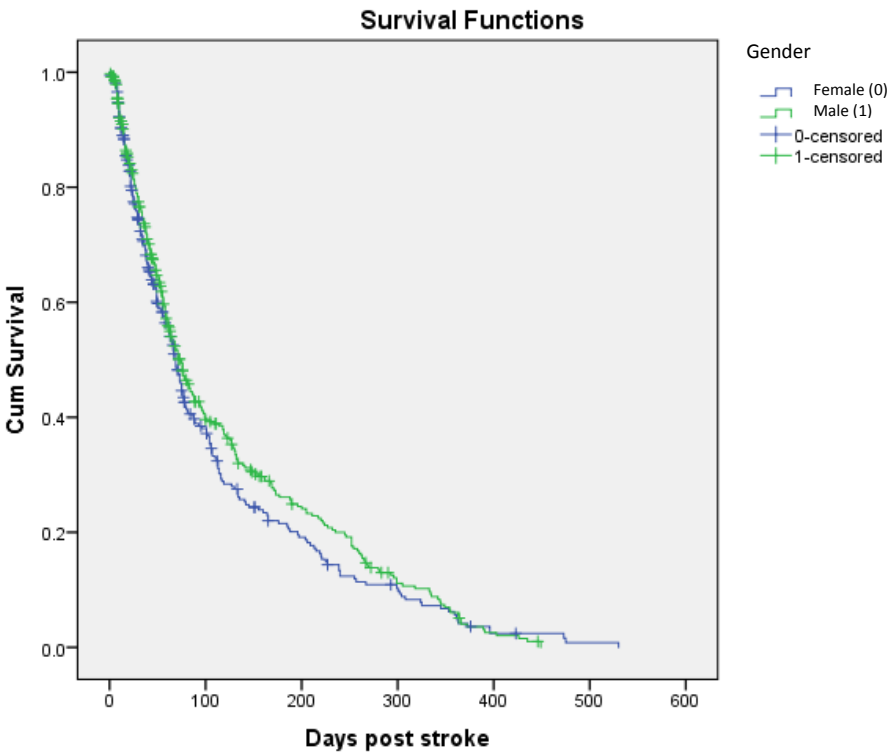


Figure 6.8: Kaplan-Meier curve showing the difference in type of stroke for complete recovery of post-stroke visual impairments.

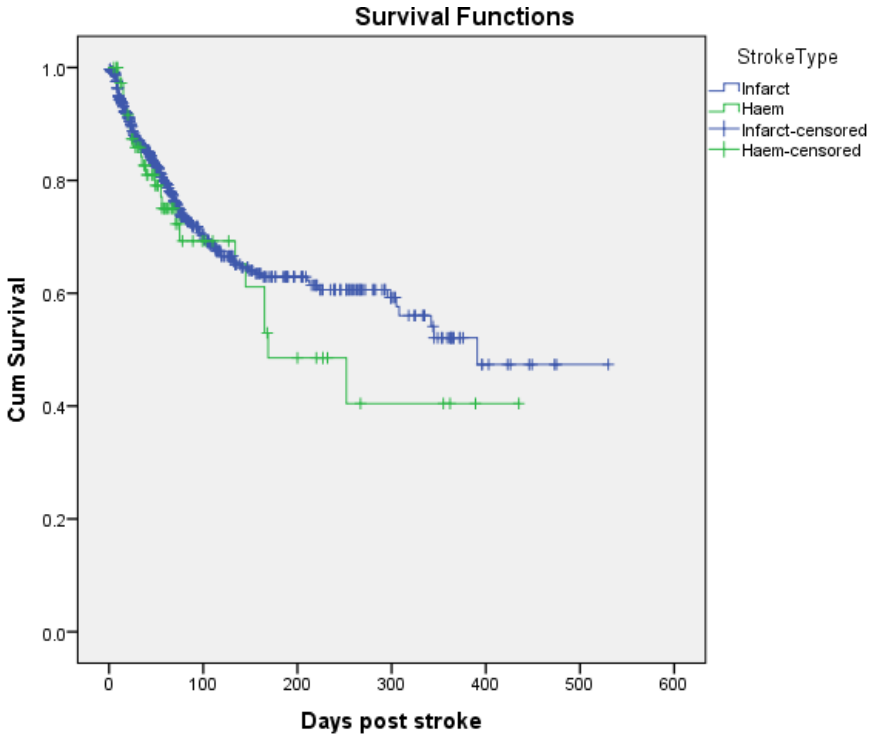
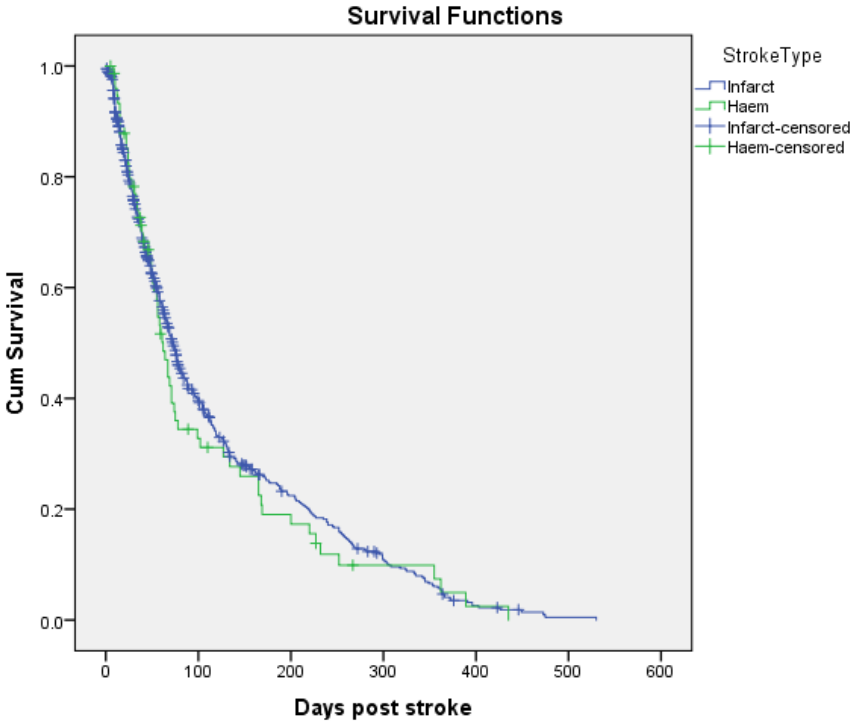


Figure 6.9: Kaplan-Meier curve showing the difference in type of stroke for partial recovery of post-stroke visual impairments.



6.5: Limitations

The Barthel index was recorded at time of admission during the study. However, the score may not always have been representative of the disabilities attained from the current stroke. Some patients may have had pre-existing general or cognitive disabilities, which could not be accounted for during the study. Future studies should aim to document pre-stroke Barthel scores for a more accurate comparison.

Furthermore, the IVIS study was unable to capture those stroke survivors who did not present to hospital following their stroke. It is widely acknowledged that a number of stroke survivors do not present to hospital following a stroke or TIA (435-437). However, this may have limited the generalisability of the study findings to the UK stroke population as a whole.

In addition, efforts were made to identify all previous ocular disorders and strokes (see 2.3.7); however, it may be possible that a number of stroke survivors were missed. If there were no previous ocular records in case notes, and the patient was unable to communicate their ocular history, then there is a chance that these would have been incorrectly treated as new stroke related visual impairments. In an attempt to control for this, patients' family members or carers were asked to provide a history of any previous eye appointments or known conditions on the stroke survivor's behalf.

During the IVIS study, it was not possible to identify whether or not a visual impairment was present in anyone that was too unwell to be assessed. The results have shown that a number of patients who were discharged before assessment was possible had a post-stroke visual impairment, which recovered before they were later assessed as an outpatient. This means that the overall number of patients with visual impairment could be higher, and that the health inequalities identified in this study are likely to affect a larger population than that reported.

Moreover, it was not possible to capture whether or not any patient diagnosed with normal vision following vision screening and discharged actually had a visual impairment. In practice, it was not found that any patient returned to the service complaining of visual symptoms after they had been discharged. However, it is well understood that many stroke survivors are not always aware of, or may not be able

to vocalise, their visual symptoms. Therefore, it may be possible that some patients were missed, for example, small visual field scotomas or obscure visual perceptual anomalies.

Additionally, some patients were discharged before further recovery potentially occurred and were unable to attend follow-up. Therefore, it is possible that fully or partially recovered visual impairments have been over estimated. Chapter 9 describes the reasons for why patients were unable to return for follow-up or were not offered a follow-up appointment.

As a number of patients had pre-existing visual impairments, it is possible that some patients may have been recorded as "partially recovered" from their post-stroke visual impairments when in fact, their vision recovered to a previous level of reduced vision. It was not always possible to identify their previous level of best-corrected vision, therefore, unless vision recovered to the "normal" levels reported in 2.3.7.1, the vision was recorded as partially recovered. This would underestimate the number of patients that fully recovered from the post-stroke visual impairments.

Lastly, although the findings suggest that patients with additional co-morbidities would be most affected by the inequalities identified in this chapter of the research (discussed below), the lack of data collected on co-morbidities does not allow for this to be studied further at this moment.

6.6: Summary

Overall, 46.6% (700/1500) of patients suffered a new visual impairment following stroke. However, this number is likely to be underestimated as it is expected that a number of patients did not present to hospital following stroke, were unable to be visually assessed or died before assessment was possible.

Following statistical analysis, gender, type of stroke, area of residence (IMD decile) and ethnicity were not found to be significantly associated with having a visual impairment after stroke. The patient demographics that were significantly associated with post-stroke visual impairment included older age, a lower Barthel index and discharge destination (supported living). This group of patients are more likely to

have a range of co-morbidities due to older age and stroke (226, 438); therefore, additional visual impairments could have significant implications for them.

None of the patient demographics were significantly associated with full recovery of the post-stroke visual impairments. However, partial recovery compared to no recovery revealed some discrepancies.

Only VP disorders (other than VN) demonstrated almost complete recovery in all cases. However, all other visual impairments showed an approximately equal split of complete or no recovery. This highlights the need to address these impairments whilst the patient is in hospital, as it cannot be assumed that visual impairments will resolve naturally over time.

Once more, the patient demographics found to be significantly associated with poor recovery of the visual impairments after stroke included, older age, a low Barthel index, and discharge to supported living. This reiterates the significant health inequality facing this group of older patients who have suffered severe strokes. They will likely have prior health problems and additional stroke disabilities unrelated to vision, and developing new visual disorders in addition to these, could have serious consequences to the patients' recovery and quality of life.

Chapter 7: Health inequalities in the assessment of post-stroke visual impairment

7.1: Background and aims

There are various assessment tools available to screen for post-stroke visual impairments (105). However, it has been reported that the investigation of post-stroke visual impairment varies greatly across the UK (2). Variation was found in the choice of vision tests, how the screening was being performed, and which clinician was undertaking the screening assessment (2). A formal orthoptic vision assessment has been described as the gold standard method for identifying post-stroke visual impairments. Despite this, it is often non-eye trained professionals who conduct the vision assessments (102, 122). If clinicians are unaware of the full range of appropriate screening tools, they may not be able to make an informed decision as to which are the best methods to use in order to effectively screen for all potential post-stroke visual impairments.

To achieve the highest possible quality of care for these patients it is essential to use screening tools with recommendations through high-quality clinical research. Evidence-based practice improves the consistency of care (439) and systematic reviews have been described as the frequent starting point in developing guidelines to implement change in clinical practice (153, 440).

However, despite it being widely accepted that research drives better clinical practice, there is evidence to suggest that some health professionals still do not change their practice to meet the recommendations of the current literature (441). Reasons for this may include lack of time for evidence-based practice activities including reading research articles, health professionals' attitudes towards research, and the healthcare professionals' previous levels of education (441, 442). One study suggested that in order to successfully implement evidence in clinical practice,

clinicians must be informed of the guidelines and materials, acknowledge and understand these guidelines and have these materials in their possession (441).

The aim of this review is to compare the screening tools used in the IVIS study (Chapter 2) to those identified in the systematic literature review (Chapter 4). This will identify:

1. The assessment options with an existent evidence base substantiated by comparative trial/case control research,
2. The assessment options with an established evidence base substantiated by observational clinical research,
3. The assessment options based on clinical experience but are, of yet, lacking a substantive research evidence base.

As a result, it will be possible to provide recommendations on vision screening tools to clinicians assessing stroke survivors with visual impairment, based on those options with adequate supporting evidence. This review will further highlight those screening tools with a weak/complete lack of evidence, thus, to caution clinicians of the potential risk in using these tools without substantial supportive evidence. By informing clinicians of the full range of available tools and the effectiveness of each method, it may be possible to reduce the national variation in post-stroke vision screening, and ensure that clinicians provide the most effective service so that all stroke survivors with visual impairments are accurately identified and referred for rehabilitation of their impairments.

Finally, the results of this comparative review will further be compared against a large, visually impaired stroke cohort - the Vision In Stroke (VIS) study -, which was conducted between 2006 and 2009. This will provide information as to whether or not clinicians screening for post-stroke visual impairment are actively changing their practice based on new research evidence. The comparison will report on those tools that are being used nationally with a strong evidence base, those that are not being used in practice due to lack of evidence, and those which are being used due to clinical experience despite a poor or lack of evidence for available tools, meaning some hospitals may not be aware of them to use for patients, leading to misdiagnosed impairments.

7.2: Method

A comparison was made between the screening methods used in the IVIS study (Chapter 2) and those identified from the systematic review (Chapter 4). Chapter 2 provides a full description of the screening tools used in the IVIS study. A description of the methods and screening tools identified in the systematic review are described in Chapter 4 and have been published elsewhere (105). The results were then compared to the VIS study (32).

7.3: Results

The screening tools identified in both clinical studies and in the systematic review have been described below in relation to the possible post-stroke visual impairments: visual acuity defects, visual field loss, visual perceptual disorders, and ocular motility defects. A comparison of the rehabilitation options offered in the IVIS study, the VIS study and those identified in the literature are shown in Tables 7.1-7.5.

7.3.1: Visual acuity assessment

A comparison of the screening tools used to assess visual acuity (VA) in the stroke survivors from the IVIS study, the VIS study and those reported in the literature revealed few similarities (see Table 7.1).

One comparison was noted between the two clinical studies with regard to the use of LogMAR and Snellen's charts (with or without a matching card for non-verbal assessments). However, their use in detecting visual impairments in a stroke population specifically had no supportive evidence. The use of these tools is common orthoptic practice in non-stroke populations (443, 444), and so research is not warranted to prove their effectiveness in a stroke-specific population. However, the need to assess VA after stroke is not well documented generally (105), and so published evidence is required to inform clinicians of the need to test VA after stroke.

Additionally, the IVIS study included the measurement of contrast sensitivity using the Mars chart, the assessment of colour vision using the City University test, and the Radner reading book to measure reading rate. City-Cardiff grating cards were also included for use on non-verbal stroke patients, those with reduced cognition or those with impaired mobility preventing the use of a matching card.

However, not all of these additional tests proved necessary. The results of the IVIS study showed that colour vision (CV) and contrast sensitivity (CS) were not frequently reduced and as such, the routine assessment of these visual functions after stroke is contraindicated. Overall 11% of patients (n=165) were found to have reduced CV, although 8% of these (n=116) were suspected of having false positive CV results due to the following conditions: reduced cognition/attention (including dementia) (n=29), fatigue (n=33) and poor health (n=25). Additional reading difficulties during test performance were noted due to speech impairments (n=8), and the inability to follow print due to eye movement disorders (n=2) and hemianopic dyslexia (n=1) that hindered CV test performance. Furthermore, nine did not have their glasses present and 12 reported their glasses being out of date.

In addition, CS was reduced in only 2.7% of cases (n=41). Moreover, the patients with reduced CS were found to have impairments that likely hindered test accuracy: poor health (3), lacking cognition/attention (7), fatigue (6), and reading difficulties due to eye movement defects (3) and hemianopia (1). Furthermore, 14 did not have their glasses present and ten reported their glasses being out of date.

This shows a lack of sensitivity with both the CV and CS testing methods within the stroke population, further reiterating the need to establish the use of visual assessments after stroke (Chapter 4).

The use of gratings cards and the Radner reading assessment during the IVIS study, however, has been shown to be a valuable asset to the post-stroke visual screening assessment. The results of the study showed a need to include these assessment tools as 22% (n=115) of stroke survivors with reduced VA required the use of City-Cardiff grating cards at some stage during the study for their assessment of VA, where testing with linear acuity charts was not possible.

Table 7.1: A comparison of the assessment methods for visual acuity used in the IVIS and VIS studies

Screening methods for visual acuity	
Linear vision charts (Snellen's/LogMAR)	**√√**
Contrast sensitivity chart	**√**
Colour vision test	**√**
City-Cardiff acuity test	**√**
Radner reading assessment	**√**

√=visual screening tool referenced in the IVIS study
√√=visual screening tool referenced in both the IVIS study and the VIS study

Eighty-two percent (n=94) of these were subsequently found to have reduced VA and would otherwise not have been identified successfully.

Furthermore, 98 stroke survivors with reduced VA were found to have an impaired rate of reading using the Radner reading test, which required subsequent advice and management.

This visual tool used in the IVIS study was also successful in identifying impaired reading rates associated with OM defects (impaired smooth pursuit), VF loss and/or VP defects, as well and reduced VA, and the cause of the reading impairment was differentiated during the visual screening process when combined with the other orthoptic findings. Section 7.3.4 describes the use of the Radner reading test in assessing hemianopic dyslexia.

Remarkably, the results of the systematic review found very little literature discussing the assessment of post-stroke VA. No specific evidence was found which reported on the adapted assessment of VA following stroke using grating cards or matching cards. It is well established that orthoptists use fading optotypes, Cardiff-acuity pictures and teller acuity cards in a non-stroke capacity, such as for the assessment of preverbal infants (445, 446). Therefore, it is likely that these methods of assessing VA would prove useful for stroke survivors with subsequent speech or cognitive impairment. Although these methods have been well described in the literature with indications that they may be suitable to assess vision after stroke (296), they have yet to be compared and validated within a stroke population specifically.

No literature was found which discussed the City-Cardiff Infant Gratings Test used in the IVIS study, as it is a relatively new tool, released in 2012. As this tool was developed after the VIS study period, it had not been included in the study. The product website states that this test is comparable to the Teller or Keeler Acuity Tests but is easier to administer due to the smaller card size (447), indicating that it may be an alternative and appropriate, non-verbal test to use at bedside compared to the other grating acuity tests, as it is easily transportable.

One study reported the use of the MIS Pocket Vision Guide to test for near VA as part of a screening tool for post-stroke visual impairment (15). However, this near VA test has not been used in clinical practice through either the IVIS or VIS study. Although there have been some additional reports of this test being used to assess VA in non-stroke participants (448, 449), there appears to be no literature which validates this test against other well-known measures. Cardiff acuity cards are a similar preferential looking assessment, which are primarily used to

assess VA in infants and preverbal children. They have been briefly discussed as a means of assessing vision in non-verbal stroke survivors or adults with learning disabilities (450).

This further suggests that the City Cardiff grating test would be a suitable VA assessment for these patients, as it exhibits similar qualities to the Cardiff acuity test. Moreover, when used on stroke survivors, it was found that although the MIS Pocket Vision Guide is portable for use at bedside, the majority of patients had uncorrected refractive errors, which the authors suggest over-exaggerated the sensitivity of this test (15).

Concurrently, another article discussed the prevalence of lost, unclean or out-of-date glasses on the hospital ward following stroke, to yield a higher rate of false-positive acuity deficits within this population (18). It was recommended that patients or their families are asked about the use of glasses wear to reduce unnecessary treatment and to aid general stroke rehabilitation whilst in the hospital (18). This was furthered by the results of the IVIS study which found 72% (n=1074) of the stroke patients required refractive correction, but only 25% of these (n=811) had their glasses with them in hospital. A further 32% of those requiring glasses (n=340/1074) had not been to the opticians in the last 18 months, indicating that their glasses prescription may not have been accurate. However, a significant number of patients (n=408) were still found to have reduced VA after stroke, despite the use of their current refractive correction, inferring the need to check VA after stroke, with the appropriate glasses wear.

7.3.2: Ocular alignment and ocular motility assessment

Table 7.2 shows a comparison of the tools used to assess OM in the stroke survivors from the IVIS study, the VIS study and those reported on in the literature.

Both clinical studies used the same range of tests to screen for OM defects. There were no additional tests being performed currently (through the IVIS study) that were not being used in the earlier VIS study, suggesting no changes to the screening for this type of visual impairment over time.

Table 7.2: A comparison of the assessment methods for ocular motility defects identified in the literature and those used in the IVIS and VIS studies to display strength of evidence base

		Post-stroke screening tools identified in the literature search			
		Prospective observational study			
Screening tools used in the IVIS study		Ocular movements (horizontal and vertical positions only)	"Horizontal gaze assessment"		Screening tools used in the VIS study
	Cover test	-	-	Cover test	
	Prism cover test	-	-	Prism cover test	
	Ocular movements (9 positions)	**√√** (does not include all positions of gaze)	-	Ocular movements (9 positions)	
	Saccades	-	-	Saccades	
	Vergence	-	-	Vergence	
	Bagolini glasses	-	-	Bagolini glasses	
	Prism fusion range/20^	-	-	Prism fusion range/20^	
	Frisby stereotest	-	-	Frisby stereotest	
	Lids observed	-	-	Lids observed	
	Pupils observed	-	-	Pupils observed	

√=visual screening tool referenced in either the IVIS study or the VIS study and reported in the literature; therefore, indicates an evidence base to support clinical use.
√√=visual screening tool referenced in both the IVIS study and the VIS study

Once more, orthoptists test for OM defects routinely, and the uses of these methods are well reported. However, the assessment of ocular alignment and motility after stroke, as reported in the literature, appears to be limited as only a few of these methods were documented in relation to post-stroke OM assessment.

The review described only gross assessment of ocular movements and observation of horizontal gaze position as part of a general stroke screening tool (NIHSS), meaning many other OM defects are missed: saccades, vertical positions of gaze, pupil and lid function, and tests for binocular single vision (BSV). The results of the IVIS study showed 478 patients had reduced OM. Overall, 234 of these presented with defective saccades: 222 presented with impaired BSV; 298 had impaired vertical gaze problems; and 130 presented with pupil (n=39) and/or lid (n=91) defects. This demonstrates the need for these impairments to be accurately screened for following stroke.

Orthoptists perform a full assessment of OM, as many stroke survivors were found to suffer from a broad range of OM defects. However, in the absence of an orthoptist assessment, the NIHSS assessment includes only a broad test of gaze and eye position, which would not detect a variety of OM defects (122). Therefore, it should be a priority of future service planning to include orthoptic input in stroke after-care, to ensure all appropriate measures are used to assess the full range of OM defects after stroke.

7.3.3: Visual field assessment

Table 7.3 shows a comparison of the screening tools used to assess visual fields (VF) in the stroke survivors from the IVIS study, the VIS study and those reported in the literature.

Both clinical studies used the confrontation method for bedside assessment on the stroke rehabilitation unit, or when the patient was too unwell for automated perimetry in the outpatient clinic. The confrontation method used red targets mounted on pale, wooden sticks. However, the quantitative VF measurements varied between the two studies, showing a possible change in clinical practice over time. Quantitative measurements of static and kinetic VF were taken using the Octopus 900 automated perimetry machine in the IVIS study. However, the VIS study reported using the Humphrey or Goldmann VF machines for separate static and kinetic perimetry assessments.

Table 7.3: A comparison of the assessment methods for visual field loss identified in the literature and those used in the IVIS and VIS studies to display strength of evidence base

		Post-stroke screening tools identified in the literature search				
		Prospective observational study				
Screening tools used in the IVIS study		Confrontation method (finger counting in four quadrants)	Humphrey automated perimetry	Oculokinetic perimetry		Screening tools used in the VIS study
	Confrontation method (red bead target)	-	-	-	Confrontation method (red bead target)	
	Octopus automated perimetry	-	-	-	Goldmann automated perimetry	
	'	-	√	-	Humphrey automated perimtry	

√=visual screening tool referenced in either the IVIS study or the VIS study and reported in the literature; therefore, indicates an evidence base to support clinical use.
√√=visual screening tool referenced in both the IVIS study and the VIS study

The change from the Goldmann to the Octopus was primarily because production of the Goldmann perimeter stopped in 2007, thus the Octopus VF machine was chosen for both kinetic and static perimetry assessment in the IVIS study.

Furthermore, following cessation of the VIS study, findings were published which recommended the use of the Octopus 900 over the Goldmann visual VF due to potential bias as a result of the manual procedure of the Goldmann, particularly in relation to speed of testing (451). These findings were validated in a mixed population inclusive of stroke patients. An additional benefit of this machine was the ability to assess both static and kinetic perimetry without need to transfer the patient from one machine to another for separate VF assessments.

The results of the systematic review identified various methods for confrontation VF assessments. One author described the "hat pin" method (108), the description of which is very similar to the method used in the IVIS and VIS studies (111). This method is believed to be the most accurate confrontation method although the authors reported that it has yet to be validated within the stroke population (108). As such, it has not yet been documented in the literature as a suitable tool to screen for VF anomalies after stroke, either at bedside or when automated perimetry has not been possible.

Additional methods of confrontational VF testing reported in the literature using hand movements and finger counting (300) have been discouraged due to lack of sensitivity (108), as these methods assess only four quadrants of the patient's VF, meaning smaller scotomas could be missed. However, these methods continue to be used in current practice in overall stroke screening tools (107, 123), despite the reported evidence.

The Oculokinetic Perimetry (OKP) static method has further been described in the literature but does not appear to be used in orthoptic practice (285). Although it was found to be more sensitive than the more commonly used "finger-counting" method in the NIHSS screening tool, it requires normal levels of cognition, language and attention, which is often not possible after stroke. This suggests that the use of this method to screen for VF defects in stroke survivors is contraindicated due to its incompatibility with the vast majority of stroke patients, particularly in the acute stage.

The Humphrey field machine was reported to be more accurate than confrontation methods although, as mentioned previously, confrontation methods are often the only feasible method of bedside testing following stroke (108).

7.3.4: Visual perception assessment

The majority of the published literature that reported on screening tools for post-stroke visual impairment discussed tools for perceptual disorders including neglect. Due to the large volume of methods described, visual neglect (VN) tests have been described separately from other visual perceptual disorders (see 7.3.5 and Tables 7.4-7.5).

Table 7.4 shows a comparison of the screening tools used to assess visual perception (VP), excluding VN assessment, in the stroke survivors from the IVIS study, the VIS study with those reported on in the literature.

The full array of VP disorders, which were screened for in the IVIS study have been described previously (see 5.2). Visual perception was assessed through careful questioning of the patient, asking them to report the presence of visual hallucinations, visual illusions or disturbances amongst other VP symptoms. Simultanagnosia and colour perception deficits were assessed by asking the patient to describe pictures of objects or scenes, including the overlapping figures test.

In the earlier VIS study, perceptual deficits were also identified after questioning of the patient and/or carers and relatives. The questions reportedly screened for a broad range of possible VP defects.

As more screening methods were used in the later study, this suggests progression in orthoptic screening to include some assessment of VP in addition to questioning the patient.

Evidence to support the questioning and assessment of stroke survivors to identify VP disorders was generally well documented. Kerkhoff et al. (452) describes the assessment and questioning of stroke patients with hemianopic alexia to include hemianopic-related reading problems, disregarding persons or objects in one hemifield, blurred vision, blinding, dark vision, and disturbed colour vision. The Hemispheric Stroke Scale screening tool includes asking the patient if they are aware of their limbs (107, 119), whilst the TVPS-3 (291) includes assessments of visual discrimination, visual memory, and visual closure, which are similar to methods used in the IVIS study.

Table 7.4: A comparison of the assessment methods for visual perceptual defects identified in the literature and those used in the IVIS and VIS studies to display strength of evidence base.

Screening tools used in the IVIS study		Post-stroke screening tools identified in the literature search																										Screening tools used in the VIS study	
		Control trial														**Prospective observational study**											**Review**		
		Picture naming	Semantics	Orientation	Sentence reading	Number writing	Calculation	Broken heart	Space asymmetry	Object asymmetry	Limitation	Verbal recall	Verbal recognition	Episodic recognition	Executive task	Visual discrimination	Visual memory	Spatial relations	Form constancy	Sequential memory	Visual-figure ground	Visual closure	Agnosia	Body scheme	Apraxia	Alcalculia	Colour		
	Overlapping figures/object recognition	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	√	-	-	-	-	-	
	Colour discrimination	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	√	-	
	Scene description	-	-	-	-	-	-	-	-	-	-	-	-	-	-	√	-	-	-	-	-	-	-	-	-	-	-	-	
	Sentence reading (Radner)	-	-	-	√	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	
	Questioning	√	-	-	√	-	-	-	-	-	-	-	-	-	-	√	√	-	-	-	-	-	√	-	-	-	√	Questioning	

√=visual screening tool referenced in either the IVIS study or the VIS study and reported in the literature; therefore, indicates an evidence base to support clinical use.
√√=visual screening tool referenced in both the IVIS study and the VIS study

Moreover, many of the VP screening tools identified in the review included the use of pictures and tasks along with questioning of stroke survivors to effectively identify disorders of picture, object or scene agnosia (116, 119, 283). The over-lapping figures test to screen for object agnosia in the IVIS study was well supported in the literature (287).

Many of the screening tools mentioned further screened for alexia with "sentence reading" tasks. The inclusion of the Radner reading test in the IVIS study was able to further identify perceptual disorders in stroke survivors, alongside reading difficulties due to field loss, OM defects including hypometric saccades, and blurred central vision.

7.3.5: Visual neglect screening tools

Table 7.5 shows a comparison of the screening tools used to assess VN in the stroke survivors from the IVIS study and the VIS study with those reported on in the literature.

Both clinical studies screened for VN using the line bisection test (26.5cm line), a cancellation task (with the use of distractor items) and a drawing task where the patient was asked to draw a clock face from memory.

The VIS study reported the use of two cancellation tasks; one with distractor items and the Albert's test which does not contain distractor items. The level of neglect was recorded in both studies as mild, moderate or severe, which were graded based on clinical opinion taken from the overall results of the various neglect assessment.

The results of the review reported that a combination of the Behavioural Inattention Tests (BIT) has been widely recommended as a more precise measure of neglect (117, 288, 290). Both studies followed this suggestion, indicating that neglect tests are selected as a result of evidence-based recommendations. However, the VIS study reported on more subtests compared to the IVIS study. As the VIS study was conducted across 20 different hospital sites in the UK with no standardised assessment protocol specific to neglect, the additional tests reflected the national variation of the orthoptists' and OT assessments. The IVIS study was conducted across only three recruitments sites using standardised assessments and as such, three neglect tests were pre-selected prior to the study commencing and were not altered during the study period.

Although it was reported that more BIT tests yield a higher sensitivity of neglect, research published after the VIS study period reported that numerous tests can become too time consuming (114, 293).

Table 7.5: A comparison of the screening methods for visual neglect identified in the literature and those used in the IVIS and VIS studies to display strength of evidence base

		Screening tools identified in the literature search																									
		Control trial						**Prospective observational study**																**Review**			
Screening tools used in the IVIS study		Line bisection	Line cancellation (Alberts)	Star cancellation	Figure copying	Text reading	Clock drawing (memory)	Copy a cross	Bells cancellation test	Writing	Modified text reading	Baking tray task	Letter cancellation	Visual extinction	Line bisection (3x lines)	Complex line bisection (12x lines)	Sentence copying	Representational drawing	Object finding	Picture scanning	Two part picture	Slide	Personal neglect	Spontaneous drawing of clock or daisy	Line bisection (2x lines)		Screening tools used in the VIS study
	Line bisection	√√	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	Line bisection	
	Clock drawing (memory)	-	-	-	-	-	√√	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	Clock drawing (memory)	
	Cancellation task (with distractors)	-	√√	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	Cancellation task (with distractors)	
	Room description	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	

Screening tools used in the IVIS study																							Screening tools used in the VIS study
-	Personal description	Line bisection	Line cancellation (Alberts)	Star cancellation	Figure copying	Text reading	Clock drawing (memory)	Copy a cross	Bells cancellation test	Writing	Modified text reading	Baking tray task	Letter cancellation	Visual extinction	Line bisection (3x lines)	Complex line bisection (12x lines)	Sentence [illegible]	Representational drawing	Object finding	Picture scanning	Two part picture	Slide	Personal neglect	Spontaneous drawing of clock or daisy	Line bisection (2x lines)	-	-
	Fixing and following	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	cancellation task without distractors: Albert's
		-	√	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-

√=visual screening tool referenced in either the IVIS study or the VIS study and reported in the literature; therefore, indicates an evidence base to support clinical use.
√√=visual screening tool referenced in both the IVIS study and the VIS study.

The IVIS study adhered to the use of multiple tests but reduced the overall number to keep testing time to a minimum, as many stroke survivors are fatigued or unwell and struggle to undergo additional assessments. This suggests that the assessment for the presence of VN has changed over time based on the findings reported in the current literature; multiple neglect tests were used to address recommendations of the literature, but reduced to a minimum assessment battery to address the needs of the patient and to preserve the clinician's time.

All VN tools used in both clinical studies have been documented in the literature and their use recommended. The line bisection test has been reported as one of the most sensitive neglect tests, providing that a line of greater than 20cm is used for the test (117). Both the IVIS and VIS study used a line of 26.5cm, which concurs with this argument and indicates good clinical practice based on the recommendations from the current literature.

However, the review revealed additional tests for VN, which were not used in the above studies, including figure copying, sentence copying and a range of alternative cancellation tests (letters, lines and objects with or without distractor items); see 2.2. Cancellation tests have further been considered extremely sensitive in detecting VN (118, 120), although the use of distractor items has been debated. Cancellation tests with distractor items have proven to be most effective (117), and as such, are considered the test of choice in screening for VN. However, it has been argued that the distractors can provide a "pop-out" effect of the target items (118). Therefore, their use cannot be favourably recommended without further research to compare these two methods. The use of cancellation tasks with distractor items in the clinical studies was therefore valid based on the current literature.

In both clinical studies, the stroke survivors were asked only to draw a clock from memory, however, figure copying has been recommended over drawing from memory in the reported literature, as it relies more heavily on visual input (117). Additionally, the scoring system of the "drawing a clock from memory" task has been debated in the literature, resulting in arguable conclusions that this test has poor sensitivity (117).

It appears that the clock-drawing task requires clear interpretation of the results in order to recommend this tool to examiners. Therefore, the use of drawing from memory tasks in both clinical studies may be contraindicated if further research compares the two forms of assessment, and confirms that the figure copying task to be more effective.

However, clear recommendations for the use of copying tests over drawing from memory cannot be made at present. The literature search results further recommended measuring the bisected line and counting the number of unseen targets on the cancellation tasks to grade the level of VN. The clinical studies abided by these recommendations, providing grades of neglect, although these were based on clinical opinion of the three neglect test results combined and not for each subtest individually.

7.4: Limitations

Due to the limited number of research groups investigating visual impairment after stroke, there were few articles to make direct comparisons to in this project. Therefore, perceived selection bias is likely and highlights the need for other researchers to investigate this topic in order to generalise the findings from the IVIS study.

7.5: Summary

Inequalities identified in Chapter 3 regarding provision of visual care after stroke, and the notable lack of the full range of clinical visual screening tools reported in Chapter 4, informed the research in this current chapter. Overall, the results of the comparative review have shown that most of the screening tools have a suitable evidence base, although not all have been specifically validated within a stroke population, and for this reason, may not be reaching the attention of the stroke teams.

Additional inequalities exist within the screening of each of the visual impairments specifically. Clinical practice has evolved over time to include grating acuity cards and the Radner reading test in the assessment of VA and reading rate after stroke.

Provision of OM assessment after stroke varies greatly when performed by an orthoptist compared to a non-eye trained clinician. A change to orthoptic clinical practice over time was shown to incorporate the use of the Octopus 900 instead of the Humphrey and Goldmann perimeters.

Where orthoptists screen for VP after stroke, they use tools with substantiated evidence. Additional VP screening methods found in the review are not being used by orthoptists in clinical practice. However, it is likely that other healthcare professionals such as, neuropsychologists and occupational therapists are administering these methods. The results showed that VN appears to be well screened for after stroke, with a strong evidence base to support the testing methods. Future recommendations would be to keep the neglect tests concise so as not to overburden the patient with unnecessary and tiring assessments, whilst using measurements to quantify the level of neglect.

Table 7.6 highlights the variation in the quantity and quality of supportive literature for the tools being used in clinical practice. Those with a supportive evidence base taken from a stroke sample should continue to be used in clinical practice. Likewise, those with supportive evidence in comparable non-stroke populations should continue to be used, although the use of new or adapted vision tests should be widely publicised to ensure other practicing clinicians can replicate these methods. Some screening methods, such as LogMAR and Snellen acuity charts and tests for binocular vision do not warrant further research to justify their use as a vision assessment tool after stroke, as these have been well established in equivalent populations. However, the overall need to use these tools to assess vision after stroke should be publicised to the relevant stroke healthcare professionals, and visual care after stroke implemented nationally. This will ensure that all stroke survivors across the UK are receiving adequate post-stroke visual assessment and rehabilitation.

Table 7.6: The screening tools recommended in clinical practice and those requiring further research

Type of visual impairments	Visual screening tools being used with supportive evidence in stroke populations ***Their use recommended***	Visual screening tools being used with supportive evidence from non-stroke populations ***Their use recommended***	Vision screening tools being used without supportive evidence ***Further research required***
Visual acuity defects	-	• LogMAR charts • Snellen's charts • Radner reading test • Cardiff acuity cards • Teller acuity cards	• City-Cardiff grating cards
Ocular alignment/ motility defect	• Ocular movements: 2 positions of gaze (horizontal) or 4 positions of gaze ("up and down")	• Ocular movements (9 positons of gaze) • Cover test • Prism cover test • Saccades • Vergence • Bagolini glasses • Prism fusion range/20^ • Frisby stereotest • Lid assessment • Pupil assessment	-
Visual field loss	-	• Octopus 900 automated perimetry	• Confrontation visual field assessments
Visual perception defect (including visual neglect)	• Line bisection (>20cm line) • Cancellation tests • Drawing from memory • Overlapping figures test • "Questioning" of visual perceptual deficits	-	• Cancellation tests with distractor items vs. without distractor items

Chapter 8: Health inequalities in the management of post-stroke visual impairment

8.1: Background and aims

There are a wide variety of rehabilitation options available for post-stroke visual impairment ranging from low vision aids (410), visual scanning training for visual field (VF) loss (335, 453) and prisms or occlusion for strabismus and ocular motility (OM) defects (130). It has been reported that the orthoptic management of post-stroke visual impairment varies greatly across the UK (2). Variation was found in which visual management options were offered to patients and in the information materials being provided (2). Additionally, use of care pathways proved to be inconsistent with many patients failing to receive appropriate referral and follow-up for their visual symptoms (2). If clinicians are unaware of the full range of appropriate management options, they will be unable to make informed decisions as to which methods to use in order to effectively treat all potential post-stroke visual impairments.

To achieve the highest possible quality of care for these patients it is essential to use those treatments with recommendations through high-quality clinical research. Evidence-based practice improves the consistency of care and is vital in ensuring that patients receive interventions of proven benefit, which subsequently improve the patients' overall quality of life (439). Furthermore, evidence-based practice is beneficial in reducing the risk of harmful or unnecessary care (441). However, as discussed in Chapter 7, evidence suggests that some health professionals still do not change their practice to meet the demands in the current literature and should be encouraged to adapt their practice using evidence-based materials, such as systematic reviews (441).

The aim of this review is to compare the rehabilitation methods used in the IVIS study (Chapter 2) to those identified in the systematic review (Chapter 5). This will identify:

1. The rehabilitation options with an existent evidence base substantiated by comparative trial/case control research.
2. The rehabilitation options with an established evidence base substantiated by observational clinical research.
3. The rehabilitation options based on clinical experience but are, as yet, lacking a substantive research evidence base.

As a result, it will be possible to provide recommendations of interventions to clinicians treating stroke survivors with visual impairment, based on those methods with adequate supporting evidence. This review will further highlight those interventions with a weak or complete lack of evidence, thus to caution clinicians of the potential risk in using these methods without substantial supportive evidence through further research. By informing clinicians of the full range of available rehabilitation options and the effectiveness of each method, it may be possible to reduce the national variation in post-stroke vision management, and ensure that clinicians provide the most effective service so that all stroke survivors with visual impairments are appropriately managed for their impairments.

Finally, the results of this comparative review will further be compared against a large, visually-impaired stroke cohort; the Vision In Stroke (VIS) study (32); conducted in 2009, to identify which, if any, rehabilitation options were being offered more frequently in current practice. This will provide information as to whether or not clinicians treating post-stroke visual impairment are actively changing their practice based on new research evidence.

8.2: Methods

The visual interventions used in the IVIS study were reported and compared against the rehabilitation options identified in a comprehensive synthesis of the published literature (Chapter 5). Full methodologies for chapter 8 have been described earlier (see 2.3.9).

8.3: Results

The comparative review described the rehabilitation methods used in the IVIS study thus suggesting which interventions are being offered in current clinical practice, which were being used ten years previous in the VIS study, identifying any changes to clinical practice during this time, and which have or have not been reported in the literature and as such, may or may not have a supportive evidence base.

Tables 8.1-8.2, 8.4, 8.6 and 8.8 outline the various management options offered to patients of the IVIS study for each of the individual visual impairments. Some patients required several rehabilitation options for one visual impairment. The tables of results show the overall number of patients (n) offered a form of treatment during the study period. A number of patients reported no visual symptoms and required no treatment. However, their recovery was monitored by the orthoptists and the presence of new visual symptoms was investigated at each visit.

The vast majority (n=651) of stroke survivors presented with multiple post-stroke visual impairments. Many of these patients (n=467) were unable to undergo a full orthoptic assessment and therefore, could not be offered the full range of available rehabilitation options until a more accurate assessment was performed.

In some cases, a complete visual assessment was not possible for a range of different reasons including, but not limited to, fatigue, reduced cognition or attention and early discharge (see 6.2). As mentioned previously, treatment could not always be offered until a more accurate assessment of vision was possible.

The management options identified in both clinical studies and in the review have been described below in relation to the possible post-stroke visual impairments; VA defects, VF loss, visual perceptual (VP) disorders and OM defects. A comparison of the interventions offered in the IVIS study, the VIS study and those identified in the literature are shown in Tables 8.3, 8.5, 8.7 and 8.9.

8.3.1: Reduced central vision

8.3.1.1: *The prevalence of visual acuity defects in the IVIS study*

Overall, 29 (2%) stroke survivors across the three recruiting sites in the IVIS study were diagnosed with new onset reduced central VA as a sole defect and 224 (15%) were found to have reduced VA co-existent with other defects. A further 307 (20.5%) stroke survivors were identified as having a pre-existent diagnosis of reduced VA alongside a new defect of VA.

8.3.1.2: *The results of the comparative review*

The management for VA as a sole defect in the IVIS study can be seen in Table 8.1. Additional management offered to patients where VA presented as a multiple defect are reported in Table 8.2. Table 8.3 shows a comparison of the rehabilitation options offered to aid central vision loss in the IVIS study, the VIS study and those reported in the literature.

The IVIS study offered those patients found to have reduced VA only a referral to ophthalmology for further investigation or for certification of visual impairment. Many received verbal advice that consisted of eccentric viewing (in cases of macular defects) and advice to attend their high street opticians after discharge to update refractive correction. If patients were found to have a pre-existent ocular condition resulting in reduced VA, such as glaucoma, diabetic eye disease or age-related macular degeneration, advice was given to continue usual ophthalmic care and follow-up of these ocular conditions. Patients and family members were asked to bring glasses into the hospital in cases where glasses were missing and significantly impacted the patient's level of functional vision.

One patient was diagnosed as having reduced VA as a result of dry eye or conjunctivitis from poor lid closure due to a facial nerve palsy. This patient was treated with eye bathing, advice to the patient and nursing staff on eye hygiene, and by referral to ophthalmology for prescription of anti-bacterial eye drops.

A treatment factsheet was developed by the orthoptists of the IVIS study and contained additional resources and information of support groups and charity organisations, such as the RNIB (454) and the Stroke Association. This provided patients with a variety of online therapies, signposted to websites that gave advice

on lighting and positioning to aid visual function, and contact information for support groups and obtaining visual aids.

Additionally, Table 8.2 shows the various other interventions offered to stroke survivors where VA presented with multiple other visual impairments, such as typoscopes and Read-right web-based therapy. This shows how the orthoptists adapted therapies to meet the specific needs of the patient, by providing rehabilitation specifically intended for other forms of post-stroke visual impairment. For one patient, yellow and orange spectral filters were issued to aid reading difficulties due to suspected visual stress. Facial palsy care was more often prescribed in cases where the patient presented with both an ocular defect (lid) and reduced central vision (blurred vision from dry eye) simultaneously.

Table 8.1: The management options offered for central vision loss as a sole impairment.

Type of management	Number of patients offered management type (n)
Advice to attend own optician	6
Verbal advice	5
No management required	4
Referral to ophthalmologist	1
Treatment factsheet	1
Facial palsy care	1
Scanning exercises (gaze)	1
Requested glasses into hospital	1

Table 8.2: The management options offered for central vision loss when presented as with multiple visual impairments.

Type of management	Number of patients offered management type (n)
Verbal advice	78
Advice to attend own optician	23
Referral to ophthalmologist	7
Scanning exercises (gaze)	4
No management required	17
Typoscopes	6
Referral to ECLO	6
Referral to orthoptist	1
Treatment factsheet	5
Registration for certification of visual impairment	5
Read-right website	3
Facial palsy care	2
Referral to low vision aid clinic	1
Referral to local voluntary service	1
Infected eye treatment	4
Coloured overlay	1
Driving advice	4
Requested glasses into hospital	5
Prescription requested for dry eye drops	1
Other	3
Referral to hospital optometrist	4
Lid hygiene care	1

Where "other" has been reported, this was recorded as, change patient's bed position on ward (n=1) and management plan discussed with the other therapy staff (n=2).

Table 8.3: A comparison of the rehabilitation options offered for visual acuity defects identified in the literature with those used in the IVIS and VIS studies to display strength of evidence base

		Rehabilitation options identified in the literature search			
		Randomised control trials	**Prospective observational study**		
Rehabilitation options used in the IVIS study		Spectral filters	Refraction		Rehabilitation options used in the VIS study
	Refraction (optometry)	-	**√√**	Refraction	
	Typoscopes	-	-	Typoscopes	
	Low vision aids (ECLO)	-	-	Low vision aids	
	Lubricating drops	-	-	Lubricating drops	
	Spectral filters	**√**	-	-	
	Advice	-	-	Advice	
	CVI registration (ophthalmology)	-	-	-	
	Antibacterial drops	-	-	-	

√=visual screening tool referenced in either the IVIS study or the VIS study and reported in the literature; therefore, indicates an evidence base to support clinical use.
√√=visual screening tool referenced in both the IVIS study and the VIS study

The VIS study reported that refraction was used most frequently to treat reduced VA (n=50). Furthermore, low vision aids (n=2), typoscopes (n=1), and verbal advice (n=6) including recommendations of lighting, ensuring they have their glasses and eccentric viewing (in which the patient practices non-foveal viewing in cases of central scotoma) (455), were provided to the patients in the VIS study with reduced central vision. Additionally, one patient received lubrication for dry eye after a facial nerve palsy.

The results of the review conveyed the importance of ensuring stroke survivors have access to their glasses in hospital or receive retest for glasses after discharge (18). Additionally, the use of coloured overlays has been described in the literature in cases where reduced VA persists after refractive correction (133).

Magnifiers and reading aids have been reported in the literature as management options for reduced central vision. Although the management would be similar for those post-stroke, the use of these aids has not been validated within this population specifically.

8.3.2: Ocular alignment and motility defects

8.3.2.1: *The prevalence of eye movement defects in the IVIS study*

Forty-one stroke survivors in the IVIS study (2.7%) were identified as having an OM defect as their only post-stroke visual impairment, whilst 254 (16.9%) were found to have an OM defects as a multiple impairment. A further two patients were identified as having a pre-existent diagnosis of reduced OM alongside a new diagnosis of OM. Only one stroke survivor in the IVIS study was identified as having an ocular alignment (OA) defect as their sole visual impairment. However, 71 (4.7%) were found to have an OA defect as a multiple impairment. Only two stroke survivors in the IVIS study (0.1%) had a binocular single vision (BSV) defect, in relation to poor fusion or stereopsis, as their sole post-stroke visual impairment, whilst 94 (18%) presented with reduced BSV as part of a multiple impairment.

A further 433 stroke survivors were identified as having a pre-existent diagnosis of impaired eye movement or BSV alongside a new defect (OA n=81, OM n=224 and BV n=128).

8.3.2.2: *The results of the comparative review*

Table 8.4 shows the rehabilitation options offered in the IVIS study for individual visual impairments of OA or OM defects. Table 8.5 shows the interventions offered for all multiple impairments. Reduced OM, OA and BSV more often presented together (n=41 new diagnoses and n=59 new diagnoses alongside previous eye movement defects) and rehabilitation with occlusion and diplopia was offered more frequently to those with multiple impairments (Table 8.5). Where 25 patients with OM defects were referred to an optician (Table 8.5), this refers to prism incorporation and lens manipulation (to aid control of an ocular deviation and relieve symptoms). In addition, refraction was performed frequently on patients with all types of visual impairment and not only for those with reduced central vision, indicating that achieving best corrected VA was an important outcome for most patients.

Table 8.6 shows a comparison of the rehabilitation options offered to the stroke survivors from the IVIS study, the VIS study and those reported in the literature, to treat OA and/or OM defects. The IVIS study used a broad range of interventions for OA or OM defects to alleviate symptoms of double vision. These consisted of Fresnel prisms, vergence and duction exercises including pen convergence and dot-card exercises. Additionally, patients were offered a paper-based scanning therapy and "off-label" Read-right or Eye-search web-based training to aid reading difficulties as a result of defective saccadic eye movements.

Verbal advice included the use of an abnormal head posture for diplopia, and "steady-eye strategy" for reading impairment following impaired saccades. Steady-eye reading strategy involves the patient moving the page/book and keeping their eyes fixed in the primary position to engage their vestibular ocular movements as opposed to saccades. Typoscopes were offered to aid with reading difficulties following defective saccadic eye movements.

Table 8.4: The management options offered for sole eye movement defects in the IVIS study.

Type of management	Number of patients offered management for OA (n)	Number of patients offered management for OM (n)	Number of patients offered management for BV (n)
Verbal advice	*1*	*7*	*1*
No management required	*-*	*3*	*1*
Scanning exercises (gaze)	*-*	*2*	*-*
Eye-search website	*-*	*1*	*-*
Duction exercises	*-*	*1*	*-*
Advice to attend own optician	*-*	*6*	*-*
Referral to ophthalmologist	*-*	*1*	*-*
Infected eye treatment	*-*	*2*	*-*

Table 8.5: The management options offered for eye movement defects when presented with multiple visual impairments.

Type of management	***Number of patients offered management for OA (n)***	***Number of patients offered management for OM (n)***	***Number of patients offered management for BV (n)***
Verbal advice	25	78	42
Prisms for diplopia	10	10	6
Occlusion for diplopia	6	8	5
Pen convergence	1	2	1
Dot card exercises	1	1	1
Advice to attend own optician	4	25	9
Referral to ophthalmologist	3	8	4
Scanning exercises (gaze)	4	11	4
Typoscope	1	6	2
Referral to ECLO	1	8	1
Treatment factsheet	1	5	3
Registration for certification of visual impairment	1	4	-
Eye-search website	1	6	5
Read-right website	-	3	3
Facial palsy care	2	2	2
Infected eye treatment	1	4	-
Referral to low vision aid clinic	-	1	1
Referral to hospital optometrist	2	3	1
Requested glasses into hospital	1	2	3
Driving advice	-	5	-
No treatment required	7	21	9
Other	1	3	-

Where "other" has been reported, this was recorded as, steady eye strategy, referral to the stroke clinic, advice for adopting a head posture and emergency referral for urgent VA assessment.

Table 8.6: A comparison of the rehabilitation options for ocular motility defects identified in the literature with those used in the IVIS and VIS studies to display strength of evidence base

		Rehabilitation options identified in the literature search						
		Randomised control trials	**Prospective observational studies**		**Survey**			
Rehabilitation options used in the IVIS study		Pharmacological	Prisms	Occlusion	Orthoptic exercises	Advice		Rehabilitation options used in the VIS study
	Reading aids (ECLO)	-	-	-	-	-	Reading aids	
	Prisms	-	**√√**	-	-	-	Prisms	
	Lid taping for facial palsy	-	-	-	-	-	Yoked prisms	
	Occlusion	-	-	**√√**	-	-	Occlusion	
	Orthoptic exercises	-	-	-	**√√**	-	Orthoptic exercises	
	Advice	-	-	-	-	**√√**	Advice	
	Refraction	-	-	-	-	-	Refraction	
	Botulinum toxin	-	-	-	-	-	Botulinum toxin	
	Strabismus surgery	-	-	-	-	-	Strabismus surgery	
	Lubricating drops (for facial palsy)	-	-	-	-	-	Certification of visual impairment	
	Scanning therapy	-	-	-	-	-	-	
	Typoscopes	-	-	-	-	-	-	

√=visual screening tool referenced in either the IVIS study or the VIS study and reported in the literature; therefore, indicates an evidence base to support clinical use.
√√=visual screening tool referenced in both the IVIS study and the VIS study

Duction exercises were not often coded for the CRF, however, scanning exercises were advised more frequently. These were used in a similar manner as duction exercises to effectively encourage the patient to use weak extra-ocular muscles.

For those that presented with a combination of eye movement defects (Table 8.5) rehabilitation options included occlusion (partial, sector or total), and referrals to optometry services for prism incorporation to their refractive correction, to the ECLO for further advice and reading aids, or to ophthalmology for botulinum toxin and surgical management of persistent OM defects causing diplopia. In cases where the patient's OM defect was not recovering and required long-term orthoptic prism management, these patients were referred to the hospital's orthoptic department for continued care following cessation of the IVIS study.

Again, some patients developed dry eye or co-existent conjunctivitis during their hospital stay as a result of poor lid closure after a facial nerve palsy.

These patients were treated for conjunctivitis in the same method described for reduced central vision, however advice was also provided to patients and their family regarding lid closure and the use of lubricating eye drops. Referrals were made to ophthalmology where prescription of lubricating or antibacterial eye drops was required.

The most common intervention offered in the VIS study for OM defects was occlusion of one eye to eradicate diplopia (n=41), followed by prisms for diplopia (n=27), refraction (n=22), and orthoptic exercises (n=1). Advice was given to 33% (n=69) on lighting, head postures, reading aids, and improve awareness of visual status (5, 456). Moreover, certification of visual impairment registration was discussed as a further option for those whose eye movement restrictions impacted on daily activities (5).

Management of nystagmus largely consisted of alleviating the combined symptoms of diplopia, blurred vision and reading difficulties (456). No drug therapies were required for the management of oscillopsia in the VIS study.

Further options were discussed by the authors as potential alternative rehabilitation options but were not required for patients in the VIS study. These included yoked prisms (placed over both eyes which shift images towards a central position where there is an inability to move gaze in one direction), extra-ocular muscle botulinum toxin and surgery (5).

Few articles reported on OM treatment specifically after stroke. One Cochrane review discussed pharmacological interventions for post-stroke nystagmus as no randomised trials relating to restitutive, compensatory or substitutive methods were found for stroke populations with other OM disorders (27, 357, 358). It was reported that Gabapentin and Baclofen were used most often to treat symptoms of nystagmus, with both showing significant clinical benefits and yielding similar risk of side effects; although Gabapentin was estimated to be slightly more effective in improving VA than Baclofen (132).

Furthermore, prisms and occlusion have a supportive evidence base through numerous observation studies. Arguably, interventions such as prisms and occlusion for diplopia do not necessitate high-quality controlled trials to prove their efficacy as their effect on alleviating diplopia is clear-cut (27, 130). In a practice survey, Fresnel prisms to resolve the symptom of diplopia were identified as the most common management for post-stoke OM defects (93%) followed by advice on head postures (64%) and convergence exercises (50%) (134).

8.3.3: Visual field loss

8.3.3.1: *The prevalence of visual field loss in the IVIS study*

Twenty stroke survivors (1.3%) suffered VF loss as a sole post-stroke visual impairment, whereas 173 (11.5%) were found to have a VF defect as part of a multiple impairment. A further 126 stroke survivors were identified as having a pre-existent diagnosis of reduced VF.

8.3.3.2: *The results of the comparative review*

Table 8.7 shows the management options offered to stroke survivors in the IVIS study with only VF loss. Table 8.8 shows the broader range of rehabilitation options offered to these patients where VF presented with multiple other visual impairments. The information leaflets provided to patients with post-stroke VF loss provided were developed by BIOS (457) and differed from the treatment factsheets provided (8.3.1) as they contained specific information and signposted to resources for VF loss only.

The rehabilitation options for VF loss can be subcategorised into compensatory, substitutive and restitutive methods (338). Table 8.9 shows a comparison of the rehabilitation options offered for VF loss in the IVIS study, the VIS study and those reported in the literature.

8.3.3.3: *Compensatory therapies*

Compensatory therapies offered in the IVIS study included typoscopes, a paper-based scanning therapy (described previously), a web-based scanning therapy (Eye-search) and Read-right online training for reading difficulties due to hemianopia.

Verbal advice included the use of exaggerated head movements, vertical reading, the use of rulers and markers for reading, and organisation of the home/ward area to compensate for the VF loss. Verbal and written information was provided to drivers with VF loss, and patients were signposted to additional online resources, support groups and charity organisations. Information was further communicated to the ward staff to ensure medications, food and other items were placed in the patient's unaffected visual space. Referrals were made to the ECLO for further aids and advice, and to ophthalmology for registration of visual impairment where necessary.

Previously, the VIS study reported the use of the above methods, with advice as the most common approach (n=474). This consisted of raising awareness of the field loss, reading strategies, scanning eye and head movements, use of lighting, compensatory head posture and registration for visual impairment. There was a crossover between active training of scanning as a rehabilitation option and provision of advice on how to access and undertake home-based training.

Additional compensatory therapies used in practice included refraction (n= 85), low vision aids (n=20), typoscopes (n=42) and Orthoptic exercises targeting associated visual impairments (n=8).

The literature search found verbal or written advice was the most common strategy for VF loss in a survey in Scotland (134), while advice on head postures was reported as the second most common form of management in a Cochrane review (64%) (126). Additional methods identified through the review included computer and paper based scanning training programmes and word search games (126, 127, 313, 318). These included two free-to-access online computer-based scanning therapies; Eye-search (326) and Read-right (325). Moreover, verbal advice for compensation of the VF loss and registration for formal certification of visual impairment were reported by Freeman and Rudge (8).

8.3.3.4: *Substitutive management options*

Peli prisms were the only substitutive method used in the IVIS study and in the VIS study (6%, n= 29) (23). Likewise, Peli prisms were the only substitutive method identified from the literature search (129, 311).

Table 8.7: The management options offered for visual field loss only

Type of management	Number of patients offered management type (n)
Verbal advice	6
Scanning exercises (field)	7
Information leaflet	7
Typoscopes	1
Registration for certification of visual impairment	1
Read-right website	2
Referral to ECLO	1
Treatment factsheet	2
Other	1

Where "other" has been reported, this was documented as driving advice.

Table 8.8: The management options offered for visual field loss when presented with multiple visual impairments.

Type of management	Number of patients offered management type (n)
Verbal advice	67
Scanning exercises (field)	29
Advice to attend own optician	19
Information leaflet	67
Referral to ophthalmologist	8
Typoscopes	4
Referral to ECLO	10
Treatment factsheet	6
Registration for certification of visual impairment	4
Eye-search website	6
Read-right website	3
Vertical reading	4
Referral to low vision aid clinic	1
Facial palsy care	2
Peli prisms	1
No treatment required	11
Driving advice	8
Referral to local voluntary service	1

Table 8.9: A comparison of the rehabilitation options for visual field loss identified in the literature with those used in the IVIS and VIS studies to display strength of evidence base

		Rehabilitation options identified in the literature search							
		Randomised control trial			**Prospective observational study**	**Survey**			
Rehabilitation options used in the IVIS study		Visual search training	Peli prisms	Visual restoration therapy (VRT)	Certification of visual impairment	Reading aids	Advice		Rehabilitation options used in the VIS study
	Visual search training	**√√**	-	-	-	-	-	Visual search training	
	Peli prisms	-	**√√**	-	-	-	-	Peli prisms	
	Orthoptic exercises	-	-	-	-	-	-	Orthoptic exercises	
	Certification of visual impairment (ophthalmology)	-	-	-	**√√**	-	-	Certification of visual impairment	
	Vision aids (ECLO)	-	-	-	-	-	-	Low vision aids	
	Typoscopes	-	-	-	-	**√√**	-	Reading aids (including typoscopes)	
	Information leaflets	-	-	-	-	-	-	Refraction	
	Advice	-	-	-	-	-	**√√**	Advice	

√=visual screening tool referenced in either the IVIS study or the VIS study and reported in the literature; therefore, indicates an evidence base to support clinical use.
√√=visual screening tool referenced in both the IVIS study and the VIS study

8.3.3.5: *Restitutive treatments*

Both clinical studies did not report on restitutive therapies as this type of treatment was not offered in NHS centres (23). Visual restoration therapy (VRT) involves presenting a light stimulus within the area of VF loss (338). It has been found to provide a limited expansion of the VF in many of the reporting articles (144, 323, 330-332), although significant variations in length of treatment sessions suggests validation of this method is required through further research (310, 333, 335). No two studies prescribed exactly the same amount of training, rendering it difficult to make direct comparisons. Furthermore, the limited expansion of the VF along the border area may reflect improved micro-saccadic eye movements rather than true field improvement, as fixation was not monitored during VRT (329).

8.3.4: Visual perception (including management for visual neglect/inattention)

8.3.4.1: *The prevalence of visual perceptual defects, including visual neglect, in the IVIS study*

During the IVIS study, nine patients (0.6%) were found to have visual neglect (VN) as their sole post-stroke visual impairment, whilst 174 (11.6%) presented with VN as part of a multiple defect. In six cases, early assessment of VN was not possible, and so it was not possible to offer management until assessment could be completed with subsequent confirmation of the presence of VN. The information leaflet provided on post-stroke VN was developed by BIOS (457).

Only two (0.1%) patients were found to have a VP defect (other than VN) as their sole post-stroke visual impairment, whilst 36 (2.4%) presented with VP defects (other than VN) as multiple impairments. A further 164 stroke survivors were identified as having a pre-existing diagnosis of reduced VP (VN=142, other VP=22) through case history and medical note review: see 2.3.7 for method of investigation.

8.3.4.2: *The results of the comparative review*

Table 8.10 shows the management options offered to stroke survivors with VP disorders, including VN, during the IVIS study. The information leaflet provided on post-stroke VP disorders (Charles Bonnet syndrome and hallucinations) was developed by BIOS (457).

Table 8.10: The management options offered for solely visual perceptual defects (including visual neglect)

Type of management	Number of patients offered management for VN (n)	Number of patients offered management for VP (n)
Verbal advice	1	1
No management required	2	-
Information leaflet	2	-
Scanning exercises (gaze)	1	-
Scanning exercises (field)	2	-
Advice to attend own optician	1	1
Lid hygiene care	1	-
Infected eye treatment	1	-
Other	1	-

Where "other" has been reported, this was recorded as "referred to occupational therapists for cognitive assessment."

The vast majority (n=651) of patients in the IVIS study presented with multiple post-stroke visual impairments. Visual neglect and VF loss were often diagnosed alongside each other (n=112 new diagnoses and n=83 new diagnoses with co-existent field loss or neglect). Therefore, management for these conditions together was wider ranging than for a sole VP or VN deficit (see Tables 8.10-8.11).

Table 8.12 shows a comparison of the rehabilitation options offered to the stroke survivors from the IVIS study, the VIS study and those reported in the literature, to treat VP disorders including VN. These can be subcategorised again into substitutive, compensatory and restitutive (27).

8.3.4.3: *Compensatory therapies*

Compensatory therapies offered in the IVIS study for VP disorders included typoscopes, a paper-based scanning therapy (described previously), a web-based scanning therapy (EyeSearch), and written advice in the form of the BIOS resource leaflets on VN and Charles Bonnet syndrome (457).

Verbal advice included eye scanning and exaggerated head movements for VN and explanation and reassurance of additional VP disorders. Patients were also signposted to local charity organisations and referred to the ECLO and ophthalmologist where required for additional aids and certification of visual impairment.

The rehabilitation options offered in the VIS study for patients with VP disorders consisted of refraction (n=8) and advice (n=88). The perceptual specific interventions largely consisted of advice on scanning strategies, compensatory head postures and general awareness (458). For those with visual agnosia, patients benefitted from specific information along with compensatory strategies and for those with Charles Bonnet syndrome, reassurance and explanation that the visual hallucinations did not signify mental illness were extremely beneficial (458).

Most perceptual interventions identified through the search were for the management of VN. This is largely due to the reporting of VP disorders as individual case reports or case cohorts from individual clinic centres (138). A survey found non-computerised scanning training along with provision of aids and modifications were largely offered to treat VN (89%) (328).

Table 8.11: The management options offered for visual perceptual defects (including visual neglect) when presented with multiple visual impairments

Type of management	Number of patients offered management for VN (n)	Number of patients offered management for VP (n)
Verbal advice	70	15
No treatment required	16	2
Advice to attend own optician	17	10
Information leaflet	15	15
Referral to ophthalmologist	8	2
Scanning exercises (gaze)	7	2
Typoscopes	7	1
Referral to ECLO	9	4
Referral to orthoptist	-	1
Treatment factsheet	4	2
Registration for certification of visual impairment	5	3
Eye-search website	7	2
Read-right website	3	1
Vertical reading	4	3
Facial palsy care	2	1
Infected eye treatment	1	-
Requested glasses to hospital	2	-
Other	1	-

Where "other" has been reported, this was recorded as driving advice.

Table 8.12: A comparison of the rehabilitation options for visual perception defects (including visual neglect) identified in the literature with those used in the IVIS and VIS studies to display strength of evidence base

		Rehabilitation options identified in the literature search											
		Randomised control trial				**Prospective observational study**		**Survey**					
Rehabilitation options used in the IVIS study		Visual search training	Hemifield eye patching	Optokinetic stimulation (OKS)	Occlusion	Smooth pursuit therapy	Word recognition training	Prism adaptation	Reading aids	Typoscopes	Advice		Rehabilitation options used in the VIS study
	Visual search training	**√√**	-	-	-	-	-	-	-	-	-	Visual search training	
	Advice	-	-	-	-	-	-	-	-	-	**√√**	Advice	
	CVI registration	-	-	-	-	-	-	-	-	-	-	Certification of visual impairment	
	Information leaflets	-	-	-	-	-	-	-	-	-	-	Refraction	
	Typoscopes	-	-	-	-	-	-	-	-	**√**	-	-	
	Vision aids (ECLO)	-	-	-	-	-	-	-	**√**	-	-	-	

√=visual screening tool referenced in either the IVIS study or the VIS study and reported in the literature; therefore, indicates an evidence base to support clinical use.
√√=visual screening tool referenced in both the IVIS study and the VIS study.

One study found added benefits from smooth pursuit therapy when compared to standard scanning therapy (312). Additional compensatory methods found through the literature search included occlusion (136) and prism adaptation (137). Other perceptual treatments reported were typoscopes (134) and cross modal word recognition training for the management of alexia (138)

8.3.4.4: *Substitutive management options*

No substitutive therapies were offered in the IVIS study, such as monocular or sector occlusion.

The authors of the VIS study reported their awareness of the use of monocular or sector occlusion and prisms to treat VN but did not use these methods in their study population.

The literature search identified one study which compared "forced-use" therapies, hemifield eye patching and optokinetic stimulation (OKS) in which sector occlusion was placed over the non-neglecting side of lenses (135).

8.3.5: Unused treatments in the IVIS study

Prior to the IVIS study commencing, it was anticipated that additional treatments may be required and thus, these were given provisional codes for inputting onto the CRF if required (Appendix 2). However, in practice, the following interventions were not offered to patients during the study period: yoked prisms, stereogram cards and Fresnel prism bar exercises. Possible reasons for omitting these interventions may include a known lack of benefit through previous clinical experience, or the methods may have been considered too complex and lengthy for stroke survivors with co-existent defects such as cognitive impairment of fatigue (459, 460).

Yoked prisms aim to improve sensori-motor actions for patients with visual field loss and visual neglect, by reducing the abnormal, subjective sense of "straight-ahead" as the visual field shifts toward the prism apex (461). However, Bansal et al. (459) reported that one third of patients with acquired brain injury did not respond well to yoked prisms. Several possible suggestions and recommendations have been postulated, including lack of supportive evidence and therefore, lack of clinical

experience prescribing yoked-prisms (459), which could further explain their lack of use on the IVIS study. Furthermore, a minimal strength of Fresnel prisms is required to maintain visual clarity, as many patients complained of dizziness, nausea and walking into objects (459, 462). However, large strength prisms are required for patients with visual neglect (as they are often unaware of their visual condition), deeming this method counterproductive for neglecting patients (459). Furthermore, current evidence varies on the time allowed for patients to adapt to the yoked-prisms (ranging from one hour to fulltime wear incorporated into daily eyeglasses), which could explain the variation in favourable patient responses to this rehabilitation method (459, 463). Therefore, it is possible that clinicians' previous negative experiences, or perceived lack of benefit of this method without further, high-quality research, explicates non-prescription in the IVIS study.

Stereogram cards and Fresnel prims bar exercises aim to restore binocular control of the eyes to reduce symptoms of diplopia and asthenopia. Several limitations have been noted with these methods, including reliance of patient motivation and perseverance, and that convergent deviations do not respond well to this therapy (460), although reasoning for this is unclear from the research. Stroke patients may suffer from co-existent defects, such as cognitive impairment of fatigue, and thus they may not be able to maintain the necessary level of motivation and effort required to train with these methods. Furthermore, the lack of robust research, mostly consisting of retrospective analyses with small numbers, could hinder the clinician's use these orthoptic methods in practice.

Monocular and sector occlusion was used for relief of diplopia symptoms but not as a substitutive management of VN. As with the VIS study authors, the orthoptists in the IVIS study were aware of the use of this management option but did not offer it specifically. Advice was given, however, to reposition the patients' hospital beds and bedside tables to encourage gaze into the neglected side when the patient was no longer acutely unwell and was more receptive to therapy. At this point family members were advised to sit on the neglected side and encourage patients to move their heads to speak to family and hospital staff. This is theoretically similar to the sector occlusion or "forced-use" therapy for neglect. However, this advice appears to be based on clinical experience alone with no established evidence base,

furthering previous recommendations to widely disseminate effective findings to ensure equitable care for all stroke patients.

Additionally, low vision aids were coded as a potential rehabilitation option prior to the study commencement. However, in practice, the orthoptists did not prescribe the use of low vision aids and instead, any patient requiring aids was referred to the low vision clinic or the ECLO. The orthoptists were not aware of the outcome of these appointments in order to record the provision of low vision aids, as patients were often discharged from orthoptics following referral to these clinics. However, it is presumed that a number of patients would have been provided with them. Likewise, several patients required extra-ocular muscle surgery for persistent OM defects and were therefore, referred to the ophthalmologist for management.

These patients were usually discharged from the stroke/orthoptic clinics and followed up in the general orthoptic department after surgery. As the specialist orthoptists of the IVIS team did not have approval to assess patients or collect data outside of the stroke-specific pathway, outcomes from the general ophthalmology assessment could not recorded.

Botulinum toxin was used diagnostically in two cases to mimic the results of the extra-ocular muscle surgery and was therefore followed up in the research orthoptic clinics for investigation of eye position and to decide on further management. These two patients were then referred back to ophthalmology for surgical management but subsequently followed up in the general orthoptic clinic. Therefore, the number of patients receiving strabismus surgery during the IVIS study is likely to be underestimated.

8.4: Limitations

Due to the limited number of research groups investigating visual impairment after stroke, there were few articles to make direct comparisons to in this project. Therefore, perceived selection bias is likely and highlights the need for other

researchers to investigate this topic in order to generalise the findings from the IVIS study.

8.5: Summary

Inequalities identified in Chapter 3 regarding provision of visual care after stroke, and the lack of some visual rehabilitation options reported in Chapter 5, informed the research of this current chapter. Overall, the results of the comparative review have shown that most of the visual rehabilitation option identified in this chapter have a sufficient evidence base substantiated with non-stroke populations and there is unlikely to be a need for such evaluation within specific populations. However, the benefits of treating stroke survivors using these methods should be highlighted to appropriate audiences, namely those working within stroke care. Inequalities have been identified within the rehabilitation of each of the visual impairments specifically.

Spectral filters were not offered in the VIS study and were offered to only two stroke survivors in the IVIS study, despite their supportive evidence base. Peli prisms have an existing evidence base although were used less frequently in clinical practice compared with search strategies, indicating better compliance or success with the paper or web-based training methods. A broad range of VP disorders can occur following stroke, however very few rehabilitation options other than those for VN have been discussed in the current literature. It is possible that a number of interventions including verbal and written advice are being used in practice with no clear evidence base and as such, further research is required to establish these options and provide clear recommendations for practicing clinicians to replicate these methods.

This research has been published elsewhere; see*: Hanna, KL & Rowe, FJ, 2017. Clinical versus evidence-based rehabilitation options for post-stroke visual impairment. Neuro-ophthalmology; 41(6): 297-305.*

Chapter 9: Health inequalities in attending outpatient hospital appointments after stroke

9.1: Background

Through the clinical follow-up of patients discharged from the acute stroke units with persistent visual impairments that required hospital follow-up (n=486), it was observed that 41% of patients (n=200) did not attend (DNA) or cancelled their ophthalmology appointments. The hospital protocol at all three sites informed that patients are routinely discharged from the outpatient department after two consecutive missed appointments. If the patient contacted the hospital in advance of their appointment, an additional appointment would be offered.

Non-attendance at outpatient appointments is detrimental to hospitals (464, 465). It results in inefficient use of staff and clinical resources, increased waiting lists and subsequent delays in patient treatment (465). The resulting high cost of missed clinic appointments has been documented (465-467) and some studies have attempted to identify patterns in non-attendance in order to target those most liable and improve attendance.

A study exploring wasted appointments in neurology and orthopaedic outpatient clinics reported no significant differences between time of day and attendance (468). However, a separate study investigated factors affecting non-attendance in an ophthalmology department in Liverpool, England, which reflects the patient demographic of the IVIS cohort. The authors reported that patients were more likely to DNA afternoon appointments as opposed to morning appointments (465), and review patients are more likely to DNA than new patients (465, 469). The authors did not investigate the patients' reasons for non-attendance due to the retrospective nature of the study, although, identifying patterns can inform the future planning of

clinics (465). This can be further aided by identifying particular patient cohorts who are least likely to attend.

These demographics include males (469-471), younger patients (<40 years old) (469-471), and those living in urban areas (469, 471), which subsequently highlights a potential health inequality amongst these groups. However, patient age has been contested in the literature, in relation to accessing services. Younger patients are frequently identified as poorer outpatient attenders in the published literature, although one study reported that patients over the age of 80 were just as likely to DNA due to health problems (472), which should be considered in the current stroke study population. Furthermore, inequalities accessing stroke services in older age groups was reported due to clinician "ageism", allocating resources to younger patients when services were stretched, due to a presumed greater need in the younger groups (473).

Other studies have explored patients' motives for non-attendance and often the reason is simply that the patients have forgotten about their appointment (467, 474, 475). Additional reported causes include clinical errors, patient or relative was unwell, their condition improved, hospital transport did not arrive, their appointment clashed with another hospital appointment and bad weather (475).

This chapter considers the factors affecting non-attendance of ophthalmology outpatient appointments at the three hospital sites. Additionally, documentation of specific patient demographics will ascertain whether or not higher rates of nonattendance are more prevalent in certain subgroups, with the ultimate purpose of identifying those patients most at risk and potential methods of overcoming these barriers.

9.2: Methods

Routine clinical practice at each site included contacting non-attending patients by phone that were deemed "at risk" to explore support options or alternative means of attendance. Patients were contacted by telephone by the clinical orthoptists if they cancelled or failed to attend two consecutive outpatient appointments, and

would therefore be routinely discharged. These phone conversations were conducted in order to identify reasons for non-attendance and potentially offer alternative arrangements, and complied with normal orthoptic practice within the three hospital sites.

The full methodologies for this section of the PhD research has been described in detail in 2.1.14. A Directed Acyclic Graph (DAG) was created to systematically organise confounding variables and minimise bias. The justification and process involved in developing the DAG has been described in 2.3.8.2. The finished DAG for Chapter 9, and topological ordering of the variables, are described below (9.3.1).

9.3: Results

From the 1500 stroke admissions in the IVIS study, 607 were discharged from one of the three hospital sites with persistent visual impairment. A total of 486/607 (80%) were offered an orthoptic appointment following discharge from the stroke unit, whilst 121 (20%) were deemed unsuitable for follow-up and were never offered an appointment by the clinical orthoptist.

Of the 486 offered an appointment, 289 (59%) of stroke survivors attended their appointments, whilst 197 (41%) cancelled (n=95, 19.5%) or failed to attend (n= 102, 21%) their outpatient appointments due to a wide range of reasons which have been discussed in the results of the telephone conversations (sections 9.3.5.1, 9.3.6.1 and 9.3.7.1). One patient did not attend an appointment and later cancelled another appointment requesting no further follow-up and therefore, was counted as both a DNA and cancellation in the above numbers. The breakdown of non-attendance across the three hospital sites is reported in Figure 9.1 and the reasons for non-attendance have been discussed separately for the entire cohort recruited and per hospital site; see 9.3.4-9.3.7.

9.3.1: Patient demographics as predictors of poor outpatient attendance

The demographics of those that were discharged and offered an appointment (n=486, 80%) and those not offered an appointment (n=121, 20%) were investigated

to identify any significant differences which may suggest a health inequality within a particular group. Of those offered a follow-up appointment (n=486), an analysis was conducted between those that attended their appointments (n=289, 59.4%) and those that did not attend (n=196, 40.3%) (cancelled/DNA). The DAG shown in Figure 9.2 displays the possible confounding variables when exploring the effect of patient demographics on outpatient attendance of orthoptic/stroke appointments. Many of the biasing lines shown in Figure 9.2 have been described previously; see 6.3. See 2.3.10.1 for further information on the DAG development.

Chapter 3 described further health inequalities relating to access to hospital services. Previous research found that females were less likely to be offered an optometry appointment (240) and older patients were less likely to be offered post-stroke follow-up appointments (242), which describes the causal pathways shown in Figure 9.2. Moreover, lower socioeconomic status (SES) led to poor attendance of optometry services, which was thought to be as a result of the perceived high costs of eye services (234). Patients residing in urban areas have also been found to have poorer outpatient attendance compared to those living in suburban areas (469, 471). The potential effect of ethnicity on outpatient attendance was explored, as it is possible that issues, which have been previously identified in the literature for non-stroke/vision appointments (476, 477), may still apply to the current study cohort. These issues include written and spoken language barriers, and religious holidays (476, 477).

The potential effect of Barthel index on outpatient attendance was further explored, as it was assumed that patients with additional health problems may struggle to attend the hospital. The results reported in 6.3 highlighted a relationship between low Barthel indices and residing in supportive living following stroke, therefore, patients residing in nursing homes may be at risk of the same difficulties. Furthermore, in these cases, the nursing homes are expected to take on the role of ensuring the patients attend their appointments, which may cause some additional biases (478). Therefore, discharge destination was also included in the following analyses to explore potential problems in attending hospital from various areas of residence.

Figure 9.1: Flow diagram to show the spread of attendance across all hospital sites, of those stroke survivors offered an outpatient appointment.

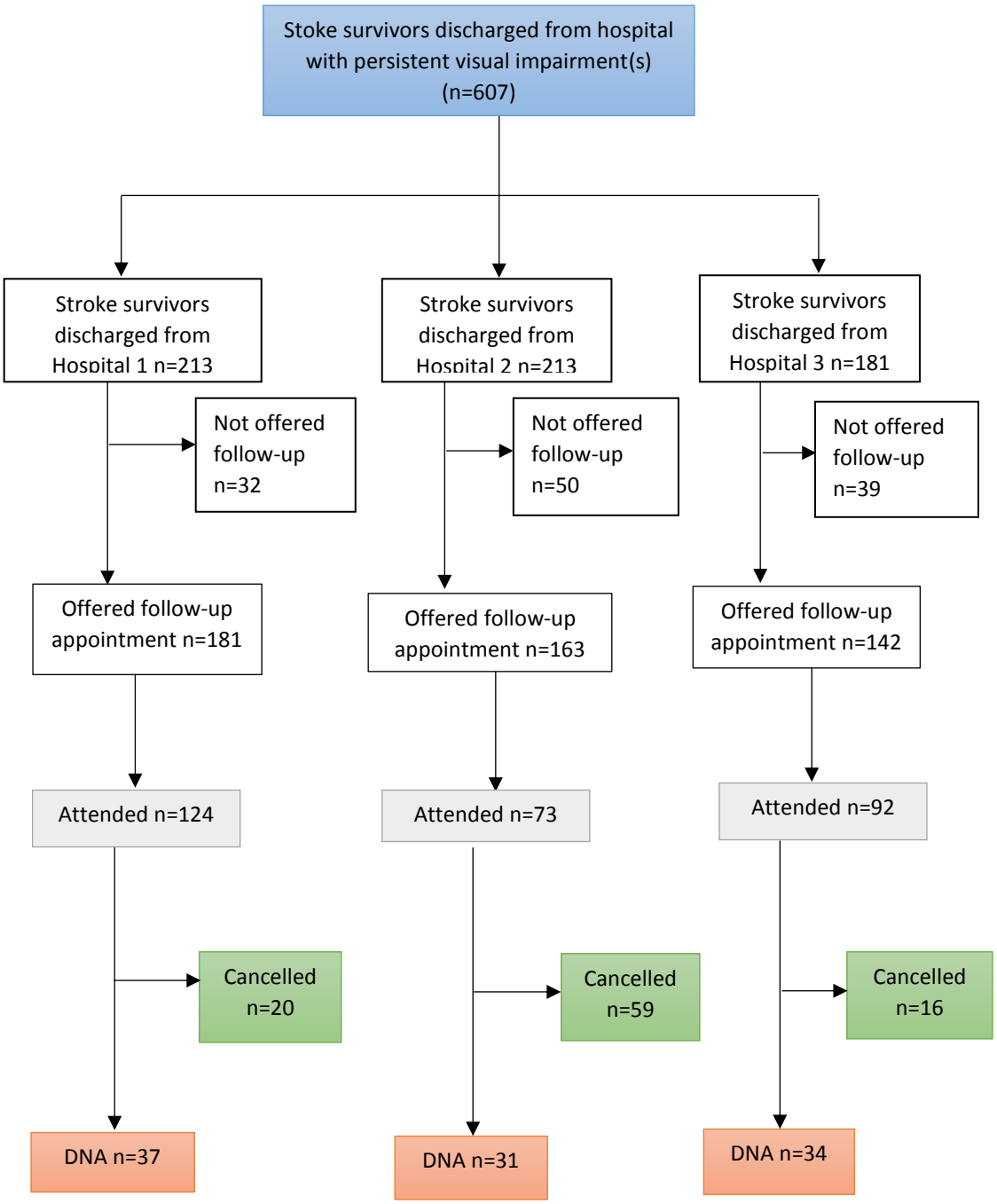
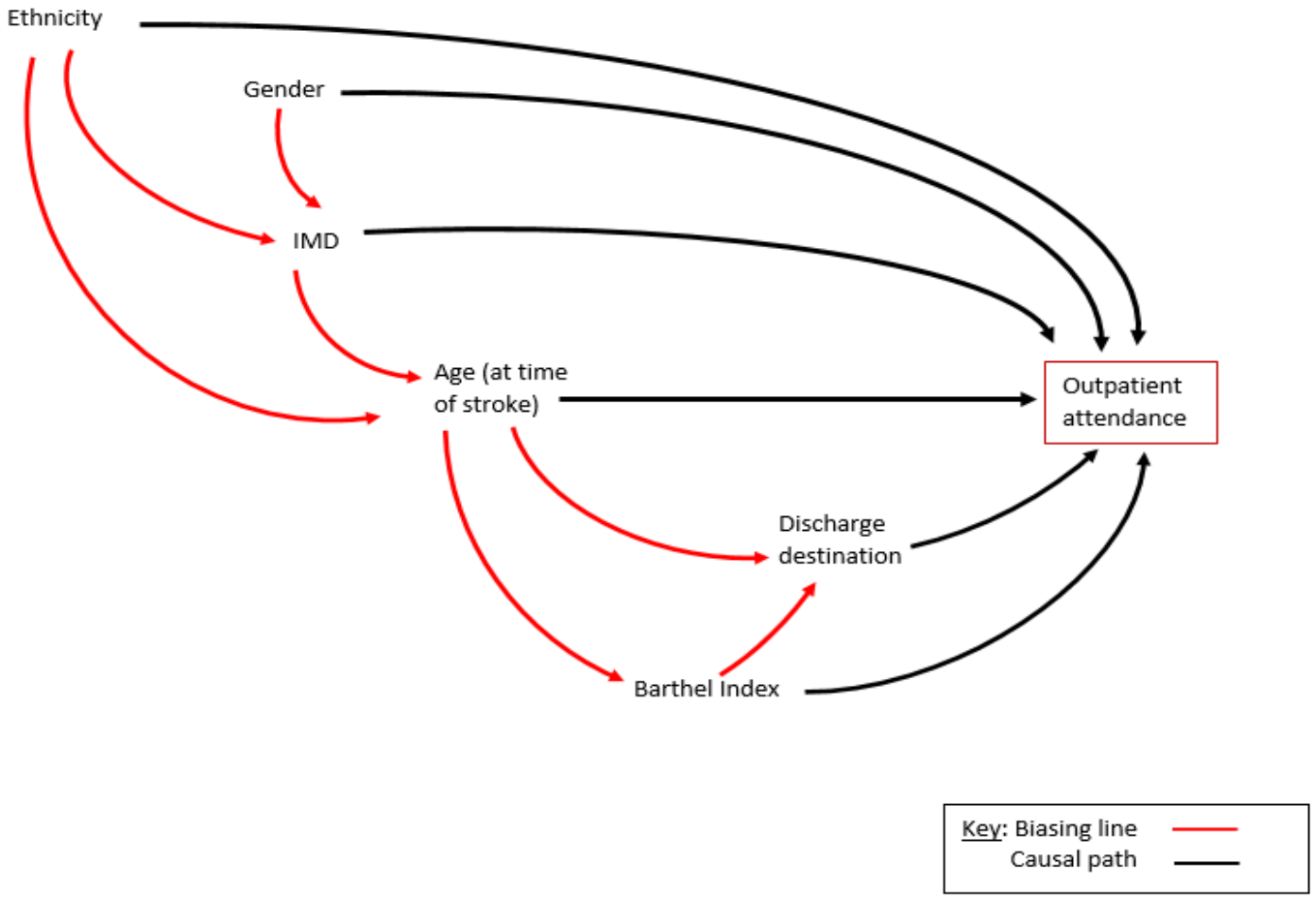


Figure 9.2: Directed acyclic graph illustrating the causal pathways of outpatient hospital attendance following stroke



Legend: A biasing line indicates a potential confounding affect from one demographic factor to another. A causal path indicates a direct affect from the demographic factor to the outcome variable (outpatient attendance).

There was no reason to believe that area of stroke would affect outpatient attendance from previous evidence, and so this variable has not been added to the DAG. The factors identified as potential confounding variables have been adjusted for in the following binary and multinomial logistic regression analyses; see 9.3.1.1-9.3.1.7.

As with Chapter 6, ethnicity has been excluded from further regression analyses due to the extremely small numbers of ethnic minorities, which skews the overall data results.

9.3.1.1: *Hospital site*

The hospital sites were initially analysed to identify any significant differences between the sites in relation to appointments offered and attendance, which may lead to conducting separate analyses of the demographic factors. The findings showed overall generalisability of the three hospital sites and the surrounding areas. There were no significant differences in relation to being offered an outpatient appointment (p=0.071); see Table 9.1. Although Hospital 2 had a larger proportion of cancelled appointments (61.7%) compared to Hospital 1 and Hospital 3 (see Table 9.2), overall, the differences were not statistically significant (p=0.385). Therefore, the patients recruited from the three hospital sites have been combined as one cohort for further demographic analyses.

9.3.1.2: *Age*

The average age of those offered an appointment and those not offered an appointment was 72.0 (±13.3) and 79.4 (±11.7) years respectively. Patient age was analysed with an independent samples t-test, which revealed significance in relation to appointments offered: p=<0.001 (difference in age between the two groups=7 years, CI: -9, -5). Those not offered an appointment tended to be older whereas, those offered appointments showed an equal spread overall across the various age groups.

Patient age was further found to be significantly associated with attendance of hospital appointments (p=<0.001).

Table 9.1: The differences between hospital sites in outpatient appointments offered to stroke survivors.

	Offered an appointment (n)		*Not offered an appointment (n)*	
Hospital 1	181	**37.3%**	32	**26.4%**
Hospital 2	162	**34.6%**	50	**41.3%**
Hospital 3	142	**29.3%**	39	**32.2%**
Total	485	**80.0%**	121	**20.0%**

Table 9.2: The spread of hospital outpatient attendance between the three hospital sites.

	Appointment attended (n)		*Appointment not attended (n)*		*Appointment cancelled (n)*	
Hospital 1	124	**42.9%**	37	**36.3%**	20	**21.3%**
Hospital 2	73	**24.3%**	31	**30.4%**	58	**61.7%**
Hospital 3	92	**31.8%**	34	**33.3%**	16	**17%**
Total	289	**60.0%**	102	**21.0%**	94	**19.4%**

Age at time of stroke was adjusted for IMD and gender in a multi-nomial regression, as per the DAG (Figure 9.2). Appointment attended was used as the reference category in this analysis due to higher numbers. This gave an adjusted p-value of 0.294 (OR: 1.010, 95% CI: 0.992-1.028) for DNA, and p=0.001 (OR 1.037, 95% CI: 1.015-1.059) for appointment cancelled. This showed significance for cancelled appointments only after adjustment for confounding variables.

The mean age of those that attended was 70.5 years (±12.5), whilst the mean age of those that did not attend was 72.2 years (±14.2) and those that cancelled were 76.4 (±12.5). There were no missing values for patient age across the three sites. Overall, those that did not attend or cancelled their appointments were older than those that attended.

9.3.1.3: *Ethnicity*

Table 9.3 shows the various ethnicities of those offered an appointment and those not offered an appointment across the three hospitals. It was not possible to obtain the ethnicity of one stroke survivor. Statistical analysis could not be performed between the various ethnic groups, as there were too many categories with extremely small numbers for accurate comparisons between hospital sites (see 6.1.1).

Table 9.4 shows the differences in ethnicity between those that attended appointments and those that did not. As small numbers of non-White ethnicities were recruited (4.3%) compared to the White British stroke survivors (94.7%), it is difficult to determine whether appointment attendance differs significantly between ethnic groups, or whether or not non-white ethnic groups are at risk of poorer stroke outcomes and subsequently, less likely to be offered an outpatient appointment for their visual impairments.

Table 9.3: The ethnicities of those stroke survivors offered and those not offered a follow-up appointment.

Ethnicity	*Offered an appointment (n)*		*Not offered an appointment (n)*		Total	
White British	463	**95.4%**	110	**91.6%**	573	**94.7%**
Irish	4	**0.82%**	2	**1.6%**	6	**1%**
Any other white ethnicity	10	**2%**	1	**0.83%**	11	**1.8%**
White and Black Caribbean	0	**-**	1	**0.83%**	1	**0.2%**
White and Black African	1	**0.2%**	1	**0.83%**	2	**0.3%**
Indian	2	**0.4%**	2	**1.6%**	4	**0.7%**
Pakistani	1	**0.2%**	3	**2.5%**	4	**0.7%**
Chinese	2	**0.4%**	0	**-**	2	**0.3%**
Other	1	**0.2%**	0	-	1	**0.2%**
Total	**485**	**80.2%**	**120**	**19.8%**	**605**	**-**

Where "other" was documented for one stroke survivor, this was recorded as Asian ethnicity in the hospital case notes.

Table 9.4: The ethnicities of those stroke survivors who attended and those that did not attend their follow-up appointments.

Ethnicity	*Appointment attended (n)*		*Appointment not attended (n)*		*Appointment cancelled (n)*	
White British	279	**96.9%**	95	**93.1%**	88	**94.6%**
Irish	0	**-**	1	**1%**	3	**3.2%**
Any other white ethnicity	4	**1.4%**	4	**3.9%**	1	**1%**
White and Black African	1	**0.3%**	0	**-**	0	**-**
Indian	2	**0.6%**	0	**-**	0	**-**
Pakistani	1	**0.3%**	0	**-**	0	**-**
Chinese	1	**0.3%**	1	**1%**	0	**-**
Other	0	**-**	0	**-**	1	**1%**
Total	**288**	**60.0%**	**102**	**21.1%**	**93**	**19.3%**

Where "other" was documented for one stroke survivor, this was recorded as Asian ethnicity in the hospital case notes.

Table 9.5: The gender of those offered and not offered an orthoptic follow-up at all sites.

Gender	*Appointment offered (n)*		*Appointment not offered (n)*	
Males	256	**52.8%**	51	**42.2%**
Females	229	**47.2%**	70	**57.8%**
Total	485	**80.0%**	121	**20.0%**

Table 9.6: The gender of those that attended, cancelled or did not attend their orthoptic follow-up at all sites.

Gender	*Appointment attended (n)*		*Appointment not attended (n)*		*Appointment cancelled (n)*	
Males	165	**57%**	47	**46.5%**	43	**45.7%**
Females	124	**42.9%**	54	**53.5%**	51	**54.3%**
Total	289	**60.0%**	101	**20.9%**	94	**19.5%**

9.3.1.4: *Gender*

More males than females were offered an outpatient orthoptic appointment (52.8% vs. 47.2%), and a higher number of females than males, that were discharged with persistent visual impairments, were not offered an outpatient appointment (57.8% versus 42.2%). The findings were found to be statistically significant (p=0.042) indicating a health inequality facing female stroke survivors with visual impairments; see Table 9.5.

To explore a reason for this finding, gender was analysed, adjusting for age, Barthel index, the IMD deciles and discharge destination. The results found that IMD was not significantly associated with gender (p=0.638), however, Barthel index, age and discharge destination were significant (p=<0.001 each). More females than males had a Barthel index of zero (30% versus 20%), whilst more males than females had a Barthel index of 20 (22% versus 13%).

However, the association between appointment attendance and gender showed no significant differences in the numbers of males and females attending, cancelling or not attending their appointments (p=0.068): see Table 9.6.

9.3.1.5: *The Index of Multiple Deprivation (IMD)*

No significant findings were identified between IMD decile and whether or not a patient was offered an appointment (p=0.470). Table 9.7 displays the IMD for both groups. It was not possible to obtain a postcode, or a valid IMD decile, which matched the postcode provided for 24 stroke survivors across the three hospital sites.

Furthermore, the IMD deciles for those that attended and failed to attend their appointments are shown in Table 9.8. There were no significant findings between hospital outpatient attendance and deprivation: p=0.487 (see 9.3.1). The IMD decile at time of stroke was adjusted for gender as per the DAG (Figure 9.2). Table 9.9 shows the results of the multinomial regression analyses. The IMD deciles were not found to be significant, and therefore, would not be considered a predictor of hospital attendance after stroke.

Table 9.7: The IMD scores of those stroke survivors who were offered and those not offered a follow-up appointment.

Index of multiple deprivation		*Offered an appointment (n)*		*Not offered an appointment (n)*	
Least deprived	10	18	**3.9%**	4	**3.1%**
	9	28	**6%**	10	**8.5%**
	8	43	**9.2%**	8	**6.8%**
	7	28	**6%**	3	**2.6%**
	6	35	**7.5%**	12	**10.3%**
	5	40	**8.6%**	19	**16.3%**
	4	43	**9.2%**	8	**6.8%**
	3	29	**6.2%**	8	**6.8%**
Most deprived	2	61	**13.1%**	16	**13.7%**
	1	140	**30.1%**	29	**24.8%**
	Total	465	79.9%	117	**20.1%**

Table 9.8: The IMD scores of those stroke survivors who attended and those that did not attend a follow-up appointment across the three hospital sites.

Index of multiple deprivation		*Appointment attended (n)*		*Appointment not attended (n)*		*Appointment cancelled (n)*	
Least deprived	10	9	**3.3%**	4	**4%**	5	**5.7%**
	9	21	**7.6%**	3	**3%**	4	**4.6%**
	8	27	**9.8%**	9	**8.9%**	7	**8%**
	7	17	**6.2%**	4	**4%**	7	**8%**
	6	22	**8%**	8	**7.9%**	5	**5.7%**
	5	27	**9.8%**	8	**7.9%**	5	**5.7%**
	4	22	**8%**	12	**11.9%**	9	**10.2%**
Most deprived	3	16	**5.8%**	5	**5%**	8	**9.1%**
	2	32	**11.6%**	13	**13%**	16	**18.2%**
	1	83	**30%**	35	**35%**	22	**25%**
	Total	276	**59.4%**	101	**21.7%**	88	**18.9%**

A lower IMD value (closer to 1) represents a more socially deprived area. A higher value (closer to 10) represents a more affluent area of residence.

Table 9.9: Multinomial logistic regression analysis for IMD, adjusting for gender.

	Variables	P-Value	Likelihood of predictor (odds ratio) Exp(B)	95% CI for EXP(B)	
				Lower	Upper
Cancelled	**IMD decile** (compared against decile 10)				
	IMD decile 1	0.257	0.501	0.152	1.655
	IMD decile 2	0.883	0.911	0.260	3.184
	IMD decile 3	0.897	0.912	0.227	3.659
	IMD decile 4	0.695	0.764	0.199	2.935
	IMD decile 5	0.149	0.342	0.080	1.466
	IMD decile 6	0.258	0.429	0.099	1.860
	IMD decile 7	0.695	0.755	0.184	3.087
	IMD decile 8	0.293	0.477	0.120	1.893
	IMD decile 9	0.189	0.357	0.077	1.658
DNA	**IMD decile** (compared against decile 10)				
	IMD decile 1	0.998	1.002	0.287	3.490
	IMD decile 2	0.911	0.926	0.241	3.565
	IMD decile 3	0.670	0.714	0.151	3.374
	IMD decile 4	0.726	1.279	0.322	5.074
	IMD decile 5	0.604	0.686	0.165	2.848
	IMD decile 6	0.840	0.862	0.205	3.623
	IMD decile 7	0.453	0.540	0.108	2.702
	IMD decile 8	0.714	0.769	0.189	3.131
	IMD decile 9	0.208	0.337	0.062	1.832

9.3.1.6: *The Barthel index*

Table 9.10 shows the mean Barthel indices at time of hospital admission for patients offered and not offered a hospital appointment. It was not possible to obtain a Barthel index for 91 stroke survivors at the time of hospital admission. Of these 91, some were assessed with a Barthel index on the ward several weeks following the stroke, and as such, these scores could not be included with the rest of the cohort due to possible recovery of stroke disabilities by the time the score was recorded. It was found that those with a higher Barthel score (fewer stroke disabilities) were more likely to be offered an appointment and those with a lower Barthel score (more severe stroke) were less likely to be offered an appointment (p=<0.001, Kruskal-Wallis test).

An association between Barthel index and age was later explored in relation to outpatient appointments offered, using a binary logistic regression, which showed significant relations between age and Barthel: p=<0.001 (OR: 0.877, CI: 0.845-0.909).

Additionally, a significant association was identified with Barthel index and attendance (p=<0.001, Kruskal-Wallis t-test). Table 9.11 shows the mean Barthel scores (at time of hospital admission) assigned to patients that did not attend their appointments and those that did attend. It was not possible to obtain a Barthel index at the point of hospital admission for 57 of the stroke survivors at Hospital 1.

The Barthel indices at hospital admission were adjusted for gender, IMD and age, as per the DAG (Figure 9.2). This gave an adjusted p-value of <0.001 (OR: 0.878, CI: 0.843-0.915) for DNA and p=<0.001 (OR: 0.906, CI: 0.868-0.945) for cancelled appointment, using "appointment attended" as the reference category.

Patients with a higher Barthel index (fewer stroke disabilities) were significantly more likely to attend their appointments, whilst those with a lower index (more severe stroke) were likely to not attend. After adjustment of the potential confounding factors, the results suggest that Barthel index could be considered a predictor of poor hospital outpatient attendance following discharge from the acute stroke unit. Furthermore, age was the only demographic factor significantly associated with Barthel index (p=0.010, OR: 1.013, CI: 1.007-1.056). Therefore, older age was seen to correlate with a lower Barthel index (poor stroke outcome) and poor attendance of outpatient appointments.

Table 9.10: The Barthel indices of those stroke survivors who were offered and those not offered a follow-up appointment across all three hospital sites

Barthel index at hospital admission	*Offered an appointment (n)*	*Not offered an appointment (n)*	Total
Mean	12.44	5.10	10.9
Standard deviation	7.14	6.53	7.63

Table 9.11: The Barthel indices of those stroke survivors who attended and those that did not attend a follow-up appointment across the three hospital sites.

Barthel index at hospital admission	Appointment attended (n)	Appointment not attended (n)	Appointment cancelled (n)	Total
Mean	14.80	8.71	9.45	12.4
Standard deviation	6.12	7.49	6.81	7.14

9.3.1.7: *Discharge destination*

Discharge destination was found to be significantly associated with being offered an appointment. Table 9.12 shows the discharge destinations for patients offered an appointment and those not offered an appointment. It was not possible to obtain a discharge destination for 121 patients across the three sites. In these cases, the discharge destination was not recorded in the hospital case notes or on the patient's discharge letter. Analysis showed that those discharged home were more likely to be offered an outpatient appointment (p=<0.001, chi-squared test).

Associations between discharge destination and IMD, gender, Barthel index and age were explored in relation to outpatient appointments offered, using a binary logistic regression (see Table 9.13). A significant association was noted for Barthel index (p=<0.001). However, gender, age and IMD were not significantly associated with discharge destination and being offered an outpatient appointment; see Table 9.13.

Furthermore, discharge destination was not found to be significantly associated with attending an appointment (p=0.127, chi-squared test): Table 9.14.

It was not possible to analyse each discharge destination in a regression analysis due to the small numbers in categories "intermediate/respite care", "never discharged/died in hospital" and "living with family." Therefore, these categories were combined with the category "discharged to a nursing home" to form a new category called "discharged to supportive living."

After adjustment for gender, age, IMD, and Barthel index, as per the DAG (Figure 9.2), the discharge destination "discharged to supportive living" was found to be significant in relation to attendance. Table 9.15 shows the results of the multinomial regression analysis, which used "appointment attended" as the reference category. Supportive forms of living would therefore, be considered a predictor of hospital attendance after stroke.

Table 9.12: The discharge destinations of those stroke survivors who were offered and those not offered a follow-up appointment across all three hospital sites

Discharge destination	*Offered an appointment (n)*		*Not offered an appointment (n)*	
Home	277	**74.5**	33	**27.3**
Intermediate/respite care	12	**3.2**	3	**2.5**
Nursing home	57	**15.3**	58	**47.9**
Never discharged/died in hospital	3	**0.8**	1	**0.8**
Living with family	8	**2.2**	14	**11.6**
Other	15	**4**	12	**9.9**
Total	372	**75.5%**	121	**24.5%**

Where "other" was documented for 27 stroke survivors, this was recorded as an out of area address (n=9), repatriated to another NHS hospital in the same area (n=6), repatriated to another NHS hospital out of area (n=5), a 24-hour care home (n=2), mental health unit (n=2), a rehabilitation unit out of area (n=1) and a hospice (n=1).

Table 9.13: Results of the multinomial regression analysis for discharge destination, when adjusted for IMD, age and Barthel index.

Variables	P-Value	Likelihood of predictor (odds ratio) Exp(B)	95% CI for EXP(B)	
			Lower	Upper
Barthel index	<0.001	0.907	0.869	0.947
Age	0.128	1.018	0.995	1.041
Gender	0.746	1.095	0.632	1.899
IMD decile (compared against decile 10)				
IMD decile 1	0.697	1.339	0.308	5.825
IMD decile 2	0.400	1.937	0.415	9.034
IMD decile 3	0.351	2.251	0.409	12.389
IMD decile 4	0.997	1.004	0.192	5.242
IMD decile 5	0.168	2.982	0.632	14.073
IMD decile 6	0.550	1.653	0.318	8.585
IMD decile 7	0.793	0.766	0.104	5.615
IMD decile 8	0.692	1.402	0.264	7.450
IMD decile 9	0.380	2.185	0.381	12.522

Table 9.14: The discharge destinations of those stroke survivors who attended and those that did not attend a follow-up appointment across the three hospital sites.

Discharge destination	Appointment attended (n)		Appointment not attended (n)		Appointment cancelled (n)	
Home	180	**85.3%**	43	**53.8%**	54	**65.9%**
Intermediate/respite care	4	**1.9%**	6	**7.5%**	2	**2.4%**
Nursing home	15	**7.1%**	23	**28.8%**	20	**24.4%**
Never discharged/ died in hospital	2	**0.9%**	2	**2.5%**	1	**1.2%**
Living with family	5	**2.4%**	0	**-**	1	**1.2%**
Other	5	**2.4%**	6	**7.5%**	4	**4.9%**
Total	**211**	**56.6%**	**80**	**21.4%**	**82**	**22.0%**

Where "other" was documented for 15 stroke survivors, this was recorded as repatriated to another NHS hospital in the same area (n=5), repatriated to another NHS hospital out of area (n=9), and discharged to an "out of area" address (n=1).

Table 9.15 Multinomial regression analyses for discharge destination, adjusting for gender, age, Barthel index and IMD.

	Variables	P-Value	Likelihood of predictor (odds ratio) Exp(B)	95% CI for EXP(B)	
				Lower	Upper
Cancelled	**Discharge destination** (compared against "home")				
	Discharged destination (supportive living) • intermediate/respite care, • nursing home, • living with family	0.890	1.064	0.441	2.568
	Discharge destination (died in hospital/never discharged)	0.751	0.674	0.059	7.751
	Discharge destination (other)	0.390	2.166	0.372	12.605
DNA	**Discharge destination** (compared against "home")				
	Discharged destination (supportive living) • intermediate/respite care, • nursing home, • living with family	0.005	3.290	1.421	7.616
	Discharge destination (died in hospital/never discharged)	0.871	0.818	0.073	9.156
	Discharge destination (other)	0.187	3.024	0.584	15.646

9.3.2: Previous ocular history as a predictor of poor outpatient attendance

Information was recorded regarding the patient's known need for glasses, and whether or not they had attended their opticians routinely for an up-to-date glasses prescription and ocular health check. Of the 485 patients requiring an orthoptic outpatient appointment at all sites, 371 of these required eyeglasses (13 did not require glasses and 28 did not know). However, only 54% (n=202) had been to the opticians in the last 18 months (124 had not been to the opticians in the last 18 months and 65 did not know).

The difference between attending and not attending routine optometry examinations prior to stroke and attendance of the orthoptic outpatient appointments during the IVIS study period was found to be significant (p=<0.001, chi-squared test); see Table 9.16. If the patient had been to the opticians in the last 18 months and had an up to date pair of glasses, indicating good eye care and appointment attendance prior to their stroke, then they were significantly more likely to attend their follow-up orthoptic appointment.

This association was further explored between each hospital site, which revealed significant associations between Hospitals 1-3: p=0.000, p=0.039 and p=0.033 respectively, chi-squared test.

9.3.3: Concluding remarks

Overall, males, younger patients (<65 years old), those discharged home and those with a Barthel index of 20 were significantly more likely to be offered a follow-up appointment. The IMD deciles were not found to be significant, whilst ethnicity could not be accurately analysed in relation to appointments offered and appointments attended due to the small numbers of minority ethnicities recruited from each of the hospital sites. Therefore, it cannot be concluded that no particular ethnic group faces increased difficulty in attending outpatient appointments following stroke.

The demographics significantly associated with poor outpatient attendance were older age and a low Barthel index, and the two factors were significantly associated with one another. Additionally, it was identified that patients with a previously poor attendance of optometry services are at a greater risk of not attending their post-stroke outpatient appointment. This group is therefore at greater risk of health inequalities. A full discussion outlining the health inequalities identified from this chapter are reported later in 9.5.

Table 9.16: The outpatient attendance rates depending on previous attendance of optometry examinations

Has been to the opticians in the past 18 months	Appointment attended (n)		Appointment not attended (n)		Appointment cancelled (n)	
Yes	148	**55.8%**	30	**44.1%**	24	**41.4%**
No	94	**35.5%**	16	**23.5%**	14	**24.1%**
Unknown	23	**8.7%**	22	**32.4%**	20	**34.5%**
Total	**265**	**67.8%**	68	**17.4%**	58	**14.8%**

9.3.4: Reasons for non-attendance at all hospital sites

The overall rate of non-attendance for the orthoptic-stroke outpatient clinics hospital was 40.5% (20.4% cancelled and 21% DNA). Despite the larger number of non-attending patients overall at Hospital 2, a greater proportion cancelled their outpatient appointments at this site compared to the other hospitals; 42% of the 140 non-attenders, compared to 23% and 18% at Hospitals 1 and 2 respectively (see Figure 9.1).

The most prevalent reason for why some patients were not offered a follow-up appointment at the three sites was due to poor health (n=92); see Figure 9.3. The orthoptist made the clinical decision not to follow-up patients based on the final discharge letter or from discussion with the patients' families or nursing homes. The patients were deemed too unwell to attend the hospital outpatient by the clinicians or nursing homes. It should be noted that 39 of these patients died shortly after discharge which, arguably, aids justification of such clinical decisions. On seven occasions, the nursing homes liaised with the hospital eye department at Hospital 1 to report that the patient was too unwell to transport into the clinic. Unfortunately, no orthoptic home visit service was available at the time and so these patients were discharged.

Several nursing homes reported a lack of visual symptoms in patients at Hospitals 2 and 3, despite known visual impairments. As these patients would have struggled to attend the outpatient clinic due to post-stroke disabilities, it was decided not to arrange follow-up in the orthoptic clinic.

When appointments were offered to the remaining patients, the main reason for cancelled appointments was a lack of self-reported visual symptoms (n=21), or because the patients already attended an eye clinic elsewhere (n=19); see Figure 9.4. On these occasions, patients were asked by the orthoptist to report new symptoms of their post-stroke visual impairments to their regular eye clinicians, as the new stroke conditions may not be reported to, or identified by, clinicians elsewhere and may require re-referral to the hospital site from which they were discharged.

Figure 9.3: Reasons for no follow-up appointment offered at all hospital sites

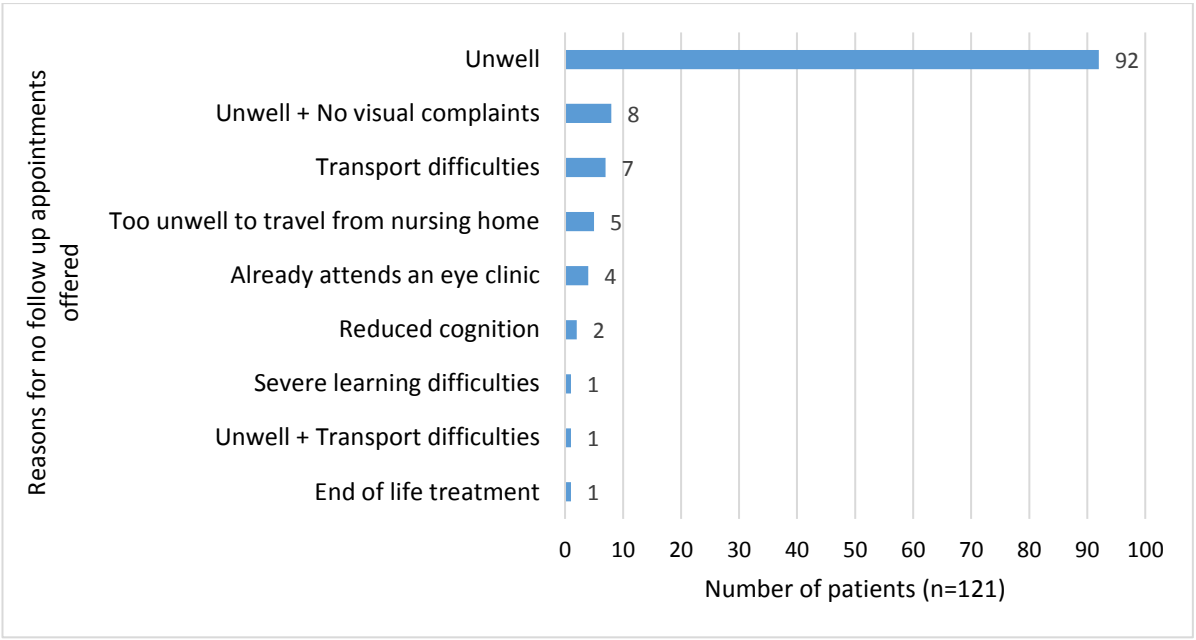
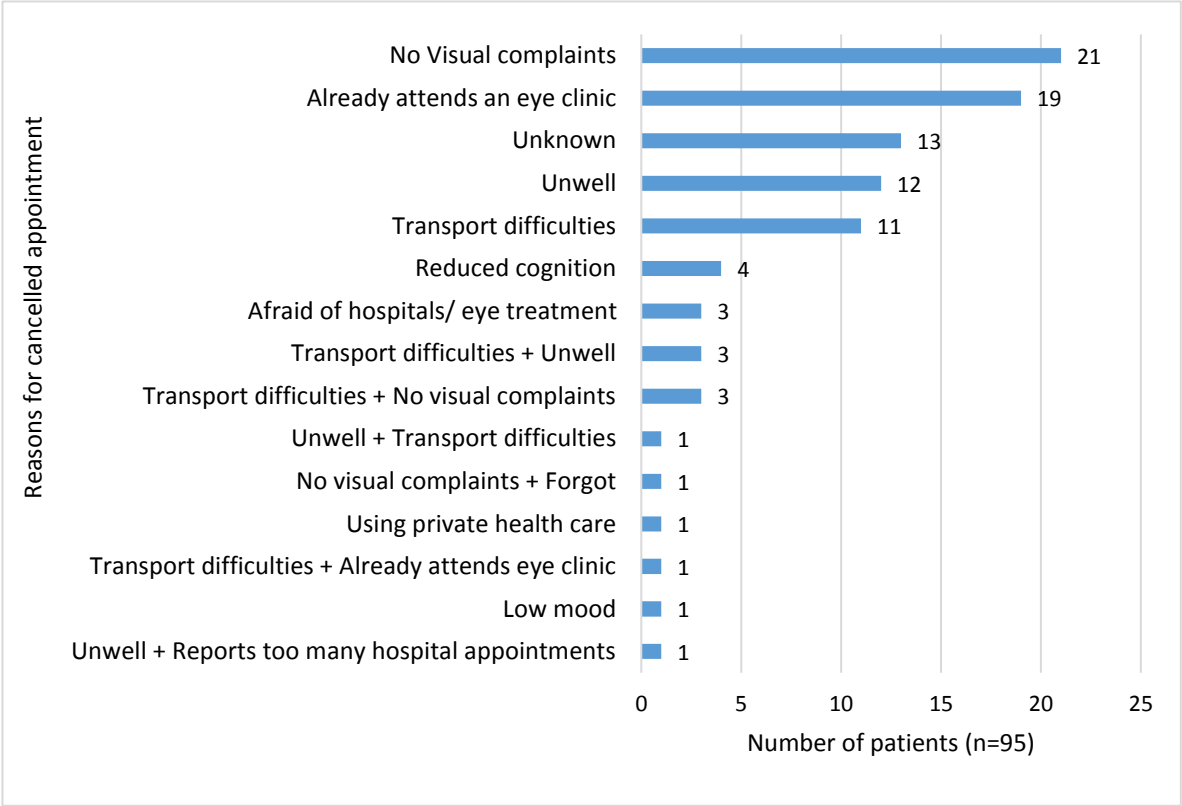


Figure 9.4: Reasons for cancelled appointments at all hospital sites



Furthermore, concerns were raised where patients decided not to attend the hospital due to lack of symptoms.

Many patients did not report visual symptoms during the IVIS study following assessment, despite the diagnoses of post-stroke visual impairments. However, these conditions may not have recovered following discharge and it was pertinent they attended for confirmation of recovery, or advice on their visual status. For example, unrecovered visual field defects would not have been suitable for driving and required formal automated visual field assessments for confirmation. Without attending their appointments, it was not possible to provide these patients with the appropriate advice.

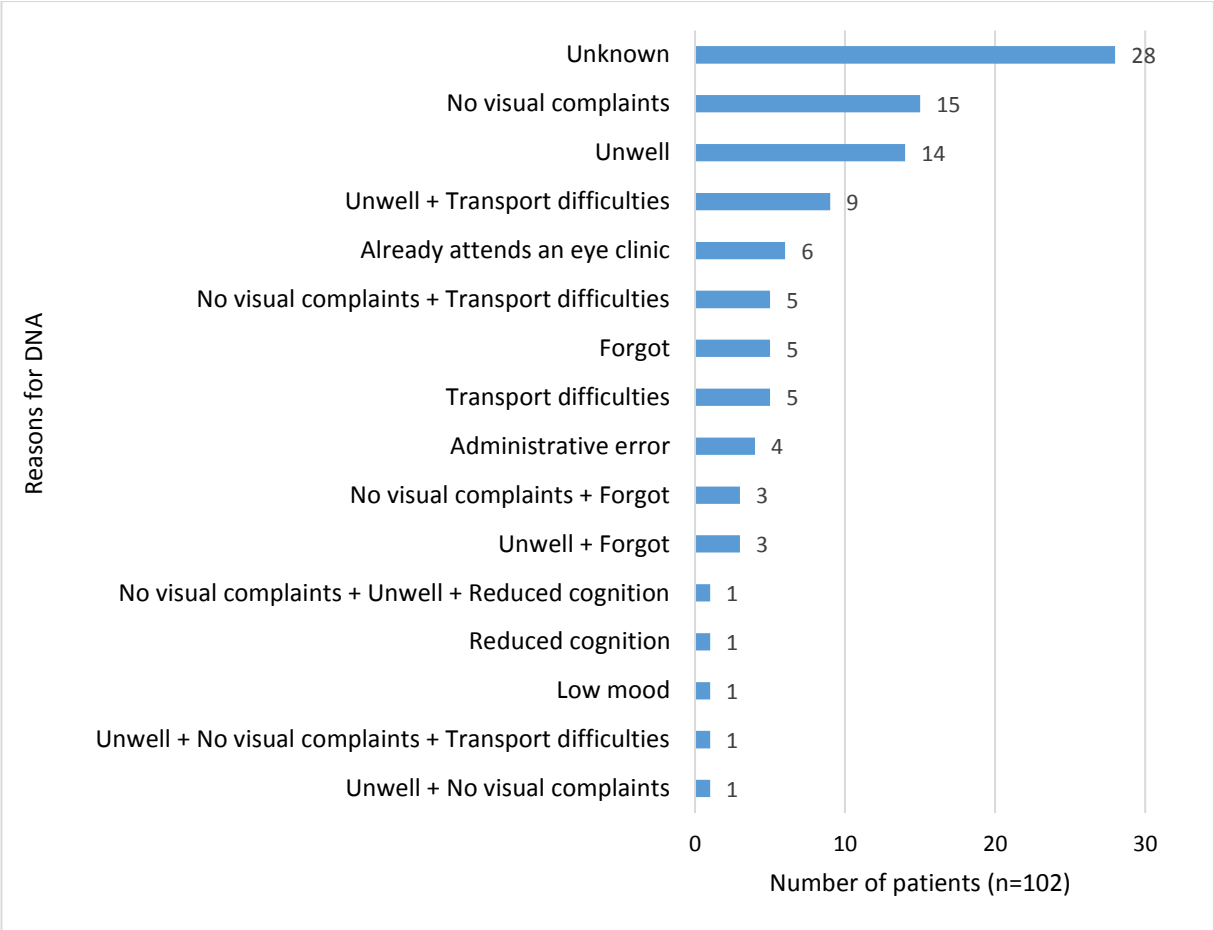
Patients reported various reasons for non-attendance including; their stroke/vision problems restricted their ability or confidence to use public transport; the high cost of transport due to many different outpatient appointments; or poor transport links to the hospital from their area of residence.

On just one occasion a patient reported having no visual symptoms indicating that the majority of patients could not seek rehabilitation for their visual impairments due to poor health or transport issues. It should be noted that several patients at Hospital 1 (n=6) requested home visits to overcome these issues, without clinician prompting. As this service was not offered within the NHS Trust, these patients could not be followed up. For those few patients (n=3) who reported a fear of hospitals and eye treatment or who were unable to read their appointment letter, reassurance and details of the appointment were provided over the phone, after which the patients agreed for further appointments to be made.

On four occasions, the nursing home cancelled the appointment at Hospitals 2 and 3 as patients refused to attend due to reduced cognition and low mood.

The main reasons for non-attendance (DNA) of post-stroke orthoptic appointments at all sites were “unknown” (see Figure 9.5). Many of the patients were suffering from severe post-stroke disabilities, including speech or cognitive impairments. Therefore, it was at times not possible to comprehend the patient via telephone. In these cases, attempts were made to contact the next of kin if the patient was suspected to be “at risk” through lack of capacity.

Figure 9.5: Reasons for "DNA" appointments at all hospital sites



Where communication was successful via phone call, many patients reported no visual complaints (n=15), raising the aforementioned concerns noted for those that cancelled their appointments. Additionally, poor health, transport difficulties and memory problems were reported, amongst other reasons; see Figure 9.5.

Those that forgot about their appointment (n=11) reported problematic post-stroke memory problems, and were subsequently contacted and a follow-up appointment rebooked. On four occasions the patients' appointment letters were sent to the wrong address, thus these patients were discharged accidentally from the outpatient department, which was only discovered as a result of this research.

For two patients, their nursing home or family reported refusal of attendance for all hospital appointments due to reduced cognition. One patient reported a loss of confidence using public transport as a result of the post-stroke visual impairments, preventing him from attending the hospital. They further enquired of the possibility of a home visit, as this was possible for other therapies, but unfortunately could not be offered at the time for orthoptics.

9.3.5: Appointment reminders

The receptionists, orthoptists and booking departments at each hospital site were contacted and asked to confirm whether or not reminders are used and if so, which type and at what time were the reminders sent out. Each site reported variation in the use of hospital reminders (Table 9.17). The booking department at Hospital 1 confirmed an inconsistent use of text message reminders. If a patient provided their mobile number, they would receive a text reminder within one week of their appointment. However, Hospital 1 did not offer an alternate form of reminder, such as postal or automated voicemail messages. Moreover, it highlighted administrative errors, in which patients were not routinely asked to provide a mobile contact number at the clinic's reception desk.

Hospital 3's booking department reported a previous use of text message reminders but admitted cessation of this service when they updated their hospital's computer system in November 2016. Previously, patients received text message reminders one week in advance and then another reminder one day before their appointment.

Table 9.17: the frequency of appointment reminders at all hospital sites.

	An appointment reminder sent out	The type of reminder	The length of time between the appointment and the reminder issued
Hospital 1	Yes	Text reminder	1 week
Hospital 2	Yes	Text reminder or automated telephone message	Between 2 weeks and 1 day
Hospital 3	No	(Not applicable)	(Not applicable)

Hospital 2 was the only site to confirm the use of an established appointment reminder service. They have used the service effectively since 2008 (479) and it is now implemented in all outpatient clinics.

Patients are routinely asked to provide a contact number at their first visit to the clinic and are asked to opt in or out of the reminder service. If mobile phone numbers cannot be provided then the patient is sent an automated voicemail message to their home phone, allowing a larger number of patients to be reached via this service.

Where possible, this information was extracted from the case notes or collated retrospectively by the research orthoptists through sufficient information within the case notes. However, a lack of nursing support during the study period, more so at Hospital 2, could explain the high number of missing values, seen especially in Area 2. Additionally, Hospital 3 changed to paperless notes at the latter end of the study, which did not retain old stroke case notes containing this information, and caused some difficulty in accessing patient records whilst the hospital was moving to an online system. Only those stroke survivors who did not attend or cancelled their hospital appointment were contacted by telephone and asked to report on potential health inequalities. However, it is not known whether those that attended their appointments also suffered from some of the difficulties identified in this study, as those that attended were not asked to disclose this information at their clinic appointment. Therefore, it is possible that the number of stroke survivors facing complications with attending hospital appointments has been underestimated.

As noted in 6.2, the Barthel index used to measure stroke severity in the IVIS study has a potential limitation, as it does not consider previous non-stroke disabilities that may falsely present as newly acquired stroke disabilities.

Future studies would need to control for this by using a screening tool of stroke disabilities that considers the patients' physical abilities prior to hospital admission.

9.4: Limitations

The Barthel scores and discharge destinations were not recorded by the research orthoptists during the study. Instead, this information was recorded by the nursing

or occupational therapy staff where possible. Some patients were discharged before a Barthel index could be recorded or were never admitted to the stroke unit.

9.5: Summary

Males, younger stroke patients (<65 years old), those discharged home and those with a Barthel index of 20 were significantly more likely to be offered a follow-up appointment. IMD and ethnicity were not found to be significantly associated with being offered an outpatient appointment.

Where appointments were offered to "suitable" stroke survivors, statistical analysis of the various attendance groups found that a low Barthel index (increased stroke severity), older patents, those discharged to supportive living and those that are wearing an out-of-date glasses prescription were found to significantly predict poor attendance of hospital eye appointments. IMD and gender were not predictors of post-stroke hospital attendance.

Main reasons for non-attendance included, the patient felt too unwell to attend, their visual symptoms had resolved, they no longer required the appointment, transport difficulties, and many stated that they were already attending an eye clinic or opticians regularly and felt they did not need the additional eye appointment.

Chapter 10: National survey of orthoptic home visits

10.1: Background

The survey discussed in this chapter was developed in response to findings from the attendance evaluation with those patients unable to attend their outpatient appointments (Chapter 9). Chapter 9 reported that many stroke survivors (n=319) from the IVIS study could not be followed up in the hospital for various reasons due to their stroke and/or visual impairments, including: transport difficulties, being too unwell, and forgetting about appointments due to various additional ongoing outpatient appointments. Twelve patients even requested home visits themselves in order to overcome these difficulties. Although this is a seemingly small number, the topic of home visits was not raised with stroke survivors during the telephone conversations and so highlighted an area of patient concern.

Furthermore, the findings from Chapter 3 identified health inequalities facing the visually impaired stroke population, in relation to poor access to stroke/vision services. Therefore, an exploration of orthoptic home visits services was planned, to ascertain whether or not such a service could be a possible means of reaching some stroke survivors with difficulties attending hospital. Langhorne et al. (480) further stated that domiciliary care services after stroke provide equivalent or better patient outcomes in the home, at a lower cost, and is preferred by patients and carers.

The majority of British and Irish allied healthcare professionals (AHPs) (excluding orthoptists) currently conduct home visits after discharge from stroke units, including physiotherapists (481, 482), occupational therapists (482) and speech and language therapists (483). For this reason, it is possible that the stroke survivors of the IVIS project had experienced home visits from various other AHPs, leading them to question the possibility of an orthoptic home visit. However, the conduct of orthoptic home visits in the United Kingdom (UK) and Ireland has not been documented in the

literature and clinical experience informs us that very few orthoptists provide this service.

An international systematic review described the benefits and barriers of home visits following stroke (484) although little has been discussed specifically for home visits conducted in the UK and Ireland. There was an overall favour for home-based rehabilitation up to six months post discharge (484). Benefits include reductions in cost (485) and in-patient hospital stay (486), along with increased physical independence and mortality (487, 488). Furthermore, stroke survivors have reported a preference for home-based rehabilitation, or domiciliary therapy, as it is more convenient, allows for better understanding of their therapy (489, 490) and offers them more clinician time per session (491).

The need for home visits amongst the visually impaired population specifically has been discussed. Lederer (492) reported that geriatric optometry patients would struggle to comprehend instructions for the use of low vision aids at home. Therefore, to accurately assist these patients, a domiciliary visit was required where lighting and magnifiers could be adjusted in their home environment, with further follow-up visits regularly needed. It was acknowledged that these visits can be time consuming and laborious, however they are usually the only acceptable means of prolonging the patients' independent lifestyle and without them the outcome for these patients is often low (492).

However, the benefits of domiciliary care have been disputed and these concerns should be addressed where possible when considering implementing this service. Many of these studies reported a lack of benefit, as opposed to negative consequences of home visits (480, 493). The Cochrane review of alternative stroke services to avoid hospital admission concluded a lack of evidence to support or discourage home-based care following stroke (480), as no statistically significant differences were reported between patient and carer outcomes following either home or hospital care. The trials identified in this review were considerably heterogeneous and so, it was not possible for the authors to draw accurate conclusions.

Furthermore, some studies found an unclear benefit from home visits (493-495), while some reported poorer outcomes of stroke survivors receiving domiciliary care,

although these were not statistically significant (496). The authors postulate that these findings apply to the older, frailer group of stroke survivors who perhaps fare better in outpatient clinics (496), as independence may be preserved if encouraged to travel to hospital. Moreover, there are varied reports on the impact of domiciliary visits on carers' mental health with some studies reporting a reduction in carer strain and improved insight into the patients' needs (486, 497), while others report an increased risk to caregivers' mental health (486, 489). A mixed model approach to include both domiciliary and outpatient hospital appointments may address both sides by providing staff with the educational opportunities from community settings and respite opportunities from day hospitals (489).

None of these studies includes orthoptic care as part of the home-based rehabilitation, as this does not yet appear to have been investigated. It has been suggested that community based rehabilitation may only be suitable for those who decline hospital admission or where hospital admission is not appropriate (498).

Furthermore, earlier research findings indicate that younger stroke survivors, with severe strokes and no previous disability, show greater improvements from home therapy compared to the elderly, frail population (499). Although the authors do not directly provide a reason for these findings, it was suggested that a supposed "greater intensity" of outpatient rehabilitation is better suited to the frail, elderly groups, whilst younger stroke survivors more frequently include home and leisure activities as a drive to improving physical impairment after stroke (499). Thus, home-based therapy protocols will differ dependent on the area and surrounding population (484, 496, 499).

At present, an orthoptic home visit service is currently unavailable within the hospital Trusts from which this project was conducted. Therefore, the aims of this survey were to investigate whether or not orthoptists in the UK and Ireland currently provide this service, whether they consider it a viable or necessary service and if so, which patients specifically would benefit from home visits. This will explore whether stroke patients could benefit from such a service in the future, to address some of the inequalities identified earlier in relation to accessing vision services. If the registered body of orthoptists do not consider this a viable service, then the survey aims to identify the limitations that could inform future service planning.

10.2: Methods:

The full details of the methodologies for this chapter have been outlined in 2.4. As stated previously, the survey questions were developed in order to explore whether or not orthoptic home visits are being conducted, or if this is something that could be considered to aid the aforementioned inequalities in accessing orthoptic services for some stroke survivors. The initial survey questions were discussed with the stroke specialist orthoptists (IVIS team) and the visually impaired stroke user reference panel (VSURP), to ensure the questions were clear and accurate in exploring this topic. As no previous literature was found documenting this service, from which to inform the survey questioning, it was suggested that questions remain open to the prospect of orthoptic home visits being used in other settings/for non-stroke populations, which could collect relevant data on the conduct of orthoptic home visits that could be transferable to stroke services. The final survey questions, and the order of questioning, are shown in Figure 10.1.

Following discussions with the above research groups, the finalised survey questions aimed to explore whether orthoptists are doing home visits, and if so, how and why this service is being conducted (strand 1). This would provide recommendations for implementation, if the findings from this research suggest that home visits are to be explored further. If orthoptists are not conducting home visits, again, their views on the perceived importance and value of such a service are to be explored through the survey (strand 2), to identify potential barriers or facilitators to implementing this change in the future. This could identify potential limitations of service implementation that should be considered if orthoptic home visits are to be recommended from this research.

Questions 9-4 (Figure 10.1) included free-text boxes to collect further data from respondents, and so a thematic analysis approach was employed to explore these responses qualitatively (10.3.3).

10.3: Results

10.3.1: Strand 1 survey responses

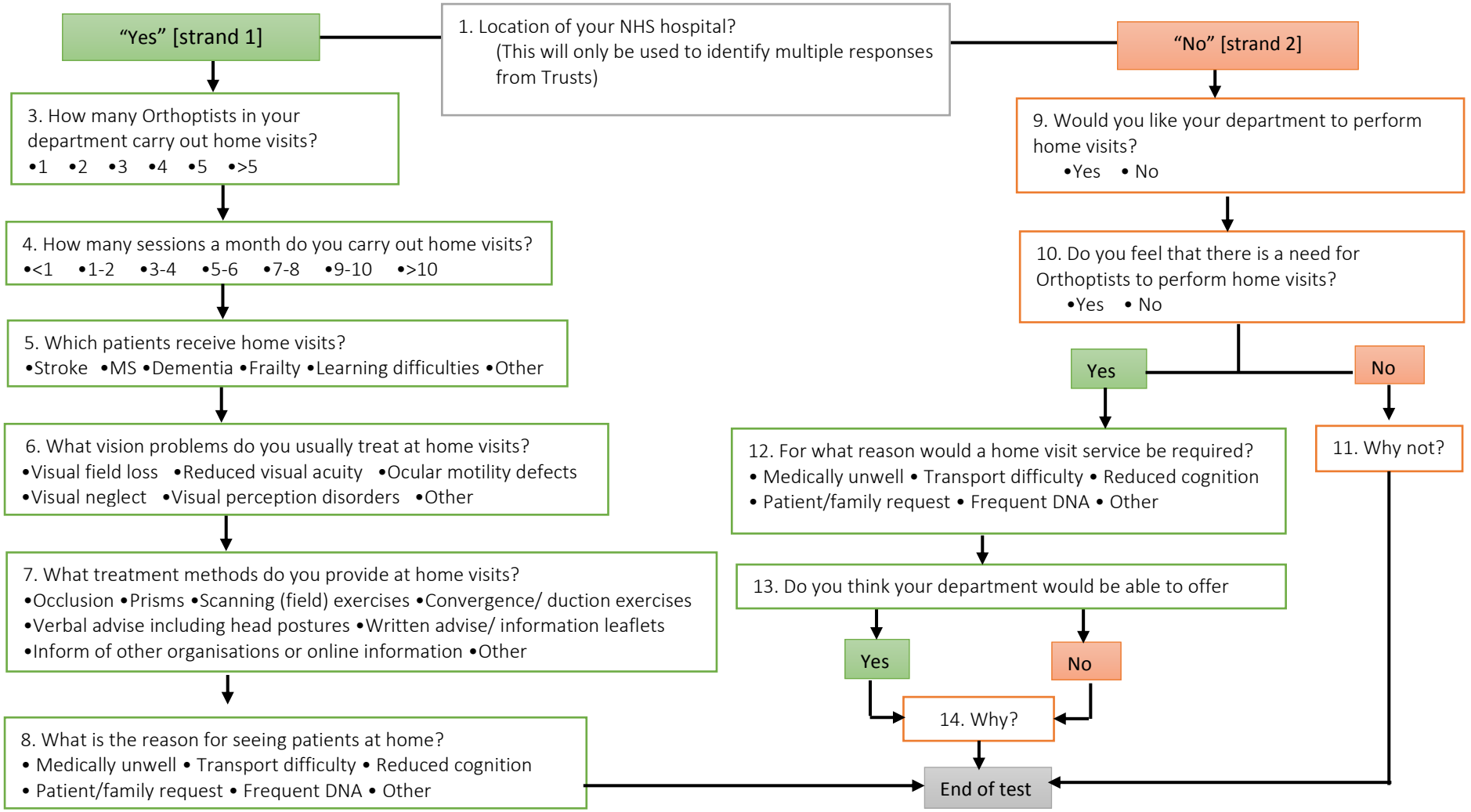
A total of 461 BIOS members, from 142 hospital sites, responded to the survey out of approximately 1500 orthoptists who are registered with the professional body, eliciting an overall response rate of approximately 30.7%. Thirty-three did not complete the entire survey and dropped out at different stages but their results up until the point of dropout were recorded and analysed. Findings from question one showed that the majority of responders were based in English Trusts, while responses from Ireland, Wales and the North of Scotland were quite poorly represented.

Orthoptists were initially asked whether or not their department offered home visits for any patient. Of 461 responders, 444 (96.3%) answered “no” and 17 (3.7%) answered “yes”. It should be noted that the latter reflects several responders from the same orthoptic service and not from 17 different hospitals or NHS Trusts. After analysis of the 17 individual responses from these sites, it was apparent that a total of ten hospital sites across the UK reported performing orthoptic home visits. However, subsequent email communication identified four respondents, who initially reported offering home visits, but later disclosed that their department does not offer this service and had never previously done so. This is discussed later in 10.3.5.1

For those responders who stated that their department offers home visits, they were asked how many orthoptists per department carry out this service, and how many sessions a month are required to undertake this work. Thirteen of 17 respondents answered question three, with six (46.1%) reporting only one orthoptist in their department carries out home visits, five (38.5%) reported that two orthoptists were required, and two (15.4%) reported that three orthoptists were conducting this service.

Five responders (38.5%) stated that <1 session is carried out a month, whilst the remaining eight (61.5%) reported 1-2 sessions are carried out per month. Overall, no more than three orthoptists carry out home visits in any one orthoptic department, and very few visits are required with no more than two being undertaken per month.

Figure 10.1: Flow diagram showing the question pathway for the survey on orthoptic home visits.



For those who reported that their department already offers home visits, further questions were asked in order to distinguish the service already in place. Figure 10.2 shows the responses from question five, stating the diagnoses of patients receiving home visits. Stroke patients and those with and learning difficulties were reported most frequently (38% each). Additionally, where respondents answered “other” to question five, this included low vision patients (which although unspecified, can affect a broad range of conditions including stroke). Some respondents reported conducting home visits for paediatric patients (n=3) or adult patients (n=2) but, again, did not specify the medical/orthoptic condition warranting a home visit.

These respondents were subsequently asked which visual deficits they would treat at home (Figure 10.3) and what management options they would perform in this environment (Figure 10.4). It was specified that all visual deficits listed could be managed in the home, ranging from reduced visual acuity as most frequent (53.8%) to field loss and neglect as least frequent (38.5% each); Figure 10.3. Those that selected “other” for question six, failed to report additional visual impairments treated at home, but instead, used the free textbox to describe the treatments offered, which have been reported below for question seven.

The most common rehabilitation options provided were written and verbal advice (61.5% each) and providing further information of additional services (46.2%).

Prisms and occlusion were prescribed equally (38.5%) with few orthoptists offering scanning and vergence exercises (Figure 10.4). The list of additional rehabilitation options reported as “other” for question seven included CVI registration, the prescription of low vision aids, and accounts of combined management plans developed in coherence with a broader multidisciplinary team.

Finally, responders already providing home visits were asked what the reasons were for seeing these patients at home (Figure 10.5). The majority (61.5%, n=8) assess patients who are too unwell to attend the hospital for their appointments. Furthermore, where respondents answered “other” to question eight, they reported the benefit of assessing functional vision in the “real-life” home environment, such as for patients with learning difficulties or low vision.

Figure 10.2: Q.5: Which patients receive home visits?

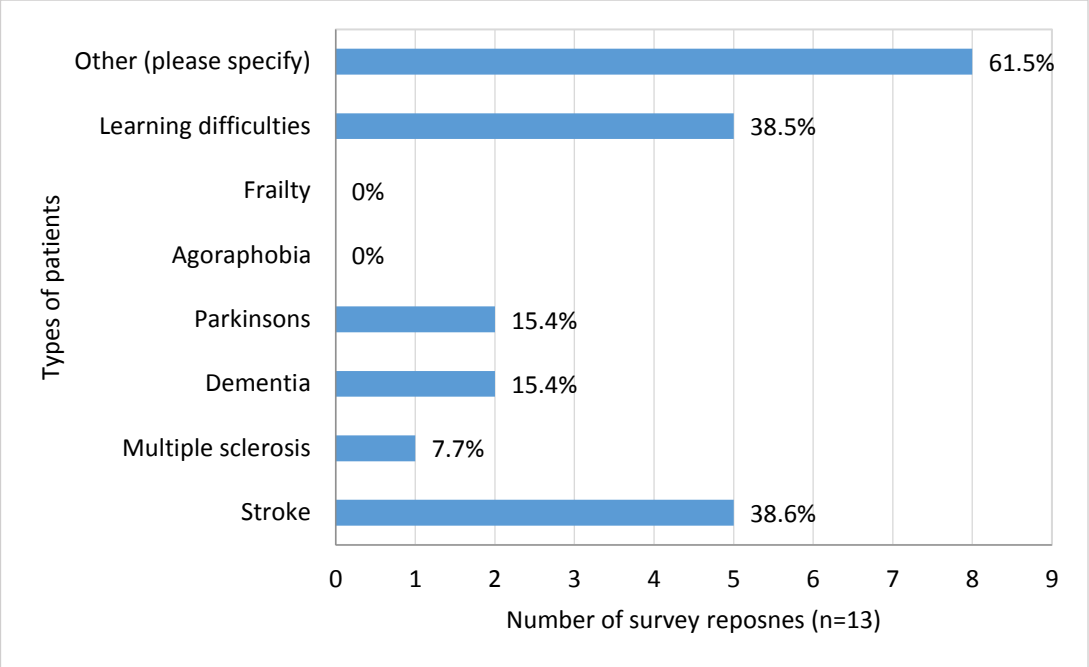


Figure 10.3 Q.6: Which visual defects would you treat at a home visit?

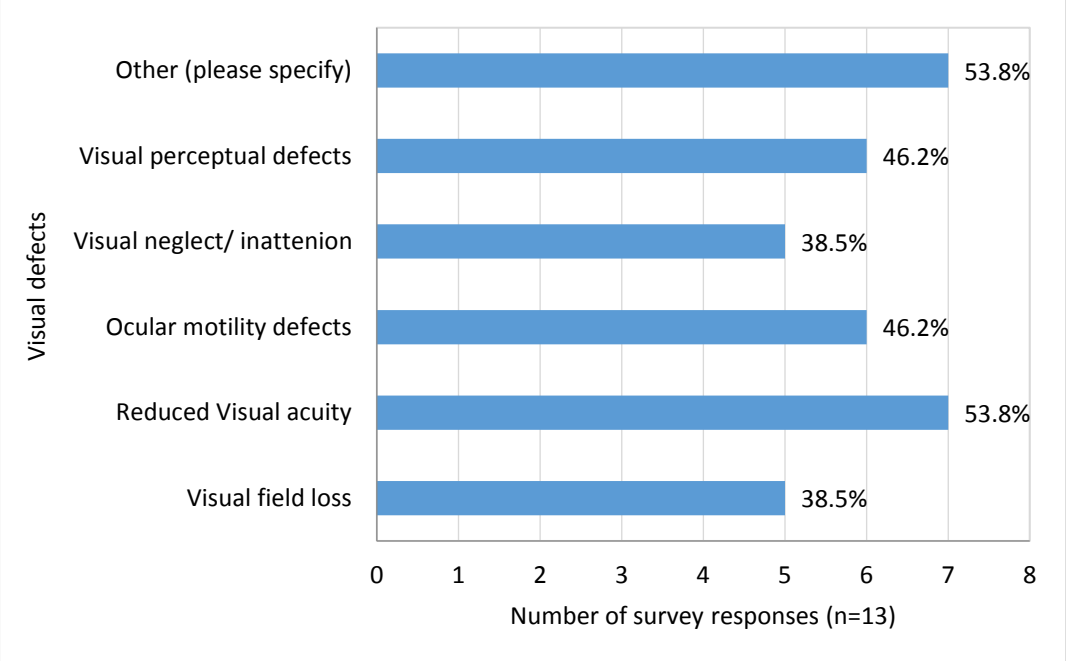


Figure 10.4: Q.7: Which visual management options would you offer at home visits?

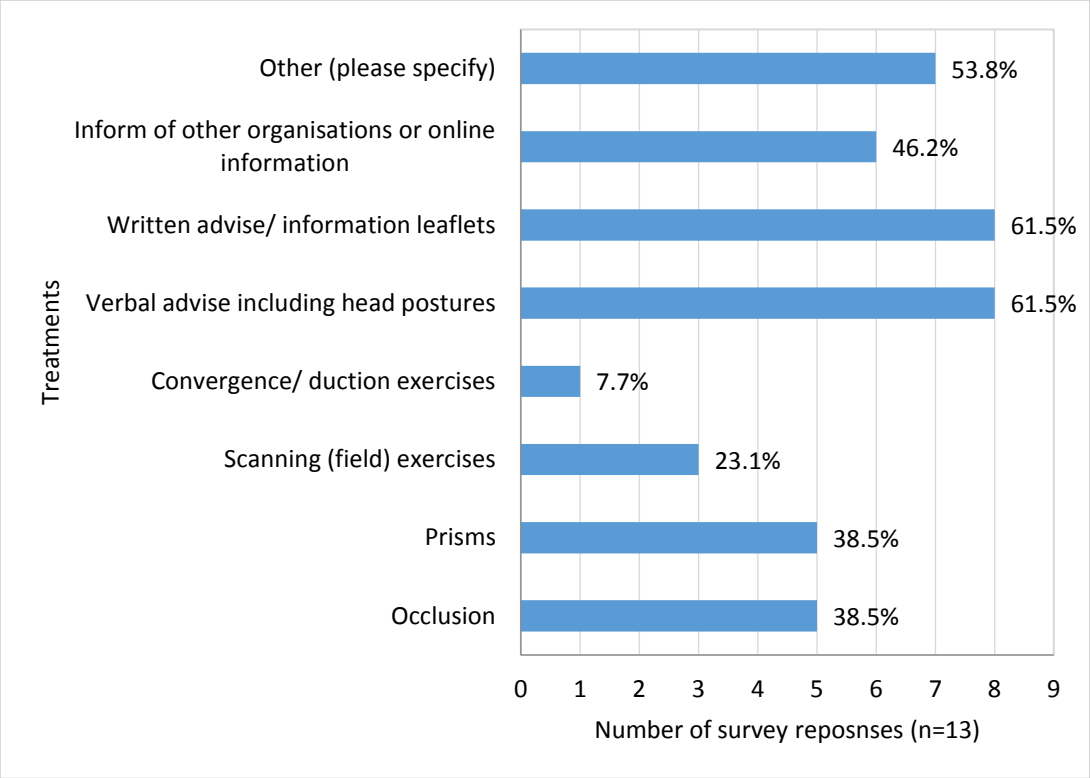
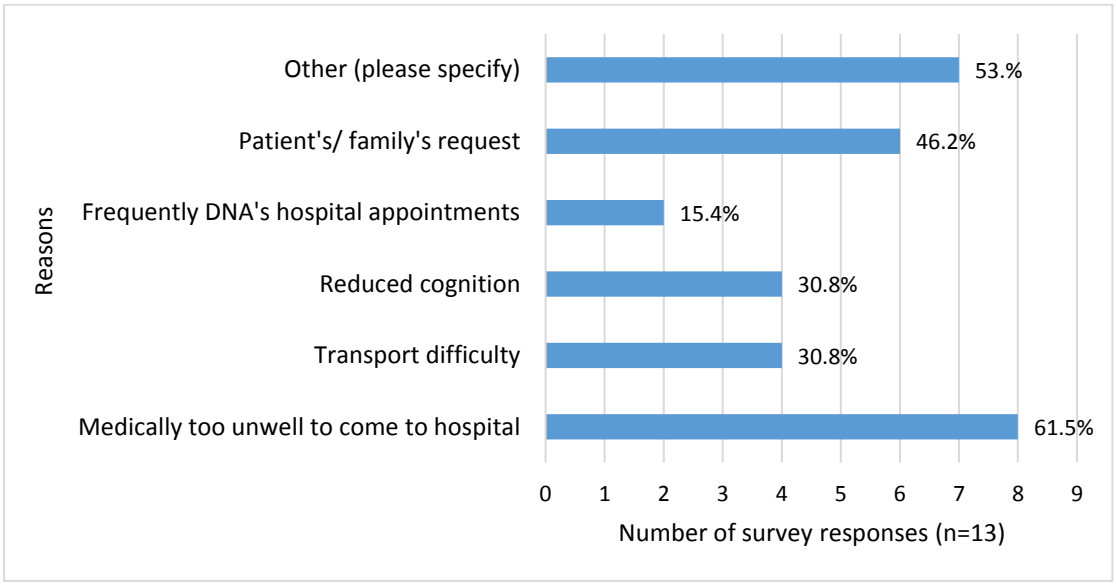


Figure 10.5 Q.8: What is the reason for seeing patients at home?



10.3.2: Strand 2 survey responses

If respondents initially answered “no” to question two, they were asked whether they would like their department to offer home visits (question nine), and whether or not they think there is a need for orthoptists to conduct such a service (question 10). Only 17.7% (77/434) reported that they would like their department to offer home visits, with the majority (82.3%, n=357) answering “no”. Ninety-seven (22.4%) stated that they felt there is a need for orthoptic home visits to be carried out, whilst the majority (77.6%, n=337) reported that they see no need for orthoptists to offer home visits.

Question 11 invited those that did not feel there was a need for orthoptic home visits to further share their views on this. The free-text responses for this question are described in 10.3.3. Question 12 asked those that did feel that there is a need for orthoptic home visits, what reason would most warrant this service. The most frequent response considered medically unwell patients that are unable to travel to hospital (Figure 10.6). Notably, where responders selected “other”, they mainly acknowledged that stroke patients would likely benefit from this service, as well as patients requiring a low vision assessment in the home setting.

Similarly, question 13 asked any responder that felt there was a need for orthoptists to perform home visits, whether their department would be able to offer this service. Of the 94 responders to this question, 29% (n=27) answered “yes” and 71% (n=67) answered “no”.

For the respondents answering the second strand of the survey, free-text boxes offered further explanation for their responses, from which thematic analysis was used to describe their reasoning for whether they would like their department to implement a home visits service, and why they felt there was/was not a need for such a service. The results from the thematic analysis are shown in Table 10.1. The key themes identified relate to “facilitators” and “barriers” to offering orthoptic home visits, and thus the responses to the following questions have been reported below in relation to these themes (see 10.3.3).

Figure 10.6 Q12: What reason would most warrant a home visit?

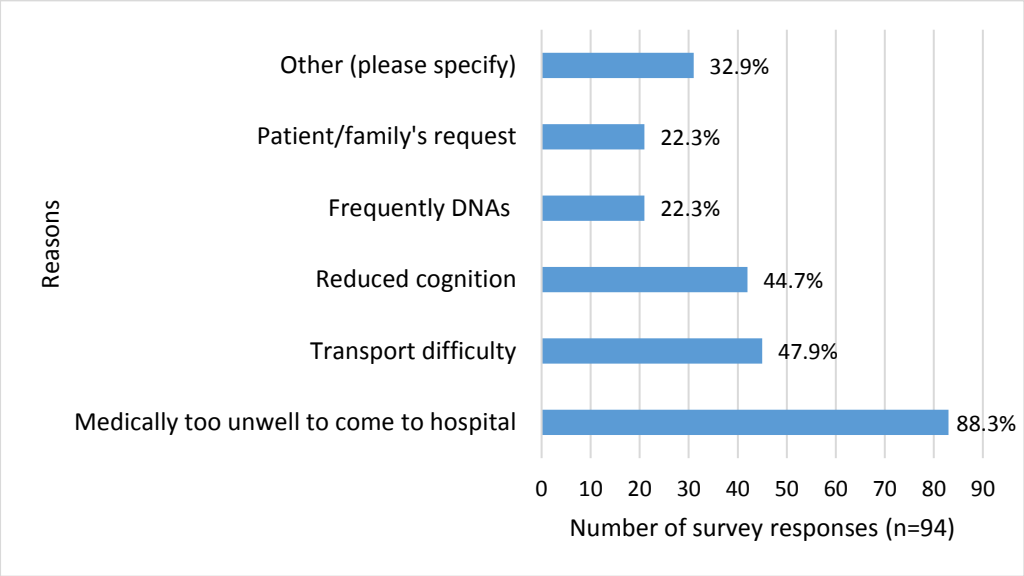


Table 10.1 Barriers and facilitators to providing orthoptic home visits.

Themes	Codes	Description
Barriers	Suitability of patients Cost Staffing Safety Setting	Unsuitable for paediatric patients Insufficient equipment Unable to release staff Staff interest Transport costs/difficulties Home environment inappropriate Too few patients seen at home
Facilitators	Suitability of patients Setting	Medically too unwell to attend hospital Transport difficulties Reduced cognition Frequent DNA's Patient/family request Adult Stroke Home environment appropriate

10.3.3: Barriers to conducting orthoptic home visits

10.3.3.1: *Staffing barriers*

Staffing issues were a main barrier identified from the analysis in preventing an orthoptic home visits service, which was apparent through both the respondent's descriptions of current job constraints, and through their language used, which expressed hesitation, and at time, astonishment, to the implementation of such services. Although the free-text survey responses were brief and interpretation cannot be as rigorous as if the data were obtained from formal interviews, the respondent's use of written-language to describe the prospect of home visits portrayed some resistance. Below, the quote from R215 uses punctuation to insinuate disbelief at the prospect of such services, with the addition of their years in practice to further strengthen their argument.

> *R215: "During my 36years as an Orthoptist I have never had a request for a home visit!"*

> *R356: "It has never been a desire in our department to do home visits."*

Moreover, the response from R356 (above) implies a certain level of control in implementing new services, dependent on the staffs' desire, and not necessarily the patients. Therefore, it appears that implementing new services requires more than just identifying patients' needs; it also requires convincing a workforce to partake in the new service.

Descriptions of departmental constraints were further offered, such as high transport costs to send orthoptists to patients' homes. Orthoptists appeared under pressure to meet current hospital demands due to staff shortages and heavy workloads, and fears of further hindering their current service outweighed the benefit of conducting home visits. One responder stated that if staffing numbers were sufficient then home visits could be possible.

R191: *"Due to our work load I feel we would be too pressed for time to do this [home visits]."*

R273: *"I think if it were required and it was done with all the correct policy and procedure then it should be considered. We do not have the staffing at present to offer such a service."*

R69: *"Capacity is growing within the hospital, we are struggling to meet the demand without releasing a member of staff to do home visits."*

The 'tone' of the response from R69 could be interpreted as frustration at the prospect of a new service adding pressure to a workforce that is barely managing. Moreover, many orthoptists raised concerns over staff safety in entering patients' homes, if they were to conduct a home visit. One respondent noted that her age and gender played a role in her concern over safety when entering a patient's home, causing a barrier, through staff resistance, to conducting home visits.

R451: *"I feel it may be unsafe as a young female to be entering a person's home, potentially alone, to provide a home visit."*

R354: *"The personal safety aspect of visiting someone at home is also a concern."*

10.3.3.2: *Unsuitable patient barriers*

Further barriers identified considered the suitability of patients, and more specifically, that paediatric patients would not be suitable for a home visits service. Notably, no survey respondent reported that adult patients, or specifically stroke patients, would be unsuitable for this service. The reason for why paediatric patients were deemed unsuitable was due to the array of additional visual services that they are required to attend alongside the orthoptist, which cannot be performed at home.

R365: *"It is not an appropriate model for the clinical population seen at [hospital name] as they are all tertiary referrals and need to see other clinicians such as doctors/electrophysiology/optometry at the same appointment."*

10.3.3.3: *Barriers to high-quality services*

In addition to unsuitable patients, reports included the unsuitability of the home environment as a barrier to conducting orthoptic home visits. Some respondents stated that the home environment could result in unrepeatability of orthoptic assessments and therefore, raised concerns that the orthoptic assessment at home would be counterproductive if accurate findings are required to manage the patient appropriately. This was furthered by respondents' concerns over the amount of orthoptic equipment required to undergo an assessment, and the difficulty of transporting this to the patients' homes. For these respondents, it would seem the difficulties of testing patients in the home outweigh the patient benefit, or, may even produce inaccurate test results due to poor testing conditions, which could hinder the patient further.

R434: *"Home settings may not allow for accurate assessment due to limited testing distances and lighting conditions, therefore limited repeatability."*

R364: *"Can you imagine how much equipment would be needed! A large amount of equipment and consumables would need to be carried in and out of patients' homes."*

Additional responders expressed concerns regarding the travel required to conduct home visits, and deemed this counterproductive and costly. This appeared to be of greater concern to those orthoptists practicing in areas that encompass a wider patient catchment area, as they could not foresee how multiple patients across the area could be seen in one session.

R53: *"[Area name] is a large county with many rural areas and so it could take a long time to travel from one home visit to the next and would not be cost effective – you would spend more time travelling than seeing the patient."*

R187: *"As a head of service covering a large geographical area, this would be logistically difficult. Maximal utilisation of staff time is the push from my trust."*

Furthermore, some responders discussed the benefits of testing patients in hospital clinics as a decider against supporting a home visits service. These responders reported that they would be able to assess and treat a greater number of patients in a hospital clinic. Similarly, responders informed that orthoptic patients would already be attending hospital to see other healthcare professionals, thus rendering orthoptic home visits irrelevant.

R266: *"Generally the hospital is better equipped to assess the patient and give them the best care."*

R282: *"If a patient has had a stroke and therefore needs orthoptic input, during the time where they are bed-bound they are likely to be inpatients therefore easy to see in hospital."*

R177: *"They [patients] need to see other clinicians and doctors at the same appointment. There aren't many orthoptic-only type patients."*

Several respondents suggested that a complete orthoptic assessment would not be possible, regardless of whether or not orthoptists conducted them. As such, other AHPs including as domiciliary optometrists and occupational therapists, could assess and treat the visual disorders whilst on a home visit. The statement below from R218 supports earlier reports that the orthoptic assessment at home would not be of high

enough quality, and thus, another AHP would be capable of performing the basic assessment possible without the need to staff and fund a new service. Another respondent (R192) went even further to query whether an occupational therapist (OT) would already include vision in their home assessment.

> R218: *"The tests possible at home would not be a thorough orthoptic assessment and should be able to be performed by a domiciliary Optometrist."*

> R192: *"…but would that not be part of an OT assessment?"*

Arguably, one orthoptist further discussed the practice of domiciliary optometrists as an established means of assessing visually impaired patients at home but highlighted that optometrists would not be able to appropriately undertake the orthoptic specific assessment and management (binocular vision) of these patients. This does not entirely contest the previous suggestions that orthoptists could not perform a more accurate assessment at home, however it illuminates an inequality if the patient's needs cannot be met through current available home-based options.

> R378: *"There is a domiciliary optometry service locally and I sometimes ask them to see adults. They would not be competent in binocular vision and diplopia however."*

Lastly, the benefits of alternative, well-established, local clinics were discussed in question 12, which may address the need to see patients in the home. Respondents concurred that a home visits service may not be feasible over large geographical areas, however, travelling to local community clinics was suggested as a consensus for both sides of the argument.

> R180: *"We have 15 community orthoptic clinics close to the patient's homes so very few need to attend a hospital assessment. This is both cost effective and convenient for staff and patients."*

10.3.4: Facilitators to conducting orthoptic home visits

10.3.4.1: *Patient-specific needs and conditions as facilitators*

The type of patient, or their specific medical/orthoptic condition, may act as a "facilitator" to conducting home visits, as particular conditions may warrant a home visit above others. The survey responders suggested that medically unwell patients, who are unable to travel to a hospital, would benefit from this service, similar to the IVIS population that requested home visits (Chapter 9).

> R301: *"Unwell adults may benefit [from home visits] especially if bedbound."*

Similarly, responses to question 12 considered patients that are too unwell to travel to hospital, and those with reduced cognition, to require a home visit (Figure 10.6), as this type of patient was deemed more suitable to be assessed accurately and appropriately in the home environment. Additionally, transport difficulties preventing the patient from attending hospital were reported as a further reason for conducting home visits, as well as instances where patients and/or their family members have requested such a service (Figure 10.6).

Notably, "stroke" was reported frequently where responders selected "other" for question 12. It was further suggested that patients with reduced mobility and patients with reduced confidence in attending hospital (for unknown reasons) would be suitable for a home visit.

> R454: *"I could see this being beneficial for stroke patients' rehabilitation."*

> R92: *"The only group of patients for whom home visits could be justified and have value, would be for stroke patients or severe traumatic brain injury."*

> R372: *"This service would suit patients with reduced mobility or visual impairment affecting confidence in new surroundings."*

10.3.4.2: *The home setting as a facilitator*

Despite previous reports of the home setting creating a barrier to orthoptic home visits, other responders suggested the benefits of testing an orthoptic patient at home to encourage the use of such a service. The above quote from R372 suggested that the home environment would be useful in assessing patients with little confidence in unfamiliar settings, such as a hospital clinic. Furthermore, R160 (below) reported that the home setting is an appropriate place to assess vision as it considers the patient's individual requirements in real-life situations.

> R160: *"I think it would benefit those that need a low vision assessment possible, as it would then be in their own realistic environment."*

10.3.5: Risk assessment, policies and procedures

Several survey respondents expressed concerns regarding staff safety when performing home visits. However, as a wide range of AHPs, including a small number of orthoptists, are already proving home visits across the UK, protocols and risk assessments have been put in place for each NHS Trust in order to address this issue and ensure safety is maintained. The possible risk of performing orthoptic home visits has been evaluated in this sub-section to address this concern.

The ten responders that completed the survey and reported performing orthoptic home visits, inputted their email addresses at the end of the survey granting further contact by the PhD researcher. A generic email was sent to these responders requesting detail of the capacity in which they provide this service, however only three replied to the email query confirming this service, with two providing their policies on risk assessment. The remaining seven hospital sites either did not respond to the email query (n=3) and were not contacted again, or, more surprisingly, reported that they do not perform orthoptic home visits and have not previously done so (n=4). Due to the anonymity of the survey, it was deemed unethical to enquire as to why these participants had initially reported providing this service, whilst this was later discovered not to be the case.

10.3.5.1: *Subsequent email contact and 'true' response numbers*

An error was noted in the initial survey response numbers following the subsequent email contact. An orthoptist at one hospital responded to the email query to say that they do not perform orthoptic home visits, despite reporting that they did offer this service when they completed the survey. However, they did describe how they carry out orthoptic assessment and management in 16 community clinics that are significantly closer to the patients' homes making attendance easier. Moreover, they reportedly conduct orthoptic assessments in 92 primary schools, allowing them to effectively assess children in a familiar environment, without the need to then assess them in their home environment also. Therefore, it would appear that they responded to the survey to report on a community-based service, which they deemed similar to an orthoptic home visit.

Further possible reasons for why the additional three orthoptists responded incorrectly may include a misinterpretation of the question; they answered the survey describing a service they would like to provide in the future; or that they do not follow a risk assessment policy for this service and chose not to disclose this information.

Of the three hospitals confirming the use of orthoptic home visits, two shared their policies, which have guided the discussion below (10.3.5.2). However, these policies have not been referenced to maintain confidentiality of the responding Trusts. The remaining hospital confirmed the use of this service for adults with specific learning disabilities but did not respond to a further request of the policy details. The two lone worker policies have been reported below to identify methods in which to prevent risk and respond to risk while performing home visits.

10.3.5.2: *Preventing risk on home visits*

The lone worker policies outlined the importance of contacting the department's receptionist to make them aware of their safety and whereabouts. Ensuring a supervisor or other member of staff is aware of the visitor's schedule and whereabouts is crucial. Furthermore, the orthoptist must inform an external person of their location, who they are visiting, the estimated timescale of the visit and if necessary, take another member of staff with them. The policies advised that

orthoptists leave their mobile phone number with the department's receptionist, phone the department when the home visit is completed, and agree on a time in which the orthoptist should be contacted should they fail to phone the receptionist. If the orthoptist answers the phone in distress, the police should be called immediately.

The lone worker policies further suggest keeping a written log of any known risks associated with patients, home settings or locations that may be visited e.g. uneven path at the patient's home or a known high crime area. All visits should then be individually risk assessed to ensure safety and visits should be rearranged if issues have been identified with a patient or location.

Whilst on a home visit, the lone worker policies advise workers to be aware of the warning signs for potential risks or hazards. These may include recognising dangerous animals, or patients or family members/carers under the influence of alcohol or drugs. Lone workers can request animals be removed to another secure area whilst assessing the patient. Additionally, the policies advise that the orthoptist sit nearest the exit when performing a home visit.

Finally, safety should be maintained if travelling by car in cases where the car may break down, equipment may be left in the car or where the worker feels unsafe in the car. It has been suggested that routes are planned carefully and ensure appropriate fuel is in the car. Valuables and equipment should be locked in the boot and out of sight when leaving the car and a torch, mobile phone and map kept in the car when performing a home visit. Further information regarding what to do if the worker feels unsafe whilst driving to a home visit destination is included in the lone worker policy.

10.3.5.3: *Responding to risk on home visits*

Although these methods can effectively help prevent dangerous scenarios occurring, professionals should be trained in what to do if these situations arise. NHS Trusts provide violence and aggression training for staff and can offer further self-defence training to help workers identify and cope with rare situations where their safety may be compromised (500). The lone worker policies outlined the importance of ensuring

staff attend risk management training if working alone. If an incident occurs, it is essential that visitors remove themselves from the situation and formally report the incident immediately. Reporting incidents aids development of effective interventions and strategies to enhance safety while performing home visits (501).
The lone worker policies outlined what action should be taken if an incident occurs. All incidents of theft or assault should be reported to the police and a crime reference number obtained and added to an incident report. The line manager must ensure the incident report is submitted. Lone workers can be provided with personal attack alarms and should be used in the same way as clinic room panic buttons.

10.4: Limitations

Later email communication with the above respondents identified a number of people that initially reported conducting home visits but in fact, do not perform this service. It is possible that these orthoptists misinterpreted the question, answered the survey describing a service they would like to provide in the future, or do not follow a risk assessment policy for this service and attempted to retract previous reported information. It is not possible to know for certain why these respondents answered the survey incorrectly, and as such, the accuracy of the findings may be limited without this knowledge. The results from Chapter 10 therefore, should be used as a guide to better understand the possibility of providing orthoptic home visits, which could be used to address the needs of the current study population. However, additional research would be required to fully ascertain the findings.

10.5: Summary

It is likely that home visits are not required for the majority of patients and only few visits would be needed per Trust. This reflects the findings from the patient attendance evaluation (Chapter 9), concluding that effort should be made to encourage patient attendance, where possible, before making alternate arrangements, such as home visits.

However, for the minority of patients found to require this service, including stroke patients, patients with reduced mobility, cognition, confidence and learning disabilities, it could be greatly beneficial. The survey identified barriers to providing home visits, which included concern that the assessments would not be performed accurately. However, the responses from orthoptists already providing home visits (albeit small numbers) felt that one of the primary reasons for providing this service was that the visual assessments were performed more accurately where patients in their own home environment. Although several orthoptists suggested that a non-eye trained clinician could undertake the assessment and management of these patients during domically visits, this should be considered with caution. Recent research has highlighted the importance of the role of orthoptists in undertaking specific visual assessments (32, 101, 102). There would be a risk of missed or misdiagnoses of visual impairments that should be avoided at all costs. Furthermore, in cases where home visits are unequivocally impossible due to cost or staff shortages, an increase in community clinics was suggested to help address both the patients' and clinicians needs.

Section 3

Chapter 11: Exploring health inequalities after stroke though focus groups and interviews

11.1: Background

The results from the systematic review of health inequalities (Chapter 3), exploration of poor hospital attendance (Chapter 9) and the survey of orthoptic home visits (Chapter 10), highlighted various inequalities amongst stroke survivors with visual impairments. These inequalities included transport difficulties, increased costs of living, and inequitable access to services including orthoptic home visits, dependent on the patient's area of residence. Changes to service planning and delivery are required in order to tackle these issues. Therefore, focus groups and interviews were conducted with visually impaired stroke survivors in order to further investigate the extent and implications of these inequalities, and to identify potential means of overcoming them.

Qualitative research has been considered effective and necessary when researching the lived experiences of stroke survivors, and in researching health inequalities (502, 503). Stroke research benefits from qualitative enquiry, particularly as rehabilitation outcomes may be reliant on people's attitudes, thoughts and motivations (502), which can only be obtained through qualitative investigation. Previous research has used focus groups to successfully offer new insights into the post-stroke experience of stroke survivors' new "selves and roles" (504), and their experiences of accessing stroke services (505).

Kroll et al. (506) reported the beneficial use of focus groups in disability research including stroke cohorts. A key advantage of qualitative research comprised the inclusion of views from patients that may normally be excluded from participating in such research due to their physical and cognitive disabilities, including difficulty in using transport to travel to unfamiliar destinations. Therefore, all stroke survivors

with visual impairments should be encouraged to take part, regardless of cognitive, physical or speech-related disabilities. Instead, the stroke survivor's disabilities should be addressed to aid participation, in order to capture the wider inequalities within this cohort.

Qualitative methods have been well established for investigating public health issues, as such issues often arise from complex social, economic, political and biological factors (503). Therefore, a range of methods, including qualitative methods, is required to fully explore health inequalities and tackle problems in public health (503). Previously, focus groups have been described as a useful method to "explain" the quantitative findings from the initial phase of a study (507). Unlike quantitative research methods, the data collected from qualitative research is not designed for generalisations, but "to provide in-depth or contextual meaning and understanding to observed phenomena" (508). Therefore, care was taken to ensure that the findings form this chapter are representative of a visually impaired stroke sample in the North West of England, but not generalised to the wider population.

Overall, the previous reported success of qualitative methods in researching stroke and health inequalities topics supports the use of qualitative methods in this PhD research to explore inequalities further within this group. However, consideration has further been given to the reported criticism of qualitative methods, to minimise potential bias. Criticisms of qualitative research have included the subjective nature of the data collection, and whether or not participants are "telling the truth" (507). Issues with truth-telling in focus groups and interviews can stem from perceived power imbalances, whereby the participants, lacking confidence, give the suspected "correct" response, as opposed to their own, personal viewpoint (509). Chapter 2 described the efforts made to reduce power imbalances during the interview process, such as effective communication techniques and comfortable interview settings. Furthermore, previous recommendations have stated that leading questions should be avoided whilst planning the topic guide, and audio recordings used instead of video recordings to avoid participants feeling self-conscious, thus, hindering the validity of the results (507). These recommendations for conducting focus groups were therefore, implemented during the planning stages of this section of the PhD research.

11.2: Methods

The methods for this chapter have been described in Chapter 2 (2.5).

11.3: Results

Overall, two focus groups and five individual interviews (n=13 stroke survivors and n=1 spouse) were conducted in three areas in the North West of England, representative of the three recruiting sites in the IVIS study. The focus groups and interviews were conducted between October 2016 and January 2017. The demographics of the recruited participants are shown in Table 11.1.

The findings presented in this section draw on lived experiences of stroke survivors across their journey from pre-stroke to life after stroke. As mentioned previously, stroke survivors can suffer from a range of visual disorders, and these varied between interview participants. Table 11.1 shows the post-stroke visual impairments suffered by each of the participants.

The first focus group consisted of five participants, all female. The second consisted of four participants, all male, although one participant (**9**) had to leave unexpectedly before the dialogue commenced. Further participants were unable to attend the two focus groups due to travel and health problems, and thus an additional four interviews were offered to those participants. Due to the immediate difficulties facing these stroke survivors in attending the focus groups, it was considered important to collect their views and experiences if possible, for the purpose of exploring health inequalities due to stroke/visual impairment. Therefore, additional interviews were offered to these stroke survivors at a more convenient time and location.

Table 11.2 shows the coding tree created following thematic analysis of the transcripts. The transcripts were coded in relation to health inequalities described by the participants, directly pertaining to their post-stroke visual impairments.

Table 11.1 Demographics of research participants from Chapter 11

Anonymous identifier	Gender	Ethnicity	Age (at time of focus group/interview)	Year of stroke	Area of residence	Vision defect	Any other stroke impairments noted	*Stroke care during IVIS?*
Focus group 1								
Respondent1	F	Black British	60	2013 & 2015	Area 1	OM	Balance, memory	*Y*
Respondent2	F	WB	46	2010	Area 1	OM, VF	Memory	*N*
Respondent3	F	WB	52	2012	Area 1	VF	Speech	*N*
Respondent4	F	WB	39	2014	Area 1	VF	Speech	*Y*
Respondent5	F	WB	65	1979	Area 1	VF	Speech	*N*
Focus group 2								
Respondent6	M	WB	53	2012 & 2014	Area 1	VF	Mobility, balance	*Y*
Respondent7	M	WB	53	2006	Area 1	OM	Memory	*N*
Respondent8	M	WB	54	2010	Area 1	OM, VF	Speech, cognition	*N*
Interviews								
Respondent9	M	WB	57	2006 & 2010	Area 1	VF, VA	Cognition, hemiparesis, mobility, memory	*N*
Respondent10	M	WB	65	2005	Area 3	VF	Cognitive	*N*
Respondent11	M	WB	63	2005	Area 3	VF	Memory	*N*
Respondent12	M/F	WB	58	2017	Area 2	OM. VF	Memory, balance	*N*
Respondent13	F	WB	52	2010	Area 2	OM, VF, VP	Memory, speech	*N*

Key: WB=White British; M/F=male/female; vision defects (see abbreviations list).

Table 11.2 Coding tree centring on the theme of “loss”

Themes	Sub-themes
The physical being	1. Talk about stroke and health inequalities 2. Talk about visual impairment and sight loss 3. Talk about mobility and loss of mobility 4. Talk about remembering and memory loss 5. The multiplicity of problems and healthcare needs 6. Talk about ‘fear’ and ‘going mad’
The psychosocial being	1. Talk about self-identity and spoiled identity 2. Talk about embarrassment and loss of confidence 3. Talk about the financial impact of stroke and loss 4. Talk about patient involvement in care to address a sense of powerlessness (loss of agency)
The systematic organisation of healthcare	1. Information giving and loss 2. Talk about vision care after stroke (or lack of care) 3. Talk about the idea of ‘just getting on with it’ 4. Talk about self-help and self-learning in the clinical environment can invert, to some degree, inequities in practitioner/patient power relations

With few exceptions, the overarching experience of stroke and visual impairment that emerged in respondent accounts were constructed, perhaps unsurprisingly, in terms of 'loss'. Embedded within this set of master narratives are a series of subtle, or nuanced, dynamics that constructed a collective understanding of the social world inhabited by this group of individuals; one where personal stories could be located within the body politic of healthcare services and health inequalities. This chapter presents a critical analysis of research findings through three broad, and inter-related, themes focused on: 1) the physical being, 2) the psychosocial being, and 3) systemic-structural factors characteristic of healthcare provision. Each of the core themes illustrates how the life-world of the stroke survivors is mediated by concepts such as place, space, and time, as exemplified in contemporary scholarship on the 'sociology of the body' (510). As shown through the stroke survivors' accounts, connections are made between the experience of stroke, the visual impairments and health inequalities, by spatial and temporal conceptions.

11.3.1: The physical being

11.3.1.1: *Talk about stroke and health inequalities*

When asked if the respondents had any previous knowledge on the topic of health inequalities, only one respondent had heard of this term. Respondent 7's description of inequalities echoed the headline of multiple news articles ("postcode lottery"), suggesting a broad/lack of knowledge around this topic.

> *"Is health inequalities then what we might think is postcode lottery?"* (Respondent **7**).

The respondents talked about strokes as being "good" or "bad". Respondent 8 (below) is describing a small number of people expressing their struggles through writing. The respondent uses the terms 'good' and 'bad' strokes but, overall the essence of the account is one of growth through adversity. Interestingly, the abstract below describes how the respondents become more expansive when they are using 'talk' that they can own and feel.

"I couldn't write... but it was getting me up there and I thought I am going to come to this every week [pause]… and since then I've seen new people come along [pause] some really bad strokes... some pretty good strokes and... and it's good to have that because it's given people something to grasp on to [pause] and if I could... I was coming, little steps like that... and all of my arm was… but I can go home on the train... and I can just do that now and its good... it's good that I can do that because its better and better" (Respondent **8**).

"Well it just depends how bad you are, doesn't it (?) If you've got somebody who's in a bit of state like that old geezer in the next bed." (Respondent **12**).

Below, Respondent 5 describes stroke as more than just an impairment in neurological activity, but as permanent damage situated in the brain. The description of stroke suggests that this respondent was unaware and unprepared for the severity, and permanency, of the related disabilities, indicating a lack of public awareness and education around stroke.

"I think a lot of people think it's brain, well I've noticed this myself. At first you think it's brain damage and it'll go away – you don't understand that you maybe could get involved with the hospital and see to your eyes and do more physio on your eyes and stuff…" (Respondent **5**).

11.3.1.2: *Talk about visual impairment and sight loss*

The visual impairments that respondents talked about included OM defects, VF loss, and VP problems, presenting as diplopia, reading difficulties, or visual disturbances. In the context of how the different respondents talked about stroke and visual impairment from uniquely personal experiences, it was noted that first presentation, and admission, was described in terms of a total lack of understanding. Offering a retrospective account, this was characterised in terms of not "knowing anything".

"... but my vision problem is if I look out the corner of my eyes I get blurred vision [pause]... I can see two of you [pause], you're fine now but if I look at you like this then [pause] well with the benefit of hindsight I am sure it was [having an impact] but when you've just had a stroke you just don't know anything" (Respondent **7**).

As patients, many of the respondents did not undergo a formal vision assessment and diagnosis, therefore, their understanding of their condition was limited, as shown by their use of basic and vague language when describing visual defects ("problems with your eyes"). This demonstrates how confusing the situation is for the respondents, and how difficult it is for them to manage something that they do not entirely understand. When asked what the participants understood about their eye conditions, Respondent 8 replied with an account of minimal, self-seeking visual care that he received further down the line after his stroke rehabilitation.

"No... only that we all have eye problems... and all that we have got is an eye test that we've gone to, after... we've had our stroke and we've got... you know problems with our eyes [pause] that's all really because there's no 'Oh... you'll have problems with your eyes... go and get an eye test'..." (Respondent **8**).

Furthermore, the disjointed language used below by Respondent 4 portrays confusion when describing visual impairments after stroke.

"... peripheral... peripheral vision... mainly on the left [pause]... I had... it was slightly impaired on the right... but that was just the whole sight was impaired... there was no impairment on the peripheral vision on the right-hand side... it was all on the left" (Respondent **4**).

The respondents further talked about the physical adaptations when asked to describe their visual impairments. Such physical adaptations included making

exaggerated head turns to see properly, and requesting large print on bills and letters, as described below by Respondents 1 and 6. Furthermore, Respondent 2 is registered as sight impaired and carries a yellow card to alert people to his disability.

> ***"...*** *peripheral vision, yeah... especially on this side [left] yeah, cause I have to turn my head then to see"* (Respondent **1**).

> *"I've started asking like... the likes of the lecky company and the water rates and that to send me bills in large [print] and they do [pause] and I have got large [print] on my phone so I can read it [pause]"* (Respondent **6**).

> *"... and... ever since... leaving hospital in 2006 I've always missed the lights flashing on the left-hand side... in fact... so badly that I've... got a yellow card now to say that I'm vision impaired"* (Respondent **2**).

These comments indicate that the visual loss has not only affected the respondents' lives after stroke, but the incessant conscious efforts required to see properly, are themselves, problematic, and were worthy of noting without prompting.

11.3.1.3: *Talk about mobility and loss of mobility*

Difficulty mobilising independently after stroke was a recurrent theme from the interviews. The use of a wheelchair following stroke was new to many of the respondents, however, their fears and apprehensions of mobilising in the wheelchair were heightened when coupled with their newly acquired visual impairments. Respondent 10 (below) describes getting lost and bumping into things on the left side when mobilising. This same respondent used humour ("run over peoples' toes") when reporting the issues using a wheelchair. Humour has been documented in previous qualitative research studies as a coping mechanism when disclosing traumatic events (511). Therefore, Respondent 10's account could be interpreted as displaying feelings of embarrassment and discomfort in disclosing sensitive information during the interview.

> *"I... find I quite often miss... things on the left hand... on the left-hand side... like corridors and... and so on... so I sometimes get a bit lost because of that [pause] and I have been known to... run over peoples' toes"* (Respondent **10**).

A notion that mobility issues are worsened for stroke survivors using wheelchairs due to newly acquired visual impairments was furthered through Respondent 11's dialogue. The stroke causes new and complex mobility issues, but those stroke survivors with subsequent visual disorders are met with additional mobility impairments due to the loss in vision.

> *"They tried me on a big wheeled one [wheelchair] but I could only go round in circles because I could only use one eye. I had to get one… with small wheels and I just drag myself along with my good leg…"* (Respondent **11**).

Driving and loss of mobility

Language used by the stroke survivors to discuss the loss of a driving license expressed their efforts to retain the ability to drive, like a battle that must be won. The respondents used words such as "surrender" (shown in the extract below), implying a sense of 'giving up' or defeat from the stroke. Furthermore, this account describes post-stroke driving restrictions as culpable to more than one stroke pathology. In this single account, physical impairment, epilepsy and fear, all contributed to Respondent 8's loss of mobility, thus indicating the multiplicity of barriers that this group perceive they must strive to overcome to continue leading their lives as they did pre-stroke.

> *"I had driving license... I drove quite a lot and... but my stroke was so bad I couldn't drive [pause] I had lots of things with my leg and arm and I couldn't drive [pause] when I got... about two years after my stroke I got [long pause]. I know it when I see it but I can't do it [pause] epilepsy… I had one epileptic fit… but once you've had an epileptic fit you can't drive for another 12 months [pause] then I had two more epileptic fits in the New Year and stayed in the*

hospital for about two days and then would you know... I had another two epileptic fits in June [pause] so because New Year to June... but I still won't be able to drive until June of next year but... the thing is, after that I don't know whether my legs will be strong enough or if my arms will be strong enough [pause] I might have to surrender it" (Respondent **8**).

Notably, in this single prose, Respondent 8 used many temporal markers to depict his lived experience of the stroke impairments. The length of time that he spent without independent mobility adds poignancy to his account, highlighting the severity of his loss.

Others used language that implied they had more control in this situation. Respondent 10 (below) acknowledged that the post-stroke upper limb impairment contributed to his loss of driving, but further described a sense of 'letting-go' and choosing to strop driving.

"...no...no...no... I've stopped [pause]... well it's two-fold... I can't use my left arm at all... my left hand [pause] so I... I... I've... it's possible to get a... a car adapted to... accommodate that... but I think it's more to do with the fact that I'd probably be a danger on the road [pause] I have a... powered wheelchair" (Respondent **10**).

Similarly, despite Respondent 6 describing a shocking account of running someone over with his car because he did not see them, he still reports "giving up" driving in terms of loss. This portrays the idea that some stroke survivors feel it important to retain a certain amount of control when so many other aspects of their lives have become powerless.

"I haven't renewed [license]… don't think I will drive again" (Respondent **1**).

"I have given up [driving] now… but I gave up voluntarily because I ran someone over, I didn't see them... so I thought that was it... I would have killed

someone... so I gave it up myself [pause] no, I wouldn't feel safe" (Respondent **6**).

The respondents described the difficulties in retaining their driving licences, but nonetheless it was a process of utmost importance to them. With their new post-stroke bodies impeding their mobility and ability to move around independently, the need to maintain their driving licenses seemed an important priority, as it preserved a certain amount of freedom. The below extracts describe efforts required in retaining one's driving license after the stroke, both physically and emotionally.

"I... I do still drive [pause] I still drive but I had to go to [area name] mobility centre…which was not good" (Respondent **2**).

"I had to learn to drive. So I basically drive with one eye. I mean I had to do that test to reassure myself… not so much the DVLA but in myself to be sure because I was so different from I was previously. But I felt like if I didn't drive, I wouldn't go out the door." (Respondent **1**)

Public transport and mobility

Respondent 1 stated that he had driven prior to the stroke, but no longer felt able. This was due to a combination of visual problems and hand-eye coordination, framed more largely by a sense of fear. Furthermore, when discussing the use of buses as an alternative means of getting around, Respondent 11 appeared embarrassed that a bus driver had once asked passengers to disembark to make room for him in his wheelchair, which resulted in a loss of confidence using buses. The below quote indicates how the respondent, in a social context, risks becoming a public spectacle (512, 513). Social interaction, and how society accepts or does not accept their newly impaired bodies, mediated many of the discussions around health inequalities. Many of the respondents reported a sense of isolation after stroke, as a result of fear and self-doubt.

"I did [lose confidence] 'cause when I walked on one bus I couldn't get in it where he... where he... he wanted me to go in. I couldn't get in it... and that knocked me a little bit, I thought... is every bus going to be the same [pause] well I don't know because... I haven't been on a bus as much since then because when the driver pulled up... and it was a good job we were at the bus station 'cause all the people that was on the bus... he had to kick them off for another bus" (Respondent **11**).

This theme of fear and shame using public transport was furthered by the respondents' awareness that their visual impairments, memory and cognitive dysfunctions are not always visible to the public, and so people do not know to give them space or time when boarding transport.

"The thing is about the stroke is it's like the bus driver doesn't know you've had a stroke" (Respondent **7**).

"It is a problem that for people not getting on the bus because they see people all around them who are alright and they've got eyes or they've got legs, and I didn't, didn't care about my legs, I was getting on that bus, but some people are really not, you know [pause] I know I can stand there waiting for a bus and I look perfectly normal standing there... it is only when I start to walk on to the bus that I could start to [unfinished]" (Respondent **8**).

Furthermore, Respondent 8 described a scenario where confusion and memory impairment after stroke hindered him from using buses, despite his ability to mobilise freely. Additionally, routine plays a key role in aiding his memory and ability to travel independently. The below account illustrates reliance on aids, such as documenting the bus number in his phone, to overcome mobility restriction caused by memory problems.

"... but I get on the bus... my father in law brought me here and will take me back again and stuff... but I... still to use my pass and I want to get on the

trains and buses and now I go to [name of hospital] and I go on the bus and I go to my speech clinic, which is two buses... you know... all on the bus [pause] I had to say, 'Look' to the girls that were around me... 'Look you... you get here by the bus... how do you get here?' and they give me my... phone and I tapped it in my phone... number seven or number nine from the bus station and that's how I got it... but now it's all in there [pause] you know... but if I don't go for four or six weeks then I will always have it on my phone" (Respondent **8**).

Even when buses offer a possibility for mobilising after stroke, Respondent 10 described new difficulties once having disembarked the bus, mobilising in unfamiliar areas, as the raised curbs outside are not practical for his wheelchair. It seems that mobility is a significant issue for these stroke survivors using all forms of transport.

"I tend not to use them [buses] I mean the... buses in this town are... pretty good, although I've not... I've not tried them because... it's not that far from here to the centre of town... unfortunately there aren't many... drop curbs [pause]... so I tend not to use my... wheelchair to get into town [pause] I've got a... I've got a [mobility] scooter that's... registered for road use so I can drive off into town" (Respondent **10**).

Research evidence indicates a loss of confidence with using public transport in relation to vision loss (230), and this was reiterated in respondent accounts. Respondents spoke (below) about support that had been made available through occupational therapy (OT) services. However, despite suggestions that the OT support in using public transport was effective, the respondents' language described fear, dread and overwhelming trauma whilst using transport.

"And I went to an occupational therapy centre and the occupational therapist took me out and took me on buses… and for me it was too much" (Respondent **5**).

"... yeah I was the same... but it was traumatic for me to the point where I didn't feel safe... like visually and unstable... probably because I was" (Respondent **2**).

"I found that, at first… I tried the bus… scared, I can't talk… cars… how do I do it? My car ride good then [pause] I could go in a car but [now], no way." (Respondent **3**).

The aforementioned issues concerning respondents' abilities to mobilise while using wheelchairs were further raised when they discussed the use of taxicabs as a means of transport after stroke, as these vehicles are not always adapted to accommodate wheelchairs and disabled persons. The inability to use taxis further affected Respondent 10's sense of independence. The description of feeling "pretty uncomfortable" (below) furthers previous suggestions that the stroke survivors are frightened of becoming a public spectacle, which likely exacerbates social isolation.

"The biggest difficulty I have I suppose is that there aren't many taxis that will carry wheelchairs [pause] there are lots of them with ramps but they're actually more often than not quite steep [pause] and I feel pretty uncomfortable trying to get up them... get down them [pause] and there aren't many taxi companies that have cabs or vehicles that have tail lifts that you can ride onto drive onto and raises the floor of the the [sic] taxi" (Respondent **10**).

11.3.1.4: *Talk about remembering and memory loss*

Issues with memory loss were a recurrent conversation in many of the interviews. Again, the quote below uses humour to describe living with adversity. As humour has been described as a tool for interviewees revealing uncomfortable, personal information, it is possible that the inability to retain information as well as he could do prior to his stroke is a significant problem for Respondent 11.

"... memory problems... short term memory problems... [pause]. It's terrible but at the same time I am dyslexic as well [laughs] so I am on a double loop" (Respondent **11**).

This respondent further described the frustration of not being able to do the things that he could previously because of memory problems (i.e. listening to music). What's more, this was a hobby that he enjoyed; the impact of stroke disabilities is so far reaching that he can no longer do some of the things he enjoys the most. His hearing is not impaired, but the multiplicity of health problems prevents him from listening to music in other ways (memory/physical impact on using electronic devices).

"... I forget so much [pause] my short-term memory is terrible... long term isn't too bad at all... I am terrible with the computer... I'll do something and then... well an hour or two later I'll think how did I do it [pause] and then I'll spend ages trying to learn how to do it again. I used to mess about with a lot of music at one time... I used to have mp3 files... and so I could play it on my computer and at one time I could convert it onto disc as audio to play in the living room [pause] so I could do it loads at one time... dead easy and then I just forgot how to do it which is so annoying [pause] so I spent hours trying to relearn it again" (Respondent **11)**.

Furthermore, Respondent 8 described memory loss following stroke in terms of space, place and time. It is apparent that a large proportion of his 'world' has been lost after suffering a stroke, however, the narrative is framed by a degree of ambivalence. He cannot recall much of his time in hospital, but the sense of 'not wanting to know' emerges, indicating fear of the severity of the stroke; 'hiding' from the reality as it could be too much to bear.

"I still ask [name of wife] if something happens on the telly or in the environment we're in... or whatever happens... I just think, what was it like

when I was in the hospital when I didn't do this or didn't do that... or was out for the count(?) sometimes... three months ago or this week... I ask her... but I have never thought... well, I have really thought about getting books and reading about the stroke but she will give me anything I will think of" (Respondent **8**).

11.3.1.5: *The multiplicity of problems and healthcare needs*

When asked about health inequalities in relation to the experience of having had a stroke, respondent accounts illustrated a range of issues that coincided with the complexity of the relationships that constructed their lives. Typically, these centred on the value of the individual in any treatment intervention and the multiple effects of the stroke.

Interestingly, the presenting signs of stroke in these patients could not be assumed to follow a clinical trajectory according to traditional textbook theorising. From this perspective, a common theme among the respondents was the way that the concept of time, or temporality, framed "talk" about stroke, situated in terms of the "long-term".

One of the respondents spoke about the experience of stroke in terms of a "severe headache" that lasted for a considerable duration. Indeed, this symptom alone precipitated the diagnosis of a stroke more than a week later. Although current, national, health promotion strategies and mediated messages, such as FAST (face, arm, speech, time), draw attention to the initial precursors of a stroke, this information tends to be delivered in a rigidly diagnostic form. Though one component of the FAST campaign prioritises "time", the research data indicated an alternative way of understanding temporal markers.

"... you've got to go to find out...what the long term is [pause] because you could get like a headache now and not get one for the next six months but then you will get a headache [pause] because that's how I found out I had my first stroke... was by a headache... because I never get a headache and on this

particular time I had a severe headache that lasted over a week." (Respondent **6**).

Elaborating on this account, the respondent proffered a parallel narrative in the context of a second stroke, which was, again, initially experienced in terms of other/atypical physical symptoms and behaviour.

> *"The second time I felt ill... like I was drunk and I was walking into doorways and bumping into people [pause]… Someone said to me, 'You're walking towards the right hand side all the time', and I had actually had the stroke and I didn't know nothing about it [pause] but it wasn't until then... after I'd had the stroke that I was diagnosed with it [pause] physically I didn't feel like anything had happened"* (Respondent **6**).

Though it was a major focus of the project, the issues around stoke-induced visual, impairments did not emerge as an immediate priority.

> *"I think it's about tackling people as an individual [pause] and it's... it's not the biggest presenting problem initially..."* (Respondent **13**).

For this respondent, it was important to acknowledge that disturbances in sight and vision, though traumatic, did not have a significant impact on their life immediately after being admitted to hospital following stroke. This was largely due to the fact that during their admission to hospital they were placed on a hyperacute ward. In these settings, individuals were not ambulatory and relied heavily on members of the multidisciplinary care team.

It was not until the chronic stage of her stroke, 6 months from the date of stroke onset, that the visual disturbances became problematic for Respondent 13. One possible reason for this is the likelihood that her physical-self recovered well enough to undertake everyday tasks more independently, whereby she started to notice her limitations due to the vision loss. National stroke guidelines recommend patients receive a generic visual screening assessment during the acute stage of stroke. It is

possible that patients would not receive the full range of visual therapies unless complaining of visual symptoms at this stage. Respondent 13 described the importance of revisiting visual consequences in the extract below, referring to the everyday activities as “other things”.

> *“But actually 6 months down the line it might be something that’s having the biggest impact on their lives so it’s about... it matters to me now [pause] it didn’t matter to me when there were so many other things that were presenting... but 6 months down the line it matters to me hugely now and its having a massive impact on my life now... when I couldn’t do all those other things before... other things are meaning that you’re not moving around... but actually maybe just come back to it”* (Respondent **13**).

The extracts below from Respondent 6 describes the collection of problems suffered after stroke to include pre-lived medical problems with diabetes. He suffered two strokes, and depicted a gradual escalation of ailments, including visual impairments secondary to both the stroke and diabetes. These impairments were described as overwhelming and appeared to have a significant impact on his day-to-day life.

> *“Mine’s diabetes as well... I’ve got type-2 diabetes [pause] I didn’t [have a specific visual problem] until I had my first stroke and things gradually got worse after the second stroke... you see I’ve had two strokes”* (Respondent **6**).

Respondent 6 further depicted himself waiting, helplessly, for his ocular condition to eventually take his sight. This demonstrates how stroke survivors may already be living with pre-existing medical issues, causing stress and adversity, worsened by their new stroke-related disabilities.

> *“I always went to get mine [eyes] checked because I’ve been told that eventually I will go blind [pause] that’s through diabetic... you know my diabetes [pause] I’m at stage two now so once it goes to three... that’s when it’s going to go [pause] they are waiting to do this test with the dye and then*

they will decide if they are going to operate or not [pause] I've built up a leakage at the back of the eye so it depends on how big that is" (Respondent **6**).

11.3.1.6: *Talk about 'fear' and 'going mad'*

A recurrent theme that emerged from the transcripts was the fear that the stroke survivors experienced from the new visual impairments, particularly the hallucinations of Charles Bonnet syndrome. This fear often resulted in further isolation, as they 'lived in fear' of being 'found out' and did not want to risk being told that their mental state had been compromised after stroke. Therefore, all of the respondents that suffered hallucinations after stroke initially hid these symptoms from their loved ones and the medical staff, connoting isolation and fear whilst they attempted to cope with their new impairments.

"...I didn't realise until afterwards that I had hemianopia... I was bumping into things... things just appeared in front of me. I also had the, oh what's the thing [Charles Bonnet syndrome], I thought I was going mad and I wouldn't tell anybody about it [pause] but of course I wouldn't tell anybody about them because I thought... I thought they'd lock me up. Why the hell would you tell somebody? At first I thought they [hallucinations] were real and then I realised from people's responses that they weren't real because you realise that pretty quickly [pause] and once I realised that I actually thought I'd gone mad so I kept very, very quiet about them" (Respondent **13**).

Furthermore, when Respondent 13 did not receive a formal diagnosis of hemianopia, she struggled to understand why she was bumping into things and why people were bumping into her. The extract below depicts her confusion and fear due lack of understanding of her new, impaired self. In stating that people were "shouting" at her, she insinuates the publics' impatience and frustration, as she could not communicate her impairments to caution others, and instead, felt that she had become a hassle.

"I had hemianopia so I couldn't [see]... but you don't know... I didn't know that I couldn't see... so I just thought people were shouting at me for bumping into them... I didn't realise I couldn't see" (Respondent **13**).

11.3.2: The psychosocial being

Previous discussion of the clinical psychopathology of Charles Bonnet Syndrome leads well into the discussion of this second key theme identified from the qualitative analysis: the psychosocial being.

11.3.2.1: *Talk about self-identity and spoiled identity*

One interesting feature of a number of respondent accounts was the deployment of humour in a non-humorous setting, which seemed to act as a mask for the sense of a damaged self and identity. In the data extract below, humour also featured prominently in a focus group setting to construct how 'good care' is described in terms of the shock and distress of having had a stroke. The concept of time, once again, featured as an organising aspect of talk, centred on special times or seasons that connoted ideas of family, celebration and happiness. These were powerfully juxtaposed with the descriptor of being a 'long-term patient', signalling a permanent change of status and identity.

"If someone had shot me [laughs]… no I was given good care [pause] as I say I was transferred from stroke to the neuro and it was just that I was there over Christmas and New Year [pause] I was like a long term patient [pause] I had good care... like it felt like very good care" (Respondent **6**).

Self-identity was further compromised after stroke, as Respondent 11 compared his post-stroke life to a demonised group of people, condemned in a spectacle of televised entertainment, public shaming and humiliation. His language suggests anger and shame in becoming that which society considers intolerable. He continues

to describe his contrasting pre-stroke life, which could suggest that he is defending or justifying his current existence.

> *"I am on benefits now... I am one of these people that you see on channel 5... they're always doing... sort of … about people on benefits [pause] I thought... you can't live my life"* (Respondent **11**).

> *"There was a time when I would just jump in the car and travel anywhere... I used to do a lot of driving... I used to go and watch a game of ice hockey over in Hull [pause] I used to do a lot of ice-skating as well... I used to go all over the North West... I did ice dance of all things"* (Respondent **11**).

Once again, the discussion of health inequalities shown above by Respondent 11, is described in terms of movement and mobility (as discussed earlier in 11.3.1.4), suggesting this is an important factor to the stroke survivors in maintaining control and power over their lives.

Loss of employment after stroke was discussed frequently, as well as the impact this has on other aspects of the respondent's self-identity. The wider social aspect of work was further lost after stroke for many of the respondents, in a way that connoted 'social death'. This loss of employment therefore, links to social isolation and a sense of invisibility.

> *"... it changes your life altogether because when you're working... it's not just a case of working [pause] the people you associate with... well you think they're your friends pause] you think... this stroke is catching... you don't see them again* (Respondent **11**).

> *"... not as much as I used to [pause] well the team that we used to go and watch lost their building and they're playing out at Blackpool now and I can't get out that far... so until we get another sort of arena in Manchester...so when that's built I'll be quite happy"* (Respondent **11**).

For the male respondents, a strong feature of the accounts centred on the sense of sexual identity. The quotes below from Respondent 11 supports the notion that the male respondents struggled with masculinity and disclosing difficult and intimate aspects of their life without the use of humour. Respondent 11 illustrated struggles with identify after stroke, as he distanced himself from the female staff on one stroke ward and formed relationships with the male nursing staff on another stroke ward. This inference to sexual identify is presented by the respondent's use of masculine language when describing the two contrasting hobbies (rock music versus a health spa).

> *"...it's nice because the ward that I used to be on... there used to be a load of male nurses that used to be into rock music so we used to talk about rock music. The first hospital where I had my stroke over in Scarborough, it was all the young girls, and all they could say was they had a good weekend...[pause] they had gone to a health spa and they had all gone for this colonic irrigation, and that was a good weekend for them [pause] and I thought... hang on I can't imagine that being a good weekend"* (Respondent **11**).

Furthermore, this respondent uses masculine language, as he continues to relate to the male hospital staff through common, masculine interests, and described a weak relationship with the female staff, as they "had nothing in common". He continues to make assumptions through gender and professional stereotypes, and once again, the use of humour in a non-humorous setting connotes feelings of discomfort in disclosing sensitive information, thus suggesting insecurities around his perceived loss of (masculine) identify after stroke.

> *[Care] was a lot better at [name of hospital] yes and there were male nurses and we could talk all the time (laughs) well I had nothing in common with these... well nice looking young girls (laughs) it was so funny because my cousin used to come in and the nurses... there were male nurses... 'they all*

must be gay' (laughs) I thought the male nurses had more in common with me because they were into rock music as well (laughs)" (Respondent **11**).

The accounts below depicts the addition of loss of employment and income, which indicates the loss of the stereotypical 'male-role' that formed a crucial part of their pre-stroke identity. These accounts introduced work as something of greater value beyond financial reimbursement. Loss of employment resulted in the loss of feeling useful, of having something to do or someone to be.

"... something to do... yeah that's the hardest part... finding something to do." (Respondent **6**).

Respondent accounts identified a consequence of loss of self-identity to be the loss of trust in oneself. The respondents described the subsequent reliance on spouses, family or carers as means of transport, as they could no longer travel independently. Previous sections discussed aspects of dependency and inability to mobilise freely, however, respondents further identified psychosocial aspects of this dependency. Respondent 1, below, described isolation after stroke, as she did not trust her new, disabled body.

"It [disabilities] just stopped me from being able to do what I want to do each day" (Respondent **1**).

The accounts below discussed the post-stroke driving assessment, whereby stroke survivors prove that they have adapted to longstanding stroke impairments, determining them safe to drive. However, many of the respondents admitted that they did not undertake the driving assessment to prove to the driving authorities that they are able to drive. Instead, they wished to "reassure" themselves that they were still "safe". This furthers previous notions that a loss of trust in oneself arises after suffering stroke and/or visual impairments.

"I had to learn to drive. So I basically drive with one eye. I mean I had to do that test to reassure myself…" (Respondent **2**).

"…I didn't drive for six months after my stroke but I had a driving assessment and they said I was ok so, yeah I do drive now… it's like what you said, I think I just wanted someone to tell me I was safe." (Respondent **7**).

11.3.2.2: *Talk about embarrassment and loss of confidence*

Embarrassment, fear of public shaming and loss of confidence have been described previously in relation to mobilising, using transport and dependency. This section coalesces these earlier discussions and adds specific insight into the lives of the respondents after stroke, and how they adapted to, or even masked, their impairments to reclaim dignity and acceptance. The respondents understood the benefits of a white cane in warning the public of their visual impairments, described below as a "parting of the waves" when used in public spaces.

"A white cane just gets you... it's like the parting of the waves... people just move out of your way all the time [pause] people are so courteous to you when you have got that white stick in your hand but they are not as courteous when you've got a walking stick [pause] like if you've got a white stick and you get on a bus people will get up and give you their seat but if you walk on with a walking stick they won't [pause] it's a hell of a difference" (Respondent **6**).

Furthermore, previous discussions on the difficulties of using public transport revealed accounts were respondents stated that their visual impairments were "hidden" from society, making it difficult to gain public support (11.3.1.3). Therefore, a white cane would appear an obvious support to most, however many refused to use one. This practice may be illuminated through sociologist Erving Goffman's theory of "passing" spoiled identities (514), which states that one can manage their 'stigma' by concealing the visible indications of the impairment. It is, therefore, possible that respondents perceive the cane to be a public marker of their visual

impairment, and thus reject the cane in a bid to retain their pre-stroke social standing (see 12.6 for full discussion of passing spoiled identities).

> *"…so there is something to say about not taking help either… I was offered sticks to walk with…but I wouldn't accept."* (Respondent **13**)

Once more, when describing the choice to use a physical crutch over the white cane, the male respondents use humour in a non-humorous setting, suggesting a sense of discomfort in disclosing sensitive accounts of their disabilities.

> *"I walk around with this [walking stick] now quite a lot [pause]…but I have also got a white stick. And when I use the white stick, it is amazing the amount of people that get out of your way and ask if you're ok… but obviously you can't use both at once but because of my balance [I need the walking stick]…"* (Respondent **6)**
> *"Can you not paint that [walking stick] white?" *laughs** (Respondent **7)**

Talk about loss of work, mobility and relationships from a sociological perspective

Many of the respondents recounted experiences of losing employment after stroke, as a direct result of their physical and visual disabilities.

> *"... no I don't really work now [pause] I had a little company that I ran... so I did everything so... if I didn't do it, it didn't get done [pause] and it's like everything is so much harder [pause] it was hard even before I had had my stroke but now it's virtually impossible... but whether that's… I am sure some of it is down to the fact that my eyes don't work properly but obviously there's loads of other things that [unfinished]…"* (Respondent **7**).

Respondent 11 described work as more than a job, but a central hub of friendships and networks that fuelled his social life. Following his loss of employment, these social networks and relationships were lost also, resulting in social isolation. One's loss of employment can therefore, have a significant impact on other aspects of the

respondent's self-identity. The wider social aspect of work was further lost after stroke for many of the respondents, in the way that sociologists have described 'social death'. This loss of employment therefore, links to social isolation and a sense of invisibility. The account below describes the knock on effect of losing employment, to affect social networks.

> *"... it changes your life altogether because when you're working... it's not just a case of working [pause] the people you associate with... well you think they're your friends pause] you think... this stroke is catching... you don't see them again* (Respondent **11**).

Additionally, loss of confidence in mobilising after stroke further impacted on the independence and freedom of the stroke survivors, and the personal responsibility of driving dependants. Respondent 13 (below) further described the additional impact from losing the ability to drive, which consequently affected her family, along with her own mental wellbeing. It appears that the core issue described here by Respondent 13 stems from a feeling of inadequacy, in that she could not be there for her daughter as she could pre-stroke.

> *"It wrecked her [daughter's] life…She went from [having] a Mum who ferried her round everywhere, she was a long way away at school… and she hadn't passed her driving test, to a Mum that just wasn't even there."* (Respondent **13**).

Furthermore, the respondents spoke of a subsequent loss of independence associated with loss of driving. The need to rely on others was a common theme throughout the interviews. Respondent 1 below described the burdensome feeling of relying on her husband, with a sense of guilt or embarrassment in having to ask to be taken places by car. Again, the description of keeping the car at home despite not being able to drive, suggests this person is living in hope, or is not ready to accept the new, dependant circumstances she finds herself in.

> *"It just stopped me from being able to do what I want to do each day [pause] like the car is still in the garage back at the house... I mean my husband still uses it at night because he had a van in the day... but it's asking people to take you place…that's what gets me"* (Respondent **1**).

Once more, Respondent 12's wife noted that he felt burdensome due to his reliance on his wife as his sole means of transport after stroke. The choice of language used by Respondent 6 indicates an unfair loss of control when he can no longer drive; his independence was "taken" from him.

> *"He kept saying he was putting [pressure] on me but it's not, you know? I want to be there to help you."* (Respondent **12's wife**).

> *"…it's your independence has gone, hasn't it? Just been taken off you…"* (Respondent **6**).

Loss of driving has been discussed in relation to loss of independence and freedom, however, this extends deeper as many lost the social relationships and networks, as they could no longer of travel to visit friends and family. Respondent 9 described his inability to drive, and added with difficulties using public transport due to the size of his wheelchair, preventing him from visiting his family. This furthers notions of unfair social isolation following stroke due to the subsequent disabilities.

> *"I used to jump in my car and drive down to my daughters', they live in London. For me to go down in this [wheelchair]… it'd cause mayhem."* (Respondent **9**)

Loss of confidence in mobilising was not only discussed in relation to transport. Respondent 11 reported mobility issues in the home that caused embarrassment. The use of humour demonstrated again in the account below, supported the respondent in disclosing information that he found embarrassing.

"I can knock over things... well the rack that's put in place for the plates drying... I can knock it over (laughs) and I have done several times and smashed loads of... it's a case of there's another one (laughs) but at the same time as well I've got the door handles... the door handles as well... they're set at a certain height and they're like little hooks and not being able to see where my arm is... because that's another thing... I have no idea where it is and sometimes I just walk past the door and it gets caught on the handle [pause] when I went on holiday once I said to Chris [wife] it's my handbag stealer [laughs] you are walking along and it strays and catches a handbag" (Respondent **11**).

11.3.2.3: *Talk about the financial impact of stroke and loss*

The personal cost of stroke to the respondents was a prevalent topic of discussion. This topic emerged from discussions in relation to the cost of losing employment, and the psychosocial impact of loss of income and self-identity.

The loss of employment, and subsequent income, coupled with greater expenditures after suffering stroke, presented as an escalation of inequalities. Respondent 7 recounted the link between loss and income and greater expenditure. Namely, the greater expenditures after stroke took the form of public transport costs required to travel to the multitude of hospital appointments.

"Well, you've got less income and more expenditures, it's not very good is it? (Respondent **7**)

Respondent 6 described his frustration when he later learned that the high cost of travel could have been aided by hospital support systems, however, he believed that this support was not communicated to him during the time of his stroke care. Respondent 10 further acknowledged that there were additional costs to attending appointments at the hospital, but that these were almost negligible in his experience. The two respondents lived in different catchment areas and attended different

hospital sites, therefore, variation in their experiences likely relates to their residing areas and the distance required to attend hospital appointments.

> *"…you have to pay for it [public transport] though at first... I've not long got my pass... my disabled pass but I didn't know that you could claim it back while you were in the hospital [pause] so it was costing me a fortune all the time... I was spending like £100 a month on buses"* (Respondent **6**).

> *"... yes it wouldn't have, made much difference... the hospital in [name of town]... is quite close to here so... it doesn't... it only takes us about say 5... 10 minutes to get there"* (Respondent **10**).

Accounts later explored the possibility of returning to work following a stroke, and tensions emerged between what the respondent wanted to do and the guidance or recommendations of the clinical team (doctors) and employers. However, returning to employment carried cost implications, particularly in terms of an increased reliance on public transport. Respondent 6 described the financial impact of being denied access to work from his physician, despite government employees deeming him fit-to-work. This reflects a possible inequality due to a breakdown in communication with his physician as to whether or not he can return to his previous employment or any employment in general, or, a rigid assessment process restricting him from receiving tax benefits.

> *"I was just told [by employer], "No, you can't do the job anymore"*
> (Respondent **1**)

> *"I am trying to get benefits and everything at the moment and it's just a nightmare. I have been refused twice and had to appeal so basically it means I'm living on 40 or 50 pounds a week…"* (Respondent **6**).

Some respondents, however, recognised that what they wanted to achieve did not always equate to what they were able to achieve in real terms. The account below from Respondent 8 portrays realism tempered by a sense of loss; from a good CV to considering stacking shelves in a supermarket. The respondent characterises this as a shift from being 'up there' to being 'down there', which is possibly metaphorical language used to capture the movement of the person/self in terms of space and time. Referring to others like him as "pie in the sky" is an acknowledgement of the possibility of false hope, where stroke survivors are in denial of their new limitations.

> *"I think that I can afford 16 hours a week... for doing [work]. I probably will go home after four hours a day and crash out... probably... but I think I could do it and I think four hours becomes five hours and then six hours... to... to the day, and I am only 53 now [pause]. I have got to... you know... I am still working for getting my job [pause] you know my CV was right up there but now that I've had my stroke... it's down there and I think getting a job in Tesco or anywhere like that... just putting the products on the shelf... you know... having somebody that would help me do that and then go away and just let me do it [pause]. I think I can do that, and if they're happy enough to get me on as a disabled person or… you know, I'll do that, because all the people who want to be pie in the sky... you know... productions managers or operations managers... you can't do it after you've had a stroke [pause] you know... I will start at the bottom and work my way up"* (Respondent **8**).

It was apparent that many were still feeling the financial burden from loss of employment. This burdensome feeling was described (below) by Respondent 13, as she could no longer work and her husband left work to care for her. This manifested later in the form of clinical depression, as she described it (the financial loss) all "became too much".

> *"My husband actually finished work to care for me… we didn't have my job but we didn't have [husband's] job either…we thought we were going to lose the house originally."* (Respondent **13**)

"… I had an absolute crash, I just decided I didn't want to live anymore." (Respondent **13**)

The lengthy extract below from Respondent 11 portrays an attempt to justify his current social and economic position, by recounting his previous income in depth, before describing a complete loss of income. This complements Goffman's theory of 'impression management' (515), whereby one employs techniques to stage the character that they wish to perceive to others. It can be inferred, then, that Respondent 11 is, to some extent, ashamed of his current financial position and attempts to influence external perceptions of his life. The final statement of this account is a powerful ending to the narrative; "I lost all that", indicating how quickly his life changed financially after the stroke.

***"...** when I first... before I had my stroke I kind of just went from one company to another from £280 a week [pause] and the company... well one of the bosses had moved to this other company and he asked me to go with him...and he said right for the same job we'll give you £350 a week [pause]and I said yeah I'll take that (laughs) and then within I think it was 2 months I got a day job with another company and the owner of the company said... well he knew I didn't want the job because my old boss said take my job I don't want the responsibility [pause] so the owner came and said I know you don't want it but if you do it for Christmas I'll give you £400 a week [pause] I thought yeah ok... he said I know it's not a lot but if you like the job and I like what you're doing I'll knock it up to something de-decent... I thought £400 a week was decent (laughs) but yeah... I lost all that"* (Respondent **11**).

Respondent 1 described his journey from being self-employed, to a reliance on government benefits. Therefore, this issue of a reduced income was further explored in terms of a change in social status and self-identity, which has been touched upon earlier. That is, the way that work is an important part of how people develop a sense

of worth and social value. Labour is productive and earning money defines one's spending power as a consumer. This could be linked to the centrality of work in Marxist social theory (41), , which states that human society progresses through a struggle between two distinct social classes.

> *"I was self-employed, well in a way, because I had to go straight on... what's it called... DSA?"* (Respondent **1**).

Respondent 2 below describes more than just sympathy with/to other stroke victims. This extract is concerned with framing the account in terms of class and status. Here, he spoke of a series of status markers (e.g. cars, jobs, financial security) to set himself apart from those in manual occupations and self-employment, which furthers the aforementioned notion that self-identity is jeopardised following financial loss due to stroke.

> *"... some... some of the stroke survivors I've spoken to weren't so lucky that they... maybe they were a taxi driver for example and they had no pension set up... so when they lost their licence they couldn't go back to work and they... they're... at the moment struggling to try and find something else they can do"* (Respondent **2**).

11.3.2.4: *Talk about patient involvement in care, and a sense of powerlessness (loss of agency)*

As noted previously, when describing the stroke condition, the concept of stroke care was further expressed in terms of being 'good', or not. This concept emerged as an issue worthy of further exploration; an avenue of inquiry that identified, or problematised, the criteria against which service user decisions were made. In short, this theme began to appear as being mediated by clinical-medical power relations, statuses, and the dominance of expert knowledge. The centrality of the statement, "I'm not a doctor", in the data extract below, makes explicit the deferential disjuncture between medical and lay language.

"No... I just don't know because you know... I'm not a doctor... I don't know [pause] again... even if someone had told me I'm not sure I would have taken it in or been in a state to understand it [pause] yeah so it's very... very difficult because what can you do if I'm… basically it would make no difference or maybe I would have understood some of it but I just don't know" (Respondent **7**)

Here, the issue about receiving or understanding information was clouded by the complexity of doctor-patient relations in a hospital setting. Information was described in terms of a privileged gift, one reminiscent of a longstanding debate about knowledge and power in clinical practice.

"We only know what we get told... [pause] not like the experts who know basically what's going to happen... we only know what they tell us" (Respondent **6**)

The respondents further described the sense of everyday things, such as hospital appointments and administering medication, being mediated through an outside agency (the 'home'). While such a service may be helpful as the respondent (10) has poor recall, it also says something about the 'agency' of the individual. Respondent 10 missed the independence of supporting himself, and at times appeared self-conscious that he relies so heavily on "the home". He reports that the hospital no longer contacts him, but instead converses directly with "the home" to make arrangements for him. What's more, the lack of independence appears to cause a loss of sense in space and time domains, from an unending routine that characterises life in "the home".

"I would have forgotten a lot [pause]… it's like my tablets…I know what tablets I'm getting when you give me them but I forget them [pause]…every day seems to run into, into one." (Respondent **10**)

Very much like Parson's concept of the 'sick role', whereby, in order to be 'sick' one must enter a role of sanctioned deviance (516), Respondent 10 appeared to adopt and play a dramaturgical part on the stage of the clinical/medical theatre. Interaction was contextually framed in terms of compliance with medical discourse. To 'nod in the right places' (as described below) does not signal an equitable relationship, rather one premised on medical power and prestige. It appears that the respondent was talking about doing things that were expected of him at that point in time. The gesture of concurrence (nodding) can be seen as a ritualised response rather than being indicative of any real understanding of what was being said.

> ***"****…No I just accepted it straightaway…cause when they done the tests, you know, I just knew, even now it's like a cloud… looking through a cloud [pause] well what they (doctors) were saying… I was nodding in the right places… but it… wasn't staying in there [pause] I wasn't grasping what they were saying sort of thing… it was going in and just going round"* (Respondent 10).

Earlier, attention was drawn to the dissonant relations between patients and healthcare providers expressed in terms of inequalities in power, status and knowledge. One respondent (**8**), alternatively, elected to express this through the experience of having attended a creative writing workshop while in the hospital. Recounted here, was a real, and authentic, challenge to being silenced by the talk of experts. In an emotive extract of data, the respondent spoke about reclaiming lives through language; a language rooted in the soul, or self, of those who had suffered, rather than diagnostic discourses that classified and categorised people in terms of pathological 'otherness':

> *"With me... I got to see [name] the first time I had come here and seen... the bloke who is dark skinned... and he is an author of poetry and [names of two men] but there was maybe only five of them and I joined them to... not put a poem down on paper but just to see how he did it and [name] his name was…. and watching what he did and watching what the others did... he gave them their words to write themselves a poem [pause] and I was good with that I*

was very... always crying... always crying [pause] we had the... not a meeting... oh gosh we had the Liverpool Library in town... we got loads of people to come down and they all did one of their poems [pause] and... aw I'm going to cry… I had written something but I wasn't going to do it but let someone do my poem [cries]" (Respondent **8**).

11.3.3: The systemic organisation of healthcare

This final section of the chapter explores the theme of healthcare and loss, through participant accounts of service evaluation. These accounts mainly reflected acceptance, apathy and resignation of their stroke condition and the proffered healthcare.

11.3.3.1: *Information giving and loss*

A large component of this research was concerned with the process of information giving in terms of timing and format. The participants discussed variations in the quality and quantity of pertinent information offered to them concerning their visual state. The respondents considered verbal and/or written information to be an important part of their post-stroke care, as it provided them with support, visual therapy advice, and reassurance regarding the recovery time. However, this was not always offered in the first instance following stroke, as recounted below.

"We didn't get leaflets until we met [orthoptist name]. I didn't know until he saw [the orthoptist] that he could read, because he kept reading and I was trying to make him rest but actually it was good for him [pause]… she [the orthoptist] gave him an exercise sheet and a plan of what to do…" (Respondent **12's wife**).

The key inequalities identified from the respondent accounts related to a lack of information, the respondent's inability to understand information in the format it was provided, and the subsequent reliance on family members to retain information, which furthered previous suggestions of a loss of independence.

Variation in information provision mainly related to the hospital staff's specific knowledge and experience of stroke-related eye conditions, which differed between hospital sites. Hospitals with reportedly inexperienced or non-eye trained staff provided little or no information to the stroke survivors. Respondent 2 offered a terse response when asked about written information or advice provided, initially, in the hospital regarding visual impairments. She reported a lack of integrated stroke and visual care was to blame for the lack of information.

> *"In a word... no [pause]... no... I got... very little information [pause]… some hospitals didn't have anything to do with any stroke or anything and the last thing would be eye problems and then other hospitals, like [hospital 3], are really good."* (Respondent **2**).

Respondent 10 spoke of the lack of information around his visual impairments at the acute stage of his stroke. He related this to the ward staff's inexperience of hemianopia and Charles Bonnet syndrome, and added that it was due to his wife's observations and comments to the staff that resulted in the appropriate referral to the eye clinic.

> *"I got very little information; it was in fact my wife [name], who first noticed that there was something wrong with my vision"* (Respondent **10**).

As discussed previously, the fear of suffering particular ocular conditions after stroke, such as visual hallucinations, further impeded the sharing of pertinent information due to fear of contention regarding their mental state. Respondent 13 reported actively withholding information regarding symptoms of hallucinations for this reason. The subsequent impact of withholding information, or not receiving it, resulted in confusion, fear and isolation. This respondent continued to discuss the anxiety and depression she suffered from this breakdown in communication and 'suffering in silence'. She postulated stronger staff-patient relations through effective communication, would have encouraged her to disclose this guarded information.

"... what they didn't do... nobody gave information on Charles Bonnet Syndrome but why would they... I'd never said a word to anybody… [pause]… maybe if she'd [clinician] been with me longer I would have probably talked to her about it [the anxieties] …yes…having somebody that you feel comfortable with [and] letting them help you." (Respondent **13**).

Furthermore, it became apparent through respondent accounts that healthcare professionals often disregarded the patient's visual and stroke impairments, which hindered their uptake of information. Respondents reported issues in reading and retaining information due to visual, cognitive and memory impairment following stroke. Respondent 13 (below), described instances where she felt scared and confused when receiving advice and information, due to poor cognition; she perceived information provision as reprimanding incorrect behaviour.

"... and they kind of did explain it to me... but actually my, my brain bit was damaged so I couldn't take it in [pause]... I'd clicked that my brain wasn't working [pause]… and so to me when people were telling me to be careful I just thought they were shouting at me" (Respondent **13**).

Further issues regarding communication emerged from the interviews. One respondent commented, in response to a question about health inequalities and ethnicity that problems were not restricted to those who did not speak English as a first language. He inferred that such communication issues would only be exacerbated for non-English speaking patients.

"Listen... communication is difficult even if English is your first language after a stroke... so if English isn't your first language and you've had a stroke… [unfinished]" (Respondent **7**).

Moreover, respondents recounted reading impairments secondary to stroke, impeded their ability to read written information or retain verbal information.

Respondent 13 acknowledged that the multiplicity of impairments prevented her ability to retain information independently, irrespective of the format through which it was offered.

> *"... I think the only impairment I had with reading was my brain... I was missing lines out while I was reading... and I couldn't read for so long because I just felt too tired [pause] I still do actually but it's not actually the vision impairment I think it's just... I've been told it's... stroke fatigue, that's the only thing..."* (Respondent **4**).

> *"... oh I think people tried enormously hard to give me the correct information... but I had sight impairment and I've got cognitive impairment [pause] how you really work out how to give somebody the right information for them is really difficult [pause]"* (Respondent **13**).

In response to the issue of 'treatment' being explained/clarified, the same respondent (**8**) demonstrated limited understanding of the different roles of the healthcare team. This implies a lack of clear communication, and raises larger issues about dignity and compassion as defining principles of healthcare practice.

> *"…you have nurses who look after you... and the nurses who come in to give you the physio [unfinished, but other members of the focus group recognise this awkwardness and add in 'physiotherapists'] yeah the physio [pause] and they would explain things to you but the nurses wouldn't do any of that" (Respondent **8**).*

In response to a description about information being 'gobbledy-gook', the most appropriate time(s) for material to be introduced in the process of post-stroke care was explored; whether on the first day, incrementally, or at a later point in time. There was a consensus within the focus group that such materials were of little value

immediately post-stroke, but the meaning of terms like 'further down the line' were contested:

> *"Further down the line would definitely be more appropriate for that... yeah... to give you time to recover and take in what's happened to you [pause] you certainly don't need information like that straight away because you're trying to deal with what's happened to you"* (Respondent **6**).

> *"Well, it's how far down the line(?) I mean it might be a year or two [pause] Yeah... I mean [name] said... I talked to someone in there [Stroke Association Support Group] and he said he feels like the first two years after having a stroke is like 'being in limbo' and I would probably agree with him [pause] like I say... you could give me all the leaflets in the world and even if I could read them... would I understand them(?)"* (Respondent **7**).

The respondents further contested the format through which information concerning their visual impairments was delivered to them. Information given verbally ('face-to-face') was deemed preferable by some, but generated concern for others in terms of memory retention. Although written information was not always useful for the respondents, they reported that this could be passed to family. Therefore, timing and format of information appeared highly dependent on the individual's stroke impairments.

> *"You forget what you read or might try and read a line over it or read one word and it doesn't make sense. You can't read the information; you can't take it in."* (Respondent **2**).

> *"I would have liked a letter because I can give it to someone and they can read it out to me… because if I got a phone call… they [family] would say, "what did they say?" and I'd say, "I don't know" because I've forgot."* (Respondent **9**).

Finally, respondents recounted experiences where a lack of information retention consequently resulted in reliance on family members. Despite Respondent 1 reporting the benefits of shared communication between hospital staff and family members, this account furthers previous notions of a loss of independence after stroke/visual impairment.

> *"…the consultant who I saw, he didn't speak to me. He spoke to one of my daughters and my husband away from us and explained for two or three days everything in our English… and they wrote everything down, what was going to happen… this, that and the other."* (Respondent **1**).

11.3.3.2: *Talk about vision care after stroke (or lack of care)*

Post-stroke appointments

When asked about hospital appointments for visual rehabilitation, and other forms of physical rehabilitation, offered after the discharge from the stroke ward, respondents reported contrasting experiences: either they received no post-stroke care, or were inundated with a multiplicity of appointments. Respondent accounts below describe a complete lack of appointments offering visual rehabilitation.

> *"... I didn't get any [appointments] hmm... no"* (Respondent **3**)

> *"I never got anything from the hospital which said I should go get my eyes tested [pause] no... nothing at all"* (Respondent **8**).

Respondent **1** spoke of attending multiple appointments for their stroke condition, which subsequently affected his life financially, due to the incurred travel expenses in attending the hospital. Moreover, his physical disabilities after stroke required the use of a wheelchair, which further required the use of more expensive forms of taxis. The financial strain suffered by this respondent was directly caused by his stroke disabilities and the lack of transport support available to him from that particular care home.

"...at first... I was in... one of the homes... and they didn't... help me with the taxis [pause] so I found that very expensive... if I... couldn't get an ambulance... a taxi would come and they were... quite expensive 'cause I can't get a private cab.... I've got to get a Hackney cab [because of the wheelchair]" (Respondent **1**).

Moreover, Respondent 6 suffered additional financial implications due to the multiplicity of health problems resulting from the stroke, which in turn led to a high number of hospital appointments. The respondents described overwhelming situations, whereby they strived to keep up with the expense of travel for the sake of their health; consequently, their poor health was both the cause, and the barrier, to attending hospital appointments.

"Oh god I had everything because I was going every couple of days for my blood clots because I was out on warfarin and I had to go and have an INR [international normalised ratio] check… every couple of days [pause]. It was working out about £5-£7 a day just for the bus... but £25 a week... it's £100 a month" (Respondent **6**).

The respondents' accounts expressed appointment attendance in the context of post-stroke memory loss and a reliance on other people for assistance. How, for instance, did people manage to get into the hospital if they could not drive? And, was using public transport an option? Subsequently, Respondent 2 discussed a loss of confidence using public transport to get to the appointments, as she lived alone and had no family to rely on for assistance. This theme of reliance on others, and loss of independence and confidence after stroke, featured heavily in all of the transcripts.

"No... I always rely on my husband" (Respondent **I**).

"And I didn't feel confident... I wouldn't have got on a bus [pause] I did with the OT but my vision is still the same and I'm still dizzy and stuff like that... even though I can drive and everything [pause] but I thought I had no

alternative because I live on my own… I had to learn to drive [pause] so I basically drive with one eye...I felt like if I didn't drive I wouldn't go out the door" (Respondent **2**)

The extract below from Respondent 1 describes his reliance on his care home to take control of travel and appointments. His account can be related to changes in spatial (space) and temporal (time) domains as a result of having had a stroke. He portrays a world without clear temporal markers; an unending repetition and routine that characterises life in/at the 'home'.

"... no... I would have forgot a lot of them [appointments]. It's like... my tablets... I've got to have a nurse that gives me my tablets 'cause I forget them [pause] I know what tablets I'm getting when you give me them but I... I forget them 'cause I... every day seems to run into, into one, you know... so" (Respondent **1**).

Appointments in the home

Despite NHS philosophy of 'seamless care' and 'available to all', Respondent 1 experienced a lack of rehabilitation available to him due to his residing area. It seemed that the available care depended upon the physiotherapist's ability to assess the patient in the home setting, which is not consistent between catchment areas.

"no... at first I had a physio... for about 18 months... and then when I moved homes... the physio stopped 'cause she said I was out of the catchment area so she said she couldn't... 'cause she had to sign me off [pause] so then it took 4 years to get another physio" (Respondent **1**).

Respondent 10 received a low vision assessment in his home setting, which arguably reduces the aforementioned inequality of lack of visual care after stroke in a hospital setting, and the previously reported transport difficulties in attending hospital where care was offered. Following discussion, it was revealed that this respondent rejected the white cane (possibly concurring with previous concepts of managing a spoiled

identity), yet he accepted the typoscope (a small reading aid that can be used solely in the privacy of his own home).

> *"... I was asked if I wanted a white cane... but I didn't feel that I needed one [pause]… it was suggested that I use... a small ruler to... slide down the page to... help me... keep to the... the lines of text"* (Respondent **10**).

Further to the publicly displayed identities discussed previously, sociologists consider individuals to adopt a 'back-stage' private identity, whereby they can "be free of the anxieties of presentation" and "rehearse the presentation of an identity backstage before trying to carry it off in public" (517, 518). This notion of variation in private and public selves is exemplified in the above account from Respondent 10; he perceives the white cane to impede his public identity and thus, it was rejected, whilst the typoscope aids reading practice in the privacy of his home and so, it was accepted.

Post-stroke rehabilitation

Previous research has identified a lack of vision services in stroke units nationally, therefore, it was not surprising that many of the stroke survivors that were interviewed noted a lack of visual input to their care. As noted in the earlier examination of home-based care, the quality and availability of visual appointments depended heavily on area of residence, illustrating the well-established inequalities of a national 'post-code lottery'. Respondents 13 and 11 (below) compared the quality of visual care between hospitals when they had experienced multiple strokes.

> *"I was offered a choice of where I had my follow-up…I'd had a really bad, negative experience of the care in the initial stages of my stroke at [hospital 4], so all I knew was I really didn't want to be anywhere near [area 4]."* (Respondent **13**).

> *"Yeah it [the care] was a lot better at [the second hospital]."* (Respondent **11**).

As visual rehabilitation was evidently not available to all, many respondents had to seek care themselves through primary care services. Respondent 1 was forced to attend their own GP in an attempt to make sense of their new, impaired vision, as 'nothing was mentioned' about visual impairment specifically whilst they were in hospital.

> *"Well I went directly to our own GP after because nothing was mentioned about my eyes in the hospital…I took it upon myself to go to the GP to see if there were more options"* (Respondent **1**)

Taking on the responsibility of their own visual care was reportedly difficult for the respondents, attributable to communication impairments following stroke. Stroke-related memory problems prevented information retention, and as such impeded the patient from recalling appointment letters and subsequently receiving their visual rehabilitation. Respondent 6 identified timing of appointments as a key a factor in this inequality, as he was unable to remember appointments letters that were sent out months in advance

> *"Sometimes you get an appointment two or three months ahead and you just can't remember."* (Respondent **6**)

11.3.3.3: *Talk about apathy and the idea of 'just getting on with it'*

Section 3.1 discussed the theme of dependency and loss of agency after the physical body had been compromised following stroke, whereby the stroke survivors can no longer support themselves independently. In addition to this, the idea of 'acceptance' certainly emerged as a theme. Respondent 11 recognised, and quickly accepted, that he could not work and 'earn' again.

> *"no... no I couldn't do anything and I accepted that"* (Respondent **11**).

The stroke survivors talk about their stroke disabilities with a sense of finality, and accepted it "straightaway". This language resonates a sense of surrendering, of giving up without a struggle. On serval occasions, respondents used the term "it comes with the territory" when discussing their stroke impairments, suggesting a common sense of acceptance of defeat across the stroke community.

> *"Well I just accepted it straightaway… I thought it had just come with the territory of the stroke"* (Respondent **1**).

> *"It (disabilities) goes with the territory, doesn't it? What can you do?* (Respondent **12**)

Furthermore, Respondent 12 portrayed things that 'come' with a stroke, i.e. the visual impairments associated with having a stroke, as unwanted visitors 'gate-crashing' into his life. The word 'territory' to describe the stroke suggested ideas about the geography and mapping of the body. Sociologists have described 'mapping of the body' as the process whereby, discourse and power relations are simultaneously mapped and embodied, and thus identities are performed and constructed (519). The respondent's accounts (above) depicts the stroke disabilities as material entities, perceived as something to 'have', thus contributing to their self-identities. While Respondent 12's use of the phrase, "what can you do?' rhetorically connoted resignation; of being resigned to how things had changed in his life.

When talking about stroke survivors receiving vision treatment, or not, one respondent framed his account in language that further expresses resignation and acceptance. With so many of the respondents reporting that they did not receive formal visual care, the idea that they resign themselves and accept the impairments indicates that they may never receive support and visual management.

> *"I just felt it [visual impairment]... it come with the stroke... it's come with the territory you know [pause] so just get on with it... that's what I thought* (Respondent **11**).

The extract below from Respondent 7 is an apathetic account of poor visual care after stroke. Initially, he reports receiving OT at home, but no domiciliary care for his visual impairments. However, he continues to justify the healthcare system and places the responsibility onto himself: "I could go and see them I suppose". This furthers previous suggestions of a power imbalance between the healthcare system/workers and the lay community. Respondent 7 appears reluctant to blame the healthcare system in failing to treat his visual impairments, accepting the caregivers as unquestionably more knowledgeable than himself; instead, he resigns to thinking that he could have taken responsibility of his visual care.

> *"I had quite a lot [home visits] I mean, I was on... what do they call it... supported discharge or something, so the occupational therapist came to see me and… but yeah... no, mine wasn't anything to do with [vision]. Like I said, I can remember going into hospital and having sight tests but nobody came to see me [pause] but then I could go and see them I suppose"* (Respondent **7**).

11.3.3.4: *Talk about how self-help and self-learning in the clinical environment can invert, to some degree, inequities in practitioner/patient power relations*

Attempts to explore interpersonal staff-patient interactions in the context of inequitable social relations as a product of 'stroke', focused on alternative techniques of 'talk' such as pictures or flipbooks:

> *"I couldn't speak... no… totally [pause] they had... [flip-books] which they could get me out of bed with [pause] they would move my legs around for when I wanted to go to the toilet... you know (?) and this leg was totally dead so they… that was all."* (Respondent **8**)

Interestingly, the respondent interpreted a question about 'communication aids' using language that was dominated by a focus on temporal aspects of institutional regimes/cultures. The clinical and physical rituals of nursing and physiotherapy staff took precedence over the most basic of human needs; to be asked (involved) and to

be heard (listened to). This sense of invisibility, another illustration of a 'spoiled identity', and the need to escape from the clinical encounter, was expressed as a plea that seems to have gone unheard.

> *"…the nurse who was giving the tablets... laxative and I didn't want them and I didn't know what they were for and I said this [pause] and he said 'don't you want them(?)' and I... you know [shakes head] and he said 'I'll take them away' [pause] and he had two little tablets left and that was magic... but when I had to go to the toilet they never came in to speak to me [pause] and when the nurses came in they would take you out to a little gym... and they would do the thing with your legs for half an hour and then you were back for the next 24 hours [pause] and then you would get you up… but it might not be until 9.30 [pause] your next half an hour is half 12 so you've had 25 hours [pause] and now I said... now I have got to get home now... I have got to get home to… but they never tried to speak to me"* (Respondent **8**).

Respondent 8 (below) is describing his physical therapy after stroke. He provides an emotive account of powerlessness, trapped in his own body, "*I couldn't speak... I couldn't use my arm…".* He compares different therapies by the length of time they took, again showing the respondent's use of spatial and temporal language to describe their life after stroke. His description, "*I thought, I have got to get them out"* implies frustration from loss of agency and his determination for independence. A strong priority for this respondent therefore, was patient-centred stroke care, whereby he chose goals that were important to him at that moment in time (making dinner and walking short distances independently), which he then interpreted as achievements that gave him hope and motivation. This approach to stroke care, which gave the patient control of their rehabilitation, ultimately reduces the perceived patient-clinician power imbalance.

> *"... the [clinician] who did my hand... she was a little bit longer... but she was... she was going... husband was a solicitor who was going for a big job down south so she was going with him... so … for my leg [pause] really, I had*

nothing... I couldn't speak... I couldn't use my arm and I couldn't... I used to have someone come in to make my dinner and I thought I have got to get them out... I will make my dinner... but I was thinking I can't bloody make my dinner because I can't butter... I can't you know, but I can make it… it's given me hope that I would go this further and walking down the hallway... and then walking down the hallway twice... and then walking down the hallway and into the kitchen in the house... and then when I went into the street and I got further and further and further [pause] because I had just put my hand in my pocket and that was it... I wasn't going to speak to anyone and I just make my leg better" (Respondent **8**).

Furthermore, this respondent's description (above) of "*I had just put my hand in my pocket and that was it...*" refers to his paretic arm that he put in his pocket (out of public sight), therefore concealing the disability. Additionally, stating, *"I wasn't going to speak to anyone*" whilst walking down the street, illustrates that his speech and arm impairments were still problematic, however, while he was concentrating on improving his walking ability, the other impairments were put to one side. This account reflects the patient-centred care approach, shown through the respondent's determination to concentrate on one task at a time, driven by his own personal priorities. What's more, Respondent 8's actions in concealing his stroke impairments could be depicted as further examples of passing a spoiled identity.

The quote below describes an abundance of hospital appointments received after stroke in a positive light (conversely to earlier discussion), as the patient/family take on a formal role of organising and attending clinic appointments, giving them a sense of purpose and motivation. This was especially noted in cases where respondents had lost their jobs, and subsequently, a major aspect of their self-identity. The extract below illustrates the patient's control (power) in choosing which appointments he is willing to attend based on his own abilities and priorities at that moment in time.

"If you look at my calendar it's absolutely full of appointments… they've also offered him how to deal with your…own fatigue but he's not gone, he doesn't want to go to that, he feels it would be too much…" (Respondent **12's wife**)

Furthermore, some respondents expressed an additional desire to control where they received their care, as well as choosing which rehabilitation programmes they would have liked to undertake. Respondent 9 would have preferred visual therapy at home due to his post-stroke memory impairments, further supporting the patient-centred approach to stroke rehabilitation, and considering the individual's preferences and requirements when designing a management plan.

"I think it would have been nicer for them [orthoptists] to come to me [at home] because… normally… I might have forgot where the appointment was."
(Respondent **9**)

11.4: Limitations

The topic of "health inequalities" could have influenced negative responses from the participants. However, it was important to inform the participants of the true topic of the research before gaining consent. To counteract this issue, a topic guide (Appendix 9) was followed to remind and encourage the interviewer to use neutral language, and participants were specifically asked to discuss positive aspects of care, as well as negative, and to reflect of aspects of their care that worked best for them. As one member of the second focus group had to leave before discussion commenced, the total number of that group fell below the minimum recommended number of focus group participants (204). Therefore, this participant was interviewed individually on a more suitable day. The same interview plan was used and the questions followed the same order as in the focus group, using the typed script as a guide in order to reduce potential bias. It was not always possible to hold focus groups and so, interviews were carried out to support the needs of the stroke survivors. Therefore, only interviews were possible for areas two and three.

The initial aim was to recruit patients that had suffered a stroke during the IVIS study period, however due to difficulties recruiting suitable participants and issues with attending interviews due to the stroke disabilities, this criterion was adjusted. Therefore, the timing of stroke onset varied, which could represent outdated healthcare systems for several participants. However, in retrospect, recruiting longer-term stroke survivors provided a representation of the long-term impact of the visual impairments that could, perhaps, not have been captured by those still within the early stages after their stroke.

Finally, the demographic characteristics could have influenced the reported results. The gender differences in the two focus groups could have impacted on the findings. The female participants in the first group naturally chose to attend with their acquaintances and discussion was therefore easier for them. The male participants were not as close, and conversation was initially quite stifled. Perhaps mixing the groups would have produced richer data and future research should consider careful selection of each individual for each focus group to aid control of the group dynamic. Overall, participants suffered a stroke between 2005-2017, however one participant suffered a stroke in 1979. Therefore, some experiences denote an earlier NHS service, and some accounts do not specifically reflect current practice. However, despite these limitations, the participants' experiences were still valuable, as recruitment was difficult (as shown by the small numbers in this section of the research) and the topic has not been previously researched in this group specifically. Future research could narrow the inclusion criteria to further refine findings.

11.5: Summary

In summary, the collective themes identified from the interviews with visually impaired stroke survivors considered "loss" in many forms. Loss of physical aspects of the respondents' lives after suffering stroke-related visual impairments, such as driving and employment, were found to subsequently impact on the loss of their psychosocial being, as many of these physical loses attributed to their self-identities. For example, the respondents' accounts showed a link between loss of

driving/mobility and employment due to stroke, which resulted in loss of independence, income, social standing, social relationships and existentiality.

The findings from this chapter coalesce earlier reports of inequitable vision care after stroke (Chapter 3) through respondent accounts of a 'postcode lottery'. This emphasises the severity of the inequality, as inequitable vision care after stroke has now been expressed by both the stroke survivors and practicing clinicians. The stroke survivors frequently reported a complete lack of visual care, with many recounting apathetic experiences, often resonating power imbalance in the healthcare system. The consequence of the respondents' resignations of their visual impairments, signifies that many will chose not to seek additional care elsewhere, through acceptance that the clinicians 'know best' and therefore, there must be nothing that can be done for their vision.

Furthermore, the findings from this chapter highlight the longer-term implications of stroke related visual impairments, beyond those collected in the clinic setting, which appears to go unrecognised and unmanaged in many cases. Examples of such implications include the social isolation described by many of the respondents, due to fear and lack of confidence. These results emphasise a need to inform and educate both clinicians and stroke survivors of the bigger picture of life after stroke, indicating what is to be expected and highlighting what support is available to patients following hospital discharge. Moreover, where suitable care is being offered after stroke, a desire for a personalised approach to rehabilitation, considering the individual needs of the patient, featured strongly in many of the respondent accounts. These findings highlight an area for future orthoptic services to consider implementing within their rehabilitation programmes.

Chapter 12: Discussion

12.1: Health inequalities in vision services: assessment and rehabilitation

The overarching aim of this PhD research was to explore health inequalities facing the visually impaired stroke population throughout the course of their hospital care and extending into their lives after stroke. At the point of hospital admission, inequalities were first identified from the findings of Chapter 3, relating to significant inconsistency in eye care provision nationally, along with variability in the assessment and management of visual disorders after stroke. Moreover, the recent publication of national stroke guidelines failed to specify the assessment and rehabilitation methods required to correctly manage visual impairments after stroke (104), representing a lack of progress in this area to inform consistent orthoptic practice after stroke. Therefore, Chapters 4-5 aimed to continue this investigation into inequitable visual assessments and rehabilitation, by identifying the full range of efficient methods that should be promoted in stroke practice. However, to fully answer this research question it would be useful to specifically identify the areas that are failing to offer visual care after stroke, in accordance with the national guidelines, to aid the future planning of stroke/vision services in tackling this health inequality. A survey of orthoptic/stroke practice in the UK, conducted in 2018 [pending publication] will support researchers and stroke care providers in addressing this need and ensuring equitable vision care after stroke.

In instances where vision care has been offered after stroke, a significant inequality exists in the inconsistent and overall lack of visual screening offered to stroke survivors nationally (2, 73). As many stroke patients cannot report their visual problems due to their acquired stroke defects, it becomes the responsibility of the stroke team to identify and treat these problems. If untreated, visual impairments have been shown to negatively impact on the patient's quality of life and stroke rehabilitation (4, 10, 520), creating a significant, and preventable health inequality. In cases where visual screening is being performed routinely after stroke, inequalities

exist in the variation of which tests are being used and which health professionals are performing the assessments (73). This variation may stem from a lack of awareness of which tools are most or least effective in assessing vision after stroke from a limited evidence base. This presents a further health inequality facing stroke survivors with visual impairments, as the vision assessments may not be accurately identifying their visual impairments, if conducted at all.

Furthermore, as visual screening after stroke is not currently being performed routinely across the UK (2, 73), stroke survivors cannot be treated for their visual impairments (see 7.5), describing further inequalities in post-stroke visual care. Variation has been noted concerning the management of post-stroke visual impairments nationally (73), in cases where individuals have been fortunate enough to be admitted to hospitals performing post-stroke visual assessments. If untreated, visual impairments have been found to greatly reduce the patient's quality of life, impact their overall stroke rehabilitation, and have been associated with an increased risk of falling and even depression (4, 10, 520). With some hospital sites offering visual management after stroke and others not, patients face a significant inequality dependent on their area of residence and which hospital they attend following stroke. Moreover, despite previous literature highlighting the benefits of including orthoptists in stroke rehabilitation (4, 521), it appears that orthoptists remain inconsistently incorporated into stroke care in the UK. The recent inclusion of orthoptists as part of the central MDT, through redeveloped national stroke guidelines, enforces the need to make vision screening and subsequent after-care a priority within stroke services (104).

Chapters 4-5 identified a lack of evidence to recommend an optimal visual screening and rehabilitation protocol after stroke, in order to inform national guidelines and ensure consistent visual care is offered to all stroke survivors in the UK. It was apparent from clinical experience that some methods were unreported in the literature or supported by weak evidence. Therefore, Chapters 7-8 aimed to offer an insight to the full range of tools available to orthoptists, and depicted change in practice overtime, either in response to new evidence or despite a lack of evidence, which highlighted a need for documentation and dissemination. Potential

inequalities noted from these comparative reviews, have been discussed below in relation to the relevant visual impairment.

12.1.1: Visual acuity

This research has shown that clinical practice has evolved over time to include grating acuity cards and the Radner reading test in the assessment of VA and reading rate after stroke. However, an inequality exists in that there is not enough evidence to highlight the need to specifically test VA after stroke, as reflected in the lack of VA assessment included in many of the generic post-stroke visual screening tools (107, 119): see Chapter 4. This ignorance to visual acuity screening deduces a barrier to consistent identification and management of visual acuity defects after stroke. No evidence was found that specified the use of visual acuity assessment tools with stroke survivors, although they have been proven effective in other, non-stroke populations (445). Therefore, it appears that some changes in stroke vision screening are being made based on results extrapolated from other (non-stroke) populations. Any changes to clinical practice, which have the potential to enhance patient care, must be formally evaluated and documented in the literature, in order to promote these methods to all practicing clinicians and ensure equitable service provision for all stroke survivors nationally. Additionally, any research that deems a visual screening method to be unnecessary or ineffective must further be documented in the literature and clinicians made aware of these findings. Refining the use of unnecessary screening tools could save on NHS resources and allow staff to use their time more effectively. Where orthoptists assessed VA after stroke, they used well-known adapted measures through clinical experience of non-verbal testing (see 7.3.1). Further research is not warranted to prove the efficacy of these tests in stroke patients specifically, however the requirement to test VA after stroke should be promoted to the stroke teams through informed national guidelines.

Comparatively, refraction was performed frequently on patients with all types of visual impairment in the earlier VIS study, and not only for those with reduced central vision, indicating that achieving best corrected VA was an important outcome for most patients. Within the recent IVIS study, patients were referred for optometry

review where reduced VA persisted, or where prism incorporation was required. However, where reduced VA could be explained by inadequate refractive correction through a pinhole examination, the patient was simply advised to bring glasses in from home or to attend their high-street optician following hospital discharge. This infers a change in clinical practice over time, by which the orthoptist can improve the patient's VA whilst preventing unnecessary, timely and costly in-hospital refractions. However, if orthoptists are not involved in post-stroke visual management, then these adapted methods cannot be used and patients may receive no, or substandard, visual care. The overall need to provide visual management after stroke must be publicised to practicing stroke teams to encourage orthoptic input.

Finally, when exploring management options for reduced VA after stroke, this research has identified a lack of use from spectral filters after stroke. It was found that spectral filters were not offered in the earlier VIS study and were offered to only two stroke survivors in the IVIS study with impaired VA. This indicated little or infrequent benefit of this rehabilitation method in stroke/orthoptic practice. Furthermore, the findings from Chapter 5 highlighted reports of inconclusive patient benefits of spectral filters, which prevents their recommendation after stroke without further validation their efficacy.

12.1.2: Ocular motility

The results of Chapter 4 highlighted a significant inequality in the provision of OM assessment after stroke, as this appears to vary greatly when performed by an orthoptist compared to a non-eye trained clinician. As mentioned above, orthoptists are not consistently involved in stroke care, leaving ocular motility assessments open to inaccuracies. It is therefore, imperative that stroke units develop links with their orthoptic departments, in line with national recommendations (104), to reduce this variation. Considering that the results of this PhD research found 20% of stroke survivors to suffer a new OM disorder (6.2), the future planning of services needs to ensure OM is accurately assessed and these patients identified.

Further gaps in the literature were identified in relation to managing OM defects, as the findings from Chapter 5 identified only pharmacological methods for nystagmus

caused by stroke. Additional methods are available to treat alternative forms of OM impairment, such as occlusion and prisms. Once more, the recommendation from this PhD work is not to research the well-known benefits from these methods, but to highlight the need to treat OM disorders after stroke using appropriate orthoptic methods.

12.1.3: Visual field loss

A change to orthoptic clinical practice over time has shown the recent incorporation of the Octopus 900, compared to the Humphrey and Goldmann perimeters used previously. The results from Chapter 4 concluded that further research is required to compare the efficacy of the Octopus and Humphrey VF machines, and the various confrontational methods, to ensure clinicians have the available evidence to make an informed decision of the most accurate choice of test when conducting VF assessments after stroke.

Several emerging computer/phone applications assessing VF loss have been developed, although were not used in either clinical study or have yet to be formally documented in the literature. However, Schute (522) suggested success from using such applications in identifying moderate to severe VF defects. If high-quality research can prove mobile applications to be effective screening methods, they could address the mobility issues identified from using automated perimetry, and address the lack of supportive evidence surrounding the various confrontation techniques. Mobile applications could provide additional impact, including access to training for the public, and increased public awareness of visual deficits. Furthermore, mobile applications overcome issues with staff training (as this is normally inbuilt), so can be used widely outside the visual care team, increasing detection of visual abnormalities and addressing aforementioned inequalities in stroke/vision screening. The BIOS developed a patient information leaflet on visual screening applications that can be used by the public at home. However, a limitation exists whereby these applications cannot, currently, be used in the NHS without MHRA approval (523).

The results from Chapter 5 concluded that not enough high-quality evidence exists to decipher the true efficiency of several of the rehabilitation options for VF loss,

mostly in relation to many of the substitutive and restitutive methods. Therefore, the current recommendation from the literature is for compensatory search strategies to treat post-stroke VF loss, which is in keeping with previous Cochrane review recommendations (126). Peli prisms have an existing evidence base although were used less frequently in clinical practice compared with search strategies, indicating better compliance or success with the paper or web-based training methods (Chapter 8). Much of the VIS and IVIS study participants were offered compensatory therapy in the form of verbal advice and compensation techniques, although there is a weak evidence base outlining this management option, highlighting an area for further research in order to clarify the content and form of this advice, and allow other professionals to replicate this method. Through clarification and dissemination of the advice offered to stroke survivors, services can aim to achieve consistent visual care provision.

12.1.4: Visual perceptual disorders

The results of Chapter 7 concluded that where orthoptists screen for VP after stroke, they use tools with substantiated evidence. Additional VP screening methods identified from Chapter 4, such as object and colour discrimination tasks, are not being used by orthoptists in clinical practice. However, it is possible that these methods are being administered by other healthcare professionals, such as neuropsychologists and occupational therapists, and therefore were not comparable in this review of orthoptic practice after stroke.

The results of Chapter 7 further revealed the screening of VN to be strongly supported with high-quality evidence. Recommendations from this research include keeping VN tests concise so as not to overburden the patient with unnecessary and tiring assessments (117, 120), whilst using measurements to quantify the level of neglect and monitor progression or deterioration in VN. Cancellation tests, with and without distractor items, and figure copying tasks versus drawing from memory tasks, should be compared in future research to ascertain true efficacy of these tools. Such findings will guide clinicians screening for VN after stroke as to the most appropriate tools to use. Once more, streamlining and disseminating the optimal

tools necessary for screening VN could contribute to reducing issues concerning inequitable stroke care.

A broad range of VP disorders can occur following stroke (458), however, findings from this research further revealed that few rehabilitation options, other than those for VN, have been discussed in the current literature. It is possible that several interventions including verbal and written advice are being used in practice with no clear evidence base and as such, further research is required to establish these options and provide clear recommendations for practicing clinicians to replicate these methods. The testing methods identified as having a poor or a complete lack of supportive evidence requires further research to explore their effectiveness and promote their use to all clinicians screening for post-stroke visual impairment (see Table 7.6 for the list of methods requiring further research).

The findings from Chapter 8 concluded that several rehabilitation options for VN, such as those for hemifield eye patching and word recognition training, have an existing evidence base, although were not used in clinical practice. One reason for this finding considers that the evidence for these options succeeded the dates of the VIS study (135, 138), whilst options such as prism adaptation have a limited evidence base and require further research to support their use with stroke patients. However, these therapies were not offered during the routine clinical practice in the IVIS study, suggesting that their use is known but not established through evidence, or there is perhaps a perceived lack of patient benefit from these methods. Further research is required before recommendations can be made for their use after stroke. New treatments with the potential to effectively treat post-stroke visual impairments must be widely publicised to inform clinicians of the development and benefit of new methods and ensure stroke survivors are being offered the best possible management.

Overall, the results of Chapter 8 identified rehabilitation options being supported with high-quality clinical research, such as scanning therapies for hemianopia and VN, and those supported by observational research such as prisms and orthoptic exercises. Where a number of management options exist for a given visual deficit, it is important to use the options that are supported with an evidence base through

trial research. However, it is of equal importance to use those methods with well-established clinical research evidence, such as prisms and occlusion that, both objectively and subjectively, alleviate symptoms of diplopia and thus, do not warrant trials to establish their efficacy. However, other options such as verbal advice and visual aids are used clinically based on experience alone and require further research to demonstrate their efficacy and superiority over other rehabilitation methods. This will provide orthoptists and other allied health professionals treating visual impairment after stroke with a substantial evidence base from which they can make informed decisions on the best choice of management, whilst deterring the use of unnecessary or ineffective rehabilitation methods.

Furthermore, Chapter 8 noted that written and verbal advice was offered most frequently to stroke survivors from both clinical studies, suffering from all possible visual impairments, indicating a significant patient benefit. This coincides with the published literature as many stroke survivors have previously reported a benefit from information resources (524). However, the details of advice options offered to stroke survivors was not documented in the literature and as such, cannot be replicated by practicing clinicians, suggesting a discrepancy in the quality of service provision between hospital sites. If this form of management is believed to be most effective, it is pertinent that stroke clinicians are widely aware of the available vision resources to signpost to stroke survivors.

The leaflets offered in the IVIS study included those developed by the British and Irish Orthoptic Society, the RNIB and the Stroke Association, as well as the treatment factsheet offered in the IVIS study. Many of these leaflets have now been updated following cessation of the IVIS study and additional leaflets have been developed which offer advice on a broader range of potential post-stroke visual impairments.

As discussed previously, many patients with VF loss required verbal advice on driving regulations. Additional online information has now been developed and is available for patients and healthcare professionals offering this advice (457). Furthermore, in response to the high volume of patients requiring written and verbal advice for post-stroke visual impairments, the VISION research unit at the University of Liverpool have developed additional resources for this purpose (525). It is imperative that

clinicians are aware of the available resources to offer stroke survivors and to ensure they are providing the most accurate, evidence-based information.

The choice to offer verbal or written advice depends largely on the patient's own needs and preferences, as recognised through many of the respondent accounts discussed in Chapter 11. The respondents indicated a preference for a patient-centred care approach, dependent on their individual needs and priorities, which applies to the provision of information (discussed further in 12.6). Where memory problems prevented information retention, the respondents deemed written advice preferable as the patient could refer to key points at a later stage. However, if stroke-related visual or cognitive impairments render written advice ineffective, then verbal advice (often provided to carers and family also) was the preferred method of communication (see 11.3.3.1). Health inequalities exist where all persons receive the same level of care (equity), with no consideration to individual determinants of health (inequality) (3, 526). As not everyone benefits from the same level of care provision, the individual's needs must be considered to ensure fair and equitable care provision is achieved.

The findings from the first section of this PhD research depicted visual assessments and rehabilitation to be inconsistently offered to stroke survivors nationally, which was later substantiated by the respondent accounts discussed in Chapter 11, who described their visual care as a "postcode lottery". Although the assessment of visual impairments is significantly more sensitive if conducted by orthoptists, appropriate referrals can still be made by non-orthoptists performing the visual screening, if utilising the correct tools or if appropriately trained (102). The earlier VIS study described in Chapters 7-8 made note of successful screening performed by non-eye trained professionals, as most of the referrals were valid when checked by an orthoptist (101). Where hospitals do not have an orthoptic department, the use of a standardised screening tool could help to reduce the divide between those patients who receive excellent visual care and those that receive nothing. The BIOS referral pathway (103), based on the earlier VIS study (32), is one example of identifying potential visual impairments, through observations and questioning of the patient.

Furthermore, following cessation of this PhD project, the VISA tool (a paper and application-based screening tool created by the VISION research team at the

University of Liverpool), was developed (527) for the purpose of accurately screening all stroke survivors, despite possible disabilities. It aims to successfully allow any healthcare professional to visually screen stroke survivors, and if ongoing research proves effectiveness, such a tool could reduce the reported inequitable visual care after stroke (527). A standardised and effective tool used by non-orthoptists could identify a greater number of patients with post-stroke visual impairments, and subsequently, reduce the inequalities caused by undiagnosed defects.

As Whitehead and Dahlgren (3) stated in earlier research, healthcare services are not the sole cause for health inequalities, and thus are not solely responsible for rectifying inequities. However, modifications to NHS services, such as those discussed above, could reduce the impact that inequalities have on patients to some extent. Therefore, the findings from this PhD research concluding which visual tools and rehabilitation methods should be promoted within stroke care, or require further research to make such conclusions, could reduce the impact of living with visual impairments after stroke. However, inequitable service provision caused by issues, such as unequal area income distribution nationally (57, 58) and thus, the variation in quality of local stroke services, must further be addressed at a higher level to ensure fair and equal care is offered to all stroke survivors in the UK.

12.2: The subgroups 'at-risk' of health inequalities

The findings from Chapter 3 suggested that the following subgroups of visually impaired stroke survivors might be at greater risk of the aforementioned health inequalities in the UK: older age, females, those with lower education attainment, minority ethnic groups and those residing in deprived areas. Health inequalities facing these groups ranged from the likelihood of having a stroke or vision impairment, to limited access to healthcare resources. In response to this finding, Chapter 6 explored the patient demographics deemed "at-risk" of suffering a visual impairment after stroke, and thus, the negative connotations that come from living with such impairments. Initial identification of all stroke survivors with visual impairments revealed the overall number of patients "at-risk", which lends to better

understanding the full extent of the inequalities by identifying the factors associated with them (42). Overall, 46.8% of patients suffered a new visual impairment following stroke, however, this number is likely to be underestimated. It was found that 20% (n=299) of stroke patients were never assessed and therefore, it was not possible to determine whether or not a post-stroke visual impairment was present. It is likely that a large number of these would have suffered visual impairments, as it can be assumed that the more severe the stroke, the greater the risk of post-stroke visual impairments (4, 10). If this information had been captured, the number of patients with post-stroke visual impairments would have increased, thus the number of stroke survivors 'at-risk' of coping with new visual impairments would increase.

Furthermore, the timing at which the assessment was carried out warrants discussion. Of the entire stroke cohort (n=1500), the time at which first visual management could be offered (including if no management was required) was, on average, seven days post-stroke (median three days with a range of 0-404 days/0-153 days for acute cohort only). This variation in time of assessment denotes that a smaller number of stroke survivors were too unwell to receive management immediately after stroke. Furthermore, several outliers that were discharged before visual assessment was possible and then failed to attend subsequent follow-up, widened the range of days after stroke in which management could be offered. Therefore, where patients had been discharged from hospital before visual assessment was performed, it is possible that they had a visual impairment that resolved by the time they were seen by the orthoptist, which would further increase the overall number of patients with vision problems due to stroke.

Although not all stroke survivors were found to have new visual impairments directly caused by stroke, it should not be ignored that a significant number of patients (32.6%) were found to have pre-existing ocular conditions, many of which required ongoing rehabilitation and monitoring. If these patients had not undergone visual screening and their vision problems had not been detected, this lack of diagnosis may have caused detrimental effects to the patient's long-term vision. Many of the stroke survivors recruited to the study were found to have dementia (n=130), speech problems (n=233) and reduced cognition/attention (n=303), which often prevented them from vocalising their previous ocular history whilst the orthoptist was taking a

case history. It appears that there is a need for all stroke survivors to be screened visually, in order to identify all possible ocular conditions, and provide advice where necessary to continue previous visual care.

The findings from Chapter 3 further hypothesised that females, older patients, those with more severe strokes (low Barthel score), those who suffered infarctions, those residing in deprived areas (low IMD decile), and ethnic minorities would suffer more post-stroke visual impairments and show poorer recovery of the impairments. Therefore, the aim of Chapter 6 was to explore these demographics as factors contributing to suffering and poorly recovering from visual impairments after stroke (see 6.3), and as such, highlight patient groups that may require additional support. Discharge destination was also analysed in order to investigate if those with visual impairment were more often discharged to supportive living following stroke (poorer outcome) as opposed to returning home (better outcome).

Following statistical analysis, gender, type of stroke, area of residence (IMD decile) and ethnicity were not found to be significantly associated with having a visual impairment after stroke. The extremely small numbers of non-white British ethnicities recruited to the study did not allow accurate conclusions to be drawn regarding differences in ethnic groups suffering and/or recovering from visual impairments after stroke. However, the ethnicity figures from the study largely reflect the surrounding demographics of the three hospital sites as shown in the 2015 census data (see 5.2) and could not be controlled in an epidemiological study collecting data on the entire stroke cohort. Observations of language barriers limiting visual assessments were noted with ethnic minorities on a small scale during the study period. This included the inability to fully understand and follow instructions for visual assessment without the help of translators, which often caused delays in appointment attendance. Likewise, some cultural demands prohibited female patients to attend hospital for an appointment without a male family member present, further limiting available appointment dates and delaying visual monitoring and rehabilitation. In these circumstances, hospital guidelines were carefully followed, and patients were not seen without employed translators, despite offers from family members to perform the translation. Where translators cancelled last minute, the patient's appointment, unfortunately, was also cancelled and

reappointed to avoid miscommunication and malpractice. Furthermore, the outcome of the appointment was carefully documented in clinical notes to aid future assessments. Nevertheless, the impact this may have had on the patient could not be fully explored in an epidemiological study, representing a limitation of this research.

It has been previously reported that language barriers cause difficulties during healthcare assessments, including the inability to understand staff or read hospital letters (528) and subsequently attend hospital appointments, miscommunication preventing the patient's adherence to treatments (529), the quality of the care provided (530) and the patients' satisfaction (531). Additionally, health services may be affected from the cost of misdiagnoses, mistreatments or prolonged hospital stays due to communication barriers (532), limiting their staff and resources with other patients. However, as these studies are not specific to adult stroke/visually impaired patients, and are mainly American studies, their findings may not necessarily relate to the current study cohort or the NHS healthcare system in the UK.

Therefore, future research should aim to specifically recruit population samples with a wide range of minority ethnicities, where possible, to accurately determine if any groups are more at risk of health inequalities following post-stroke visual impairment. The later part of this thesis aimed to recruit visually impaired stroke survivors to undergo qualitative exploration of such inequalities, however, broad recruitment strategies were unsuccessful in recruiting individuals from ethnic minority backgrounds (see Table 11.1), which is in keeping with the general UK stroke demographic. Recruitment strategies that specifically target ethnic minorities during the study planning stage should be employed in future research to formally capture suspected inequalities suffered by this group due to issues such as language barriers, and to help identify means of tackling patient and staff concerns.

Previous studies have identified lower SES to be significantly associated with stroke, mainly due to a further association with pre-stroke factors such as smoking and hypertension in lower SES groups (232-234, 238). As it has been reported that those of lower SES often reside in more deprived areas (91), IMD was therefore used in this PhD research to investigate the relationship between deprivation and suffering visual impairments after stroke, however, no significant associations were noted. The IVIS

study population did, however, reveal higher numbers of patients residing in areas with IMD decile one (most deprived), in both the visually impaired cohort (28.4%) and the general stroke cohort (28.3%), which is not representative of each of the surrounding areas (533). It appears that the general stroke population typically reside in areas representative of lower IMD deciles, compared to the rest of the population, which adheres to findings in previous studies (225, 226, 234, 238). It would seem visual impairments are directly caused by the stroke and are no more likely to occur in the most deprived residents compared to least deprived. Overall stroke incidence is likely to be associated with low IMD deciles, although due to the nature of the IVIS study data was not collected on the non-stroke population to make direct comparisons.

Additionally, patient gender was explored as a potential predictor of post-stroke visual impairment, as a higher incidence of stroke within the female UK population was previously noted (232). However, other reports found no significant differences between gender and stroke incidence, and pre-stroke risk factors, such as smoking and poor diet, were not significantly different between males and females in the UK (223). The findings from the current study likely reflect the latter view in relation to gender and the occurrence of post-stroke visual impairment.

Similarly, the type of stroke (infarction versus haemorrhage) was included in the analyses as it was previously identified that ischaemic strokes were often associated with older age (231) and were linked to poorer functional recovery (226, 258) after stroke. However, the results of the current study found no direct associations with post-stroke visual impairments and either ischaemic or haemorrhagic strokes.

Of note, many studies exploring inequalities suggested the presence of unhealthy risk behaviours as the link to various inequalities, as reported in Chapter 3. However, this theory has been disputed, arguing that unhealthy behaviours are, in fact, related to the social context in which people live (51). Wilkinson (51) postulated that the true cause of health inequalities in conditions such as stroke, largely relate to unequal income distribution and the psychosocial effect of this, but cannot be explained categorically by unhealthy behaviours alone. This argument considering the root cause of inequalities is supported by the current study findings, as patient groups that were associated with pre-stroke risk factors in earlier research studies, were not

found to be associated with inequalities in developing stroke/vision related inequalities in this PhD research.

The findings from Chapter 6 identified older age, a lower Barthel index and discharge destination as the patient demographics significantly associated with having a post-stroke visual impairment. Older age as a predictor of stroke has previously been reported in the literature (222, 236, 241) and so, supports the finding of a further increased risk of post-stroke visual impairment within this group. An earlier study that concluded contrasting reports of younger persons showing a greater risk of stroke and therefore, a possible increased risk of post-stroke visual impairments, was only significant for ethnic minorities (223), thus providing a possible explanation for this difference in results. As the IVIS study did not recruit significant numbers of non-white British patients, this finding could not be explored further.

In conclusion, the patient's age and Barthel index may be considered predictors of visual impairment in stroke survivors. Older patients who have suffered severe strokes are likely to have a range of co-morbidities, due to or prior to the stroke, besides vision impairment (226, 438, 534). Previous studies have already shown the benefits of addressing visual problems after stroke, which includes reducing the risk of falling and depression, and contributing to rehabilitation therapies (10, 14, 535). Therefore, if vision impairments are not accurately addressed, the consequences facing this cohort would be extensive, as such issues could directly affect the patient's quality of life. Where patients have been discharged to nursing homes before formal visual assessment was possible, it is likely these patients have suffered a post-stroke visual impairment (as they were significantly associated with the above criteria of older age and a lower Barthel index). Therefore, this group are at further risk of the consequences described above (520, 535). It is imperative that visual screening is addressed to ensure no stroke survivor goes undiagnosed and mismanaged; forced to cope with their visual impairments alone. By screening vision in all stroke survivors before hospital discharge, or by ensuring these patients receive adequate visual management through follow-up assessments, this health inequality could be reduced.

12.3: The recovery rates of the post-stroke visual impairments

A recent systematic review (6) identified ambiguity in relation to the recovery of visual impairments after stroke (see 1.4), impeding the information and management planning that orthoptists can provide to patients and carers during rehabilitation. This can only add to the issue of inequitable and variable visual rehabilitation offered to stroke survivors, as reported in Chapter 3. In response to this finding, Chapter 6 further explored the recovery rates of these impairments, to inform stroke/vision service planning and ensure consistent quality of information is provided to these patients, thus addressing this inequality.

The findings from Chapter 6 revealed that recovery of the visual impairments was associated with the severity of the stroke and not the type of stroke suffered. The extent of visual recovery likely relates to the extent of the cerebral damage and the ability for brain tissue to recover post-stroke. Neuroplasticity of neuro-pathways occurs following stroke, by which the rehabilitative process is determined by "remapping" of functional circuits between the central nervous system and cortical regions (536). After suffering a stroke, the patient has a "time-limited window" for rehabilitative therapy to be effective resulting in neuroplasticity (536). Therefore, a large stroke may result in significant loss of brain activity, whereby the remapping process cannot sufficiently occur to regain function, irrelevant of how the stroke occurred (haemorrhage or infarction).

None of the patient demographics collected in the IVIS study were significantly associated with full recovery of the post-stroke visual impairments. However, partial recovery (compared to no recovery) revealed some discrepancies. Only VP disorders (other than VN) were found to show almost complete recovery in all cases. However, all other visual impairments showed an approximately equal split between complete recover and no recovery. This highlights the need to address these impairments whilst the patient is in hospital, as it cannot be assumed that visual impairments will resolve naturally over time. However, the findings from this research offers useful information that orthoptists can provide to patients and families/carers when planning rehabilitation.

Once more, gender, type of stroke and area of residence (IMD decile) were not significantly associated with recovery of the post-stroke visual impairments. Therefore, these factors do not predict the occurrence, and subsequent recovery, of post-stroke visual impairments. Whereas, older age, a low Barthel index, and discharge destination were again, the demographics significantly associated with poor visual recovery. This research previously identified older stroke survivors to have lower Barthel indices (increased severity of stroke) (p=<0.001; see 6.3), with this group of patients likely to have additional co-morbidities and health problems due to the stroke. This finding was expected to result in the increased likelihood of being discharged to supportive living, reiterating the significant health inequality facing this group of older patients who suffer severe strokes; they will likely have health problems and additional stroke disabilities unrelated to vision, and developing new visual disorders in addition to these, could have serious consequences to the patients' recovery and quality of life. Developing newly acquired visual problems would only widen the pre-existing inequality gap for older, more unwell, stroke survivors. In a continuous growing and ageing population, it is expected that issues relating to older age will begin to affect more people (96). By quickly assessing stroke survivors and offering visual care at the first possible instance, it may be possible to reduce the co-morbidities brought about by untreated visual problems, whilst addressing inequalities in service provision identified earlier in Chapters 3-5.

12.4: Inequalities in accessing services after stroke

Following discharge from the acute stroke setting, inequalities were identified in relation to access to services following stroke and/or visual impairment (Chapter 3). Research by Whitehead and Dahlgren (3) concluded that, overall, access to NHS services is a small determinant of health in the wider context of health inequalities, but one that the health sector must tackle directly. Therefore, Chapter 9 further aimed to investigate the attendance rates at the three orthoptic outpatient clinics of the IVIS study.

Many stroke patients in the IVIS study were not offered a vision follow-up appointment due to perceived issues attending hospital due to poor health, inferring a barrier to accessing vision services. Overall, IMD and ethnicity were not found to be significantly associated with being offered an outpatient appointment. This contradicts previous findings that stroke survivors from more deprived areas are less likely to be offered stroke care (222, 234); see 4.3.3.1. However, these relate to non-visual stroke services and may not compare to the findings of the current study, thus explaining these differing results. The topic of "postcode lotteries" has been discussed in the literature in relation to healthcare services (537-539), and more specifically, to the visually impaired stroke population, where it was reported that approximately 45% of stroke survivors would not receive adequate care depending on the area they have their stroke due to inconsistent hospital care nationally (73). It was not possible to explore this inequality through the longitudinal clinical study in the second phase of the research project, as the stroke survivors recruited were known to have been admitted to a stroke unit and received sufficient visual care. Therefore, it was not possible to collect the views of stroke survivors' that did not receive adequate care. In response to this study limitation, Chapter 11 explored access to vision care through focus groups and interviews with visually impaired stroke survivors (discussed later in 12.6).

As noted previously when discussing findings from Chapter 6, ethnicity could not be accurately analysed in relation to appointments offered and appointments attended due to the small numbers of ethnic minorities recruited from each of the hospital sites. Therefore, it cannot be concluded that any particular ethnic group were not offered appointments or face increased difficulty in attending outpatient appointments following stroke. However, previous studies identified issues experienced by ethnic minorities in attending hospital appointments, which included written and spoken language barriers, and religious holidays (476, 477). Once more, it is possible that the IVIS study cohort experienced such issues, as clinically significant incidents were noted anecdotally during the IVIS study (discussed earlier), but these were not statistically significant due to the small numbers recruited. One recommendation from this research is therefore, to employ a different method of

data collection, or to specifically recruit minority ethnic groups, in future research studies exploring potential inequalities further.

The findings from Chapter 9 identified males, younger stroke patients, those discharged home and those with a Barthel index of 20 as significantly more likely to be offered a follow-up appointment. Few studies have previously explored which groups of stroke survivors are more at risk of inequalities accessing post-stroke services to make direct comparisons. Furthermore, there are no previous studies that directly discussed access to vision-specific care after stroke for individual patient demographics.

The findings from Chapter 3 identified gender inequalities relating to variation in accessing (non-visual) care after stroke (see 3.3.3.3). It was reported that males were less likely to be offered ECGs (234), whilst females were less likely to be offered brain imaging (236). However, in both studies the authors offer little explanation for the gender differences, even alluding the findings to chance (236). A greater number of additional studies found no significant differences between genders in accessing post-stroke or vision services (238, 239, 261). Therefore, it is unclear as to why this PhD research found that more males than females were offered an orthoptic outpatient appointment during the IVIS study. One possible explanation could be the fact that significantly more males had a Barthel index of 20 (see 9.3.14), suggesting fewer post-stroke disabilities. Considering that appointments were not offered in the IVIS study where the patient was deemed too unwell to attend the hospital, it is possible that this finding relates to the health of the patient and not their sex.

However, possible reasons for why more female patients suffered poorer outcomes after stroke, and thus had lower Barthel indices, must be addressed, as interpretation is not clear. Previous studies also found females to have poorer stroke outcomes compared to men (540). Ridker et al. (541) suggested that female gender contributes to the inflammatory response in cerebral ischemia. The baseline level of high-sensitivity C-reactive protein, which is the only inflammatory marker independently associated with stroke risk (541), is increased in women between 30 and 65 years compared with men (542). This finding, and other markers, could play a role in female brain ischemic injury (540).

Alternatively, older age (relating to poorer health pre-stroke) could be a key aspect to this finding (540, 543). It is well reported that females live longer than males and previous reports have linked this fact to higher rates of disability observed in women (544). The female patients with lower Barthel indices in the IVIS study were significantly older, which further supports this hypothesis that older age, and the medical complications associated with older age, contributed to the finding that females were less likely to be offered post-stroke care.

If the true reason for the association found in this study between gender and Barthel index is genetic, thus associated with the patient's gender, then the nature of this variable is not deemed an unfair and preventable health inequality (3). However, if patients are being withheld visual care after stroke due to clinicians' judgement alone, then Rudd et al. (473) recommends education and development of staff is required. Further research would be required to ascertain the overarching reason for this finding.

Discharge destination has not been reported previously in the literature as a predictor of receiving post-stroke care for comparison to the findings of this research. However, as older patients with lower Barthel indices were significantly more likely to be discharged to forms of supported living following stroke (see 9.3.1.7); this corresponds with the above argument regarding gender.

Where patients have been withheld vision care after stroke, it seems likely that clinicians have based decisions based on perceived poor health associated with stroke and/or older age. Therefore, this research has identified a significant health inequality; those patients discharged to supportive living, who were significantly older and more unwell, were not offered an outpatient appointment by the hospital staff. This coincides with previous literature on patient-clinician power imbalance and medical dominance (545, 546), as the decision was made by hospital and nursing home staff. Although this decision was supported through the significant poor attendance noted when appointments were offered to this group, this does not address the fact that patients may have been suffering from untreated visual impairments due to difficulties such as, transferring to the hospital. This reflects earlier discussions of health inequalities facing persons with untreated visual impairments (see 6.6), including depression, risk of falls and delayed rehabilitation,

which are already more prevalent in an older, more unwell, population. Possible means of addressing this inequality are discussed later in 12.4.1. Similar patient-clinician power imbalances were noted in Chapter 11, and respondents implied that a patient-centred care approach, or alternative, home-based orthoptic care, could further tackle this inequality by giving power back to the patients regarding their rehabilitation.

The results of the statistical analysis of the various attendance groups found that IMD and gender were not predictors of post-stroke hospital attendance, whilst a low Barthel index (increased stroke severity), older patents, those discharged to supportive living and those patients wearing an out-of-date glasses prescription, were found to significantly predict poor attendance of hospital eye appointments.

It was unsurprising that gender was not found to be a significant predictor of hospital attendance, which concurred with previous findings, as there was no suspected reason for such a relationship (90). Where studies have previously reported males to be less likely to attend outpatient appointments, these studies either included non-stroke patients (470), or had a much lower average age of patient (471), and therefore, were not representative of a stroke population for direct comparison to the IVIS study.

However, it was hypothesised that lower IMD would result in poor attendance, often due to poor education attainment and health awareness within lower SES groups (87), however this was not a significant finding of the study. Previous studies reported post-stroke services to be poorly attended by lower SES patients (234), and researchers have argued whether or not eye services are poorly attended by this group (235). The cost of using community vision services has been suggested as a possible explanation for this inequitable uptake of eye care between the higher and lower SES groups (90, 240). However, previous studies have related their findings to high street optometry services, and as such, are not comparable to the free NHS orthoptic care offered to stroke survivors during the study. This may explain the conflicting finding that the IVIS study patients with lower IMD deciles, representing lower SES, attended appointments as well as those with mid-high IMD deciles. However, where patients have poorly attended eye care appointments in the past, they were significantly more likely to DNA their orthoptic appointment after stroke

(9.3.2). It is possible that in these cases, a previous experience of costly optometry appointments has resulted in perceived high costs of hospital vision treatment, resulting in poorly attended appointments. In order to explore the true nature for this finding in greater depth, appointment attendance was incorporated into the topic guide for the interviews (Chapter 11), discussed later in 12.6.

Barthel index and discharge destination have not been previously investigated in relation to outpatient attendance for comparison. Older age was identified as a risk factor for poor hospital attendance, although contrasting studies reported that younger patients DNA appointments more so than older patients (469, 471). However, these earlier studies represented visually impaired, non-stroke populations, whereas the IVIS study represented a stroke population with additional comorbidities, of which older-age is more prevalent (see 4.2.3.4). Therefore, the findings from this PhD research recommend that when arranging outpatient appointments for stroke survivors, older-age should be considered a risk factor of poor attendance.

Overall, the results of the attendance evaluation showed broadly similar findings at all sites, although, Hospitals 1 and 3 had more common findings compared to Hospital 2. This may be explained by the different types of hospitals: Hospital 1 is an acute hospital, Hospital 2 is a hyper acute centre, and Hospital 3 was a district general hospital at the time of the study commencing and is now classed as an acute hospital. Hospital 2 further comprises a large tertiary centre with more stroke cases, covering a larger catchment area and as such, differs significantly from Hospital 1 and Hospital 3.

In the cases of those patients that were offered appointments by the orthoptists, their main reasons for non-attendance were; the patient felt too unwell to attend or that their visual symptoms had resolved, and they no longer required the appointment. However, patients further reported transport difficulties, particularly at Hospital 2, and many stated that they were already attending an eye clinic or opticians regularly and felt they did not need the additional eye appointment.

It should be noted that several patients could not be contacted at the time of investigation as they had died (n=9, 1.9%) or because their contact details were incorrect (n=486, 8.6%). For those that died after discharge, it is possible that they

would have also struggled to attend their hospital appointments due to poor health, further adding to the number of non-attenders. This would however, aid justification of the clinical decision not to follow-up to these patients due to expected difficulties attending.

Surprisingly, few patients did not attend because they had forgotten their appointment (3%, n=11). This contradicts the previous study findings where the majority of ophthalmology patients DNA for this reason, although these studies were not inclusive of stroke patients (467, 475). For the visually impaired stroke population, poor health and transport difficulties as a result of their stroke were more significant factors of non-attendance.

Several patients who attended their hospital appointments may still have faced difficulty in doing so, although this was not directly investigated in the study. It may be useful for clinicians to ask patients or families during outpatient appointments as to whether or not they are having difficulties in attending the hospital and advise them of any support or alternative arrangements that can be offered to them. This suggestion corresponds with the findings from Chapter 11 (discussed later in 12.6), as the respondent's indicated a desire for personalised care that revisits their "main problem" at each hospital visit, allowing for support to be offered at the most suitable time for them.

12.4.1: Overcoming poor attendance in outpatient clinics

In order to tackle the aforementioned inequalities in accessing stroke/visual services, several approaches could be implemented. Only a small number of stroke survivors reported specific memory impairments impeding outpatient attendance, although they should not be dismissed in future service planning for this reason. To improve outpatient attendance in cases of memory impairment (related or unrelated to the stroke) and where multiple outpatient appointments are overwhelming for the patient, various approaches have been suggested. These include postal reminders, telephone calls or short message service reminders (464, 469, 476, 547), which have been found to reduce DNA rates by up to 38% (467). A review by Hasvold and Wootton (464) comparing all forms of reminders included ten UK studies for

comparison with the IVIS study population (466, 467, 547-553). The authors concluded that attendance improved from use of each form of reminder. However, text message reminders, although supposedly more expensive, have shown to be the most effective in improving attendance (464), suggesting that this mode of communication reaches more patients. One complication with this method of communication however, relates to the finding that text reminders were deemed most effective when sent from a healthcare professional (464), as opposed to an automated computer, which may not be feasible in large clinics. Arguably, however, sending a text message is less laborious than rearranging missed clinic appointments (467). Moreover, as only a small number of stroke survivors reported problems with memory impairment, it is possible that they could be easily identified and targeted with this form of communication specifically, reducing clinician burden whilst addressing the needs of those stroke survivors.

Beauchant and Jones (469) recommend sending a reminder within 8 weeks of the patient's appointment as DNA rates significantly increase beyond this point, while more recent studies recommend sending the reminder out within a week of the prospective appointment (467, 547, 549). Hospital 2 was the only site to confirm sending text or phone reminders out on a regular basis, and as such, Hospital 2 had the lowest DNA rate and highest cancellation rate of the three sites. Some patients however, still failed to attend their appointments, with two patients reporting cognitive/memory impairments as a leading factor. As the reminders can be sent to patients up to two weeks before appointments, this may be too far in advance for patients to adequately remember, explaining the small, remaining number of non-attenders. Moreover, it should be noted that the orthoptic outpatient appointments for patients discharged from Hospital 2's stroke unit are carried out in a community clinic in Area 2, approximately five miles from the hospital. Therefore, it is likely that attendance was less of an issue when travelling to a community clinic. Recommendations from this research therefore, suggest making orthoptic services more accessible to patients, and exploring the possibility of more community-based orthoptic rehabilitation, where possible, to address inequalities in accessing services after stroke.

Hospital 3 reported the cessation of automated reminders when they updated their hospital's computer system in November 2016. This is reflected in the peak of non-attendance in the outpatient clinic after this date, further highlighting the benefits of appointment reminders. Further ways to address nonattendance include involving the patient in the appointment booking process; allowing them to choose a date that suits them before leaving the clinic has been found to improve DNA rates compared to when appointments are sent out at random (554). Unfortunately, patients were not included in the booking process during the IVIS study due to the nature of the research clinics; the orthoptists had to make the appointments retrospectively, with limited booking slots. Therefore, this could potentially explain the higher DNA rate observed in the IVIS study compared to the figures in the published literature for nonattendance in ophthalmology clinics (465, 475). This suggestion of including patients in the booking process concurs with the respondents' discussions of patient-centred care as a means of addressing their difficulties at an individual level, and a recommendation from this research asks orthoptists to considering adopting such an approach.

A significant number of patients at all sites chose not to attend as their symptoms resolved but did not cancel their hospital appointment. These findings concur with the current literature, which highlights the importance of encouraging patients to cancel unwanted appointments as much as encouraging them to attend (474), and further recommends identifying these patients early on to prevent unwanted appointments being made (555). Thus, clinicians should encourage patients to cancel unwanted or unnecessary appointments as well as reminding them to attend. However, this recommendation should be implemented with caution, as many patients in the IVIS study were asymptomatic of their symptoms, yet were outside of the visual requirements for driving after stroke and required advice (see 8.3.3). Thus, it is important that orthoptists use their clinical judgement to identify potentially asymptomatic patients that may still require visual monitoring and encourage attendance.

For those with symptomatic and troublesome post-stroke visual impairments who cannot attend their appointments due to poor health, cost or transport difficulties etc., further action must be taken to address these inequalities and ensure these

patients receive adequate visual care. It should be recognised that a significant number of patients at all sites (38%) were deemed unsuitable by the orthoptists to receive an outpatient appointment. This is mostly as a result of the perceived limited benefit of transporting very unwell patients into the hospital for a short clinical visit, which was confirmed through significant poor attendance rates noted when appointments were offered to patients with more significant disabilities and travelling from nursing homes. The issue of stroke survivors residing in nursing homes not receiving the care they require poses a significant health inequality, as these patients were found to have significantly lower Barthel scores (indicating greater disabilities) and significantly more visual impairments with poorer visual recovery (6.3-6.4). Therefore, it is likely that this group would have benefitted greatly from visual care. Difficulties transferring patients to hospital from nursing homes has been previously reported, and includes factors such as the little support from family members or poor staffing skills in transferring patients (478). Interviews with nursing home managers reported a preference for allied health professionals to collaboratively deliver care within the nursing home setting to address these issues (478). Further research is required to report on attempts to address poor attendance and inform future services of the means to aid outpatient attendance and reduce missed hospital appointment for stroke survivors with visual impairments. A means of addressing poor attendance and meeting the visual needs within this group, could be a domiciliary orthoptic service. Moreover, a small number of patients requested home visits during the study but could not be offered this service. The patient demand for an orthoptic home visits service, albeit potentially small, cannot be ignored. Thus, home visits should be explored further as a potential solution to continue managing this potentially small but significant population, which could also be transferable to a broader, neurological population.

Another possible suggestion for overcoming the observed inequitable access to vision care for patients travelling from nursing homes, could be the incorporation of orthoptists within early supported discharge (ESD) teams. The NICE guidelines describe ESD as, “an intervention for adults after a stroke that allows their care to be transferred from an inpatient environment to a community setting”. It enables people to continue their rehabilitation therapy at home, with the same intensity and

expertise that they would receive in hospital."(556). Typical ESD teams have included speech and language therapists, physiotherapists, occupational therapists, nurses and stroke physicians (557, 558). Orthoptists are not routinely involved in the ESD planning of stroke survivors, which is unsurprising as the role of the orthoptist is often neglected in stroke rehabilitation (4). However, if included, this could potentially address inequalities of treating visual problems following stroke for those patients unable to attend hospital, which in turn, could impact the overall quality of stroke rehabilitation (10). Furthermore, the role of the Eye Care Liaison Officers (ECLO) in signposting stroke survivors with visual impairments to the appropriate vision care pathways is an effective means of supporting these patients. Establishing links between the ECLOs and orthoptic departments, and ensuring appropriate methods of visual screening are employed in a basic visual screen through education, could ensure stroke survivors receive suitable care in cases where the orthoptists are not undertaking the acute visual screening.

The findings from Chapter 9 further revealed that asking patients if their glasses prescription is up-to-date, or if they have visited their optician in the last 18 months, could predict later outpatient attendance. If asked during the case history, this line of questioning could help to identify the patients at greater risk of poor attendance therefore, indicating where greater care should be given to encourage attendance. This may ensure these patients receive the eye care they require, reducing inequalities in access to care.

12.5: An evaluation of orthoptic home visits: a possible solution to inequalities in service provision after stroke

The vast majority of responses to the home visits survey (Chapter 10) came from English hospital sites, limiting the potential generalisability of the views to the entire UK and Irish orthoptic population. However, this may be an accurate reflection of a lack of orthoptic departments in the rest of the UK, or a lack of orthoptists registered with the professional body, as opposed to a considerable number of departments who chose not to respond to the survey. Moreover, it is possible that devolved

countries chose not to respond to an English-based survey due to a perceived lack of relevance to their local health Trusts.

Overall, most orthoptic departments in the UK and Ireland do not provide a home visit service, with only three confirmed hospital sites offering this service. The facilitators to implementing orthoptic home visits, as identified from the survey, included certain patient requirements, mainly unwell or bedbound patients, including those with reduced cognition and a diagnosis of stroke, with difficulties transporting to hospital. This concurs with the findings from the evaluation of patient attendance (Chapter 9) as similar patient groups struggled to attend outpatients. The findings from the survey suggest that where home visits are being used routinely, they support the use in stroke/neurologically impaired patients requiring visual rehabilitation. Furthermore, the home setting could facilitate the orthoptic assessment in some cases, specifically for patients with low vision that would benefit from an eye assessment their "real-life" environment. Such assessments could potentially identify hazards in the home, or beneficial repositioning of furniture to compensate for the visual impairments. Not all rehabilitation methods were identified as suitable for home visits, however, those that were recommended included, advice options, prism fitting for adults and occlusion therapy for children.

This concurs with the current literature, which states that clinicians must identify those patients who would benefit most from home visits, as there are some groups who would be better treated in a hospital setting (499). Furthermore, Hillier and Inglis-Jassiem (484) recommended that "client-preference" should be used to determine delivery style if both (home and hospital outpatient) appointments can be offered by a flexible agency on discharge from hospital inpatient settings. This corresponds significantly with the findings from this PhD research, as particular patient groups and requirements were suggested to benefit from home visits more than others (described above), highlighting the need to include patients and carers in the decision process. Moreover, the interviewed respondents (Chapter 11) expressed a preference for this form of rehabilitation, further supporting this method. Currently, no literature has been published on the use of orthoptic home visits, therefore future research is required in order to establish the effectiveness of

domiciliary care in these groups, in order to inform clinicians of the potential benefit of this service.

Nevertheless, for the majority of orthoptic departments there is currently no home visit service, nor do these orthoptists consider it is a necessary or feasible service, mostly due to a perceived lack of need for home visits, alongside trepidations and reservations of cost, staffing, and safety. Overall, the key barriers to implementing orthoptic home visits, as identified from the survey, included staffing (constraints and concerns, including cost and travel), particular patient groups that would not benefit from home-based services (namely paediatric patients), and limitations of assessing and managing patients in the home setting.

Several responders further reported concerns over unsuitable testing conditions within patients' homes. Although, it could be argued that for patients on acute wards such as stroke, this is often the case anyway. Furthermore, many responders conveyed the potential difficulty of bringing all necessary equipment into homes and the predicted expense of purchasing additional equipment. Again, in cases of ward assessments, a small case of equipment is usually all that is required for transporting essential tests and treatment options (32). Orthoptists across the UK carry similar bags of equipment when conducting preschool vision screening assessments (559-561) and orthoptists should be reassured that although the cost of some additional items may be required, the overall equipment should not be too cumbersome to bring on home visits.

A recent systematic review concluded that, "service provision should shift towards more home-based services for the rehabilitation of people with stroke living at home, especially if cost is factored in" (484). As yet, studies have not evaluated cost-effectiveness of post-stroke visual care, however, the National Clinical Guideline Centre (562) suggested that any additional cost of orthoptic input to stroke rehabilitation, in general, would "be offset by the long-term benefit of patients in terms of improved quality of life". Therefore, it is possible that home visit services after stroke, ensuring visual rehabilitation is proffered to all patients, could be cost effective, although further research employing health economics would be required to explore this specifically.

Many orthoptists, who are not currently offering home visits, raised concerns over staff safety when entering a patient's home. Concerns regarding staff safety whilst performing home visits for a range of professions have been acknowledged in the current literature (484, 500). Moreover, it has been reported that if the visitor is distracted by safety concerns then the quality of assessment is compromised (500). However, various methods to address these concerns have been suggested and should be followed to ensure security and protection for staff. After contacting those departments with an established home visits service, it was revealed that policies and procedures are followed to ensure staff safety is maintained, as is the case with the many other allied health professions performing home visits. Procedures such as ensuring others are aware of the visitor's whereabouts; regularly checking in with others whilst performing the home visit; avoiding unsafe areas and planning the route before travelling can help prevent risk. Providing staff with the appropriate training can further enhance their safety if met with risk, whilst reporting incidents can improve the service for future visits. Moreover, it should be noted that clinical orthoptists often work alone in individual clinic rooms and face the same risks as those entering a patient's home to do an orthoptic assessment. Thus, lone worker policies should be developed and followed closely, to support orthoptists offering this service in the future.

12.6: Stroke survivors' lived-experiences of health inequalities

The findings from the final chapter of this thesis (Chapter 11) explored the longer-term, lived experiences of stroke survivors with visual impairments, to investigate the impact of living with any inequalities, such as those identified from the earlier chapters. Overall, the experiences of the visually impaired stroke survivors, as reported in the focus groups and interviews, comprised of inequalities concerning the physical being, the psychosocial being and the systematic organisation of healthcare, which all centred on the overarching theme of "loss".

Inequalities concerning the physical being described the loss of virtual possessions after stroke (driving a car, maintaining employment and a sustainable income), in

addition to the loss of the respondents' ability to mobilise and undertake everyday tasks as freely as they could prior to suffering stroke. The recounted loss of so many aspects of one's physical life following stroke and/or visual impairment, concurs with previous findings concluded in Chapter 3, which highlighted cases of transport difficulties and loss of employment due to stroke/visual impairment (227, 230).

However, the respondent accounts expressed strong links between the various physical losses such as, loss of driving influencing loss of employment, which subsequently led to financial strains for the patient and their families. Although it has been widely stated that socioeconomic disadvantage often precedes poor health, links to "reverse causation" have been noted at "an individual level", whereby poor health and social problems effect loss of earnings (563). This phenomenon has been described as a "cascade of health disparities" in previous research concerning adults with learning disabilities (564, 565), but seems equally pertinent to inequalities suffered following stroke. A cascade of disparities is described as the culminating effect of issues that results in poorer health outcomes through consequences such as, lack of attention to specific care needs and inequitable access to healthcare (565). Therefore, to reduce inequalities, health disparities at all levels must be considered and addressed. Krahn and Fox (565) recommended preventative care and health promotion strategies to improve health outcomes for adults with learning disabilities. However, researchers have argued that "strengthening individuals" is only one step in reducing health inequalities, and emphasise the need to strengthen communities, improve access to services and encourage macroeconomic change (566). Moreover, in the case of the visually impaired stroke survivors, the above recommendations could be furthered to meet needs specific to their cohort, as identified from this PhD research. If clinicians are made thoroughly aware of the possible impact that stroke and visual impairment can have on patients, at all stages of their lives, including those outside of the clinic room, then they can prepare patients and signpost to support services that could reduce travel and financial complications.

A further theme that emerged from the respondent accounts described inequalities concerning the psychosocial being; namely, a loss of self-identity and loss of agency following the aforementioned physical losses. Goffman (514) described the concept

of a “spoiled identity” as living with a discrediting attribute, a concept originally published by Mead (567). Similar experiences of loss of identify after stroke have been observed in the literature due to visible changes in the body (504, 568). The psychological effect of stroke and the consequential loss of one’s identity have been described by Murray and Harrison (569). The authors reported themes of disrupted embodiment and loss of self when interviewing stroke survivors on their experiences of having a stroke. Their views are comparable to those of the current study participants, who struggled to come to terms with their new post-stroke bodies and the outward markers that display their disabilities. The respondent accounts discussed in Chapter 11, conveyed emotional consequences of coping with a new, spoiled identity.

Little is known regarding spoiled identity following visual loss, which for some of the respondents was their only remaining physical impairment in the years following their stroke. The respondents described the “invisibility” of visual impairments through apprehensive and fearful accounts, whereby their families and even the hospital staff could not successfully identify their visual impairments. In comparison, the respondents noticed differences in the public’s acceptance and curtesy of outwardly visible impairments. However, such acceptance was not always offered to those living with solely visual impairments that presented with no outward marker of disability. For example, Respondent 11 described a situation where passengers were asked to disembark a bus to allow him on with his wheelchair (his visible marker of impairment). Comparatively, Respondents 8 and 13 remarked that complete hemianopia, mobility and cognitive impairments are not visible, and therefore, were met with hostility when they accidentally bumped into people on buses or on the street.

The respondent accounts therefore, suggested that living with a visual impairment “protects” against a spoiled identity, although for this group, a visible marker of impairment would, potentially, be of greater benefit in gaining public support and assistance. However, when later discussing the use of a white cane, which is a purely visible indicator of impairment, the respondents collectively refused. Their accounts were consistent with the theory of “passing” a spoiled identity through impression

management (514, 515, 570), by refusing to accept a supportive aid that could be observed as a marker of a spoiled identity.

The act of "impression management" assumes the use of coping strategies for "passing" spoiled identities, described as social interactions adopted by the affected persons, to "normalise" themselves in the presence of "normal others" (514). Royer (571) identified seven cognitive strategies of normalisation that people with chronic illness engage in. These included: minimising the struggles and adjustments they have to make; redefining normal state as the present level of functioning; reordering priorities and values; seeking out information that validates personal experiences; making favourable comparisons to others worse off; and denying damaging information or new symptoms (571). Many of the stroke survivors interviewed demonstrated a range of the above points, shown mainly through the male accounts that deflected or "played-down" their impairments. Respondent 8 admitted to suffering from a broad range of impairments (visual, physical and emotional) and yet, frequently compared his own perils to those less fortunate. These behaviours therefore, followed notions of "making favourable comparisons to others worse off" (571), suggesting the act of impression management succeeding a loss of self-identity.

Additionally, humour was frequently used by the respondents (again, mainly by male respondents) in non-humorous settings, which suggested discomfort disclosing intimate, post-stroke adversities (511). This concept is supported in the current body of literature, which identified humour as a useful tool for coping with the difficulties experiences after stroke (511, 572). Additionally, the use of humour has been noted in other accounts of qualitative research using focus groups, when power imbalance is at play (511). An imbalance of power between the interviewer and the stroke survivors of this PhD research could offer a reason for why humour was used more frequently in the older, male respondents, who may have felt uncomfortable disclosing sensitive information to a younger, female interviewer. The use of humour therefore, diminished the severity of their responses, allowing the respondents to appear less vulnerable during discussions (511, 573). This analysis exemplifies the severity of their emotional turmoil and furthers previous notions of shame that respondents associate with their lives after stroke. Furthermore, the use of humour

due to discomfort caused by a perceived power imbalance may suggest a limitation of this PhD research, despite efforts made to control for power imbalance during the study design (see 2.5.5).

Additionally, shamed and masculine language was observed in the male respondents' accounts describing loss of agency, implying a loss of the stereotypical male-role (their pre-stroke identity). This idea that gender influences one's self-identity, and thus is worthy of preserving, is furthered by philosopher Judith Butler's theory on "gender performativity" (574). Butler (574) argued that one may over-play their gender role when their identity is threatened, which offers a possible explanation for the unexpected outbursts of masculine language observed during the interviews with male respondents when describing their trepidations caused by the stroke. Similar findings have been reported that support this sub-theme of loss of (masculine) gender-identity, whereby social identity leads to "self-stereotyping", which is exacerbated in the social settings, such as focus groups (575, 576).

Comparably, earlier discussions presented gender as a possible factor in the uptake of healthcare, postulating that males tend to demonstrate poor help-seeking behaviours (see 1.1.1). Therefore, it is possible that perceived societal expectations of the male-role, noted in Chapter 11, could further affect stroke patients by creating a barrier to voluntarily seeking or accepting healthcare, despite a known need, due to embarrassment, fears of public opinions, and a desire to avoid situations that they are not in control of (77, 78). Therefore, the loss of identify after stroke was a prevalent theme for all, but arguably affected the male respondents in more ways than females, emotionally and even physically (if they were to refuse support/healthcare to preserve their identity).

These findings therefore, suggest that an inequality exists where patients who have suffered a stroke have to cope with this additional social 'trauma' through loss of self-identity, compared to those that have not. Consequently this group are at greater risk of "hidden" physical (e.g. visual defects) and "psychosocial" (e.g. depression) impairments (577). Not only do stroke survivors have to adapt to their new disabilities, but they are also burdened with the insistent efforts required to conceal their impairments from the public, and in some accounts, even their families. This subsequently results in unaddressed and unmanaged impairments, which have

shown to impact on the patients' health and quality of life (4, 139). This impact was demonstrated through Respondent 13's account of depression and social isolation, as she refused to disclose impairments such as, cognition issues and visual hallucinations, to her family and health workers.

Recommendations from similar research studies have suggested offering longer rehabilitation periods to stroke survivors, to allow for time to adjust to their new "selves" with the necessary psychological support networks in place (578). Taule et al. (577) further identified a need to support stroke patients in making sense of their new, altered bodies, and processing the emotional reactions caused by a changed body, through their interviews with stroke survivors and healthcare professionals. This supports the current research findings and highlights a clear desire by both clinicians and stroke patients for better support informing them of what they can expect after stroke, and offer advice on how to adjust to their new bodies.

The final theme identified from the stroke survivor accounts considered inequalities in the organisation of healthcare after stroke, which furthered many of the earlier findings from the former two sections of this thesis work. These findings included issues with stroke and vision services, mainly a lack of care, or healthcare that did not meet the needs of the stroke survivors' new impairments. Chapter 3 reported a significant health inequality in the delivery of visual care after stroke, which was frequently unavailable or inadequate (2). This inequality was observed by the stroke survivors who reported a "post-code lottery": they recognised differences through their own experiences in the care offered, dependent on the hospital site.

A strong theme of apathy and acceptance came through in all of the interviews, which followed on from previous discussions of loss of agency after stroke and vision loss. Some of the stroke survivors sought additional support due to a lack of visual care provided by the hospital sites, whilst others quickly accepted their fate. This apathy, coupled with the respondents' inabilities to mobilise of communicate effectively, resulted in social isolation and the loss of relationships and social networks. The consequence of social isolation after stroke is one that has been mentioned in the literature, but with no clear recommendations for overcoming such difficulties. One, broad suggestion was to "accommodate all existential aspects of

stroke recovery" (577), which could be interpreted as the use of person-centred care models in stroke recovery (discussed below).

However, many of the respondents identified specific problems with accessing care due to their impairments, which supports the findings from Chapter 9, where stroke survivors with greater disabilities and co-morbidities were less likely to attend hospital follow-up. The respondents identified issues with reading hospital appointment letters, transport difficulties - including cost implications associated with travel - and a lack of home-based care for visual rehabilitation. These concerns were exacerbated through the multiplicity of health appointments offered to them.

A possible solution to these attendance issues is the implementation of patient-centred care models. Patient-centred care allows the patient to regain ownership of their physical recovery and reduces dissatisfaction that arises from disappointing recovery (579). The NHS recommends offering care tailored to the individual's needs, however, in practice this is not always followed, with NHS England (580) identifying barriers to supporting this care approach to include lack of time, inefficient support services, unhelpful pathways and inadequate clinician skills, as barriers to supporting patient-centred care. A clear recommendation from this PhD research is for clinicians to discuss the range of rehabilitation options available after stroke, offering their recommendations based on clinical experience, but ultimately placing the patient at the centre of the decision-making process.

The eight principles of patient-centred care (581) is a well-established and accepted model of patient-centred care that aims to consciously adopt the patient's perspective. This model consist of respect for a patient's values, preferences and expressed needs, access to care, emotional support, information and education, coordination of care, physical comfort, involvement of friends and families, and continuity and transition (581). Later discussion within this chapter will demonstrate how the recommendations from this PhD research considers the above values, suggested by Cott (581), in pursuing a patient-centred care approach to vision rehabilitation after stroke.

The findings from Chapter 11 identified numerous accounts of power-imbalance within the healthcare setting. This patient-centred care approach recommended shifting the power to the patient so that they can assume responsibility for managing

their own condition (581), and not be pre-empted by clinicians. The findings from Chapter 11 further identified a multitude of issues facing stroke survivors, dependent on pre-existing medical conditions, pre-existing support networks and the severity of the stroke. Therefore, it is unlikely that clinicians would be able to accurately pre-empt the full trajectory of adversities and rehabilitation goals required for all stroke survivors; these must be discussed on an individual basis with the patient and their families (581).

A further approach recommended by Wiles et al. (579), suggested improving communication between clinicians and stroke survivors, informed by the evidence base concerning the recovery of stroke impairments. Clear and appropriate information was further emphasised by the study respondents (Chapter 11), as a key priority for support their stroke care. A clear understanding of recovery rates encourages realistic expectations (579); however, the previous body of evidence around visual recovery after stroke was found to be weak (see 1.4). Therefore, the information gained from this PhD research (see 6.4) allows orthoptists and other stroke clinicians to better understand the extent of the visual recovery, in order to effectively plan patient-centred management goals through this approach.

This research has identified that stroke survivors suffer from a vast range of physical and visual disabilities following stroke, which subsequently result in different preferences in how information is provided according to the individual's needs and requirements. It would appear to be beneficial to the patients for these needs to be addressed prior to hospital discharge, and so the appropriate form of information and communication can be used. However, it may be of further benefit to revisit the patient's preferred choice of communication during their rehabilitation process, as their needs may alter as their disabilities change over time.

Furthermore, in order to address the inequalities identified in information provision for stoke survivors, future research is required to address the information offered to patients by NHS hospitals and stroke charity organisations, to ensure patients can receive information appropriately, despite barriers from their stroke disabilities. Furthermore, this PhD research recommends that information promoting access to services and available benefits must be widely accessible by patients from the start of their hospital care.

The psychosocial impact of stroke was discussed comprehensively in 11.3.2. Many of the respondents reported an expectation that the clinicians and hospital staff should encourage and motivate patients to attend appointments, comply with treatments and form an empathic rapport in which the patient may feel comfortable discussing issues, including those outside of the clinician's area of expertise e.g. psychological and financial issues. Therefore, findings from this research recommend that clinicians become educated to the long-term impact of stroke, and the various support networks available, in order to signpost resources, charity organisations or refer the patient to the relevant health professional to ensure they receive the support they need.

Finally, the respondents frequently reported inequalities in accessing services, often due to their stroke/visual impairments resulting in transport difficulties, financial complications and a loss of agency, independence and confidence mobilising. The subsequent outcome of this poor access resulted in social isolation and further health problems where rehabilitation could not be undertaken. In order to address inequalities in attending hospital appointments, it is suggested that patients or carers should be asked whether or not they expect any difficulties at the point of discharge e.g. living alone, perceived difficulties using public transport, or financial difficulties, and clinicians must signpost all available benefits at this early stage. Furthermore, some of these patients should be considered for home visits, where possible. Measures should be put in place to aid attendance for these patients prior to discharge, as opposed to waiting for them to fail to attend their appointments.

Conclusions

Through this research, a number of health inequalities have been identified which affect the visually impaired stroke survivors pre-stroke, during their hospital stay and following hospital discharge. Older age was the only pre-stroke patient demographic found to suggest a higher likelihood of having a visual impairment after stroke. The findings from this PhD research have excluded gender, a low IMD decile and the type of stroke, as significant predictors of post-stroke visual impairment. Further research should aim to include a more diverse ethnic population to ascertain whether or not ethnicity plays a role in predicting visual impairment after stroke. A recruitment strategy that specifically targets this population of stroke survivors could be employed to undertake this research in the future.

During hospital stay, inequalities have been identified with regards to how accurately visual impairments are screened and managed. The full range of appropriate screening tools and rehabilitation options do not have a suitable evidence base, particularly in demonstrating their use with stroke survivors. This is unsurprising, as orthoptic input to stroke services appears variable and unsupported, despite the evidence confirming the importance of visual care after stroke. The IVIS study found that 58% of stroke survivors had a visual impairment acutely, 47% of which were directly caused by stroke. Furthermore, there is reason to suggest that this figure is underestimated due to the number of patients unable to be assessed (12%), but suspected to have a visual impairment (see 6.5). Many stroke survivors will not receive visual management, where an orthoptist is absent, as they cannot communicate their symptoms to the stroke team. In other words, these patients are at risk of not receiving management for their post-stroke visual impairments as a result of their general stroke disabilities.

The recent inclusion of orthoptists as core members of stroke multidisciplinary teams highlights the caregivers' responsibility to address the visual requirements of stroke survivors, and urge hospital Trusts to take action and form links with their eye departments. The full range of visual screening methods and rehabilitation options available have not always been clearly documented in the literature, specifically for

their use after stroke. If practicing clinicians are made aware of the full range of effective tools then a national standard of screening and management of visual impairments could be achieved.

Following stroke, a low Barthel index and discharge to supportive forms of living were identified as the outcomes significantly associated with having a visual impairment, as well as poorly recovering from these impairments and failing to attend visual follow-up appointments. These outcomes were further linked to older age, portraying a profile of older and more unwell stroke survivors facing a greater risk of the health inequalities associated with post-stroke visual impairments, as a result of their poor health and disabilities.

The rate of non-attendance at post-stroke orthoptic follow-up appointments was found to be higher than previous reports at non-stroke eye appointments. Additionally, it was found that the hospital staff were unlikely to offer these patients follow-up appointments if found to be very unwell, with no alternative service to offer them. Where appointments have been offered, these patients often DNA or the nursing homes fail to transport them into hospital, putting this group of patients at risk of further health inequalities, as visual rehabilitation cannot be offered. Where possible, efforts should be made to encourage patients and nursing home staff to attend eye appointments. Hospital appointment reminders suitable to the stroke survivors' acquired disabilities could address some of the issues with attendance, although the use of reminders were found to vary between hospital sites, further demonstrating inequalities after stroke as a result of inconsistent service delivery. Therefore, efforts should be made across all Trusts to ensure the patients' contact details are correct before discharge from hospital, and their preferred method of contact is documented, as a systematic and cost-saving approach to tackling this inequality.

This research has identified that orthoptists are perhaps the only allied health professional that do not provide formal home visit services for stroke survivors. However, the results of this study have shown that many stroke survivors fail to attend hospital to receive eye care as a direct result of their impaired vision. Orthoptic home visits, or established links with nursing homes, and the ESD teams, could address these inequalities, and should be explored further. However, the

survey from Chapter 10 results showed some resistance from orthoptists to the introduction of orthoptic home visits, suggesting that a cautious approach should be taken when exploring this service in the future, with a likely need to provide education on the stroke survivors' needs following hospital discharge.

The findings from this research suggest that recommendations for improving many of the inequalities at individual level, does not necessarily require additional funding to improve vision services in stroke care. Instead, highlighting the opportunities that already exists and raising awareness of existing vision services and established support networks could effectively ensure patients receive appropriate vision rehabilitation. Therefore, education strategies for non-orthoptic staff, and establishing connections with the ECLO teams with access to stroke survivors, could effectively support the identification and onward referral of stroke survivors with visual impairments to the orthoptic department for visual management.

Patients showing no recovery from their visual impairments were, on average, discharged four months following stroke onset. However, interviewed stroke survivors reported life-long inequalities relating to the post-stroke visual impairments: transport and financial implications, struggles with self-identity and existentiality, the emotional impact of coping with their impairments, and problems accessing support independently after specific care was not offered to them at their time of stroke. The information gained from this PhD research on recovery rates of visual impairments, allows orthoptists and other stroke clinicians to better understand the extent of the visual recovery, in order to effectively plan patient-centred rehabilitation, whilst considering the wider implications of the stroke, which could be affecting the patient's life.

If the visual impairments cannot be treated further, and show no signs of recovery, it would be helpful for clinicians to consider addressing the potential long-term issues before discharging patients. Once more, this recommendation suggests an immediate, cost-free strategy to improving patient care and wellbeing through simply educating stroke clinicians to the greater impact of the vision impairments. This could ensure that patients and their families are informed of any financial, travel or emotional support available to them, which may reduce these inequalities during and after their hospital care. Future studies exploring the long-term impact of

additional support, by monitoring patients after hospital discharge, could highlight the potential benefits of addressing the wider picture of post-stroke visual impairments, and the detrimental effect these can have on the patient's life after stroke.

The key recommendations from this research include:

- Ensuring all stroke patients receive adequate and equitable orthoptic visual input nationally at the acute stage of stroke.
- The screening tools and visual rehabilitation options identified as having a weak evidence base should be trialled and compared against other established tools.
- The use of effective visual screening and rehabilitation options in stroke patients must be widely publicised to practicing clinicians to ensure equitable care nationally.
- If the stroke patient is discharged with persistent visual impairments, efforts should be made to ensure the patient attends hospital appointments through information provision regarding transport and financial aid, hospital communications tailored to their needs, and involving patients centrally within the rehabilitation.
- Information provision for visually impaired stroke survivors should be improved through future work with charity organisations and the NHS to promote public education, access to services and available benefits.
- Educating non-orthoptic healthcare professionals on visual impairment after stroke, and establishing links between other AHPs and ECLOs, to support the identification of these patients and make appropriate onward referrals to orthoptics.
- Exploring home visits and community orthoptic services in future research as a means of overcoming some of the health inequalities identified in this research regarding access to visual care.

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Appendices

Appendix 1: IVIS study ethics approval document

Health Research Authority
National Research Ethics Service

NRES Committee North West - Haydock
HRA NRES Centre - Manchester
3rd Floor - Barlow House
4 Minshull Street
Manchester
M1 3DZ

Telephone:
0161 625
7827
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13 March 2014

Dr Fiona Rowe

Senior Lecturer

University of Liverpool

Department of Health Services Research

Whelan Building (1.10)

Brownlow Hill

Liverpool

L69 3GN

Dear Dr Rowe

Study title:	**Incidence and prevalence of visual impairment after stroke**
REC reference:	**14/NW/0166**
Protocol number:	**UoL000974**
IRAS project ID:	**150590**

The Proportionate Review Sub-committee of the NRES Committee North West - Haydock reviewed the above application on 11 March 2014.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Mrs Rinat Jibli, nrescommittee.northwest-haydock@nhs.net.

Ethical opinion

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see
"Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved were:

Document	*Version*	*Date*
Covering Letter		04 March 2014
Evidence of insurance or indemnity		05 August 2013
Flowchart	1	03 March 2014
Investigator CV		

Letter from Funder		16 August 2013
Protocol	1	24 June 2013
REC application 150590/574029/1/273		04 March 2014

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website. Information is available at National Research Ethics Service website > After Review

14/NW/0166 **Please quote this number on all correspondence**

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project.

Yours sincerely

On behalf of

Dr Tim S Sprosen

Vice Chair

Email: nrescommittee.northwest-haydock@nhs.net

Enclosures: List of names and professions of members who took part in the review
"After ethical review – guidance for researchers"

Copy to: Mr Alex Astor, University of Liverpool
Ms Michelle Mossa, Aintree University Hospital

NRES Committee North West - Haydock

Attendance at PRS Sub-Committee of the REC meeting on 12 March 2014

Committee Members:

Name	*Profession*	*Present*	*Notes*
Professor Ravi S Gulati	Consultant Physician	Yes	
Dr Valerie E Siddall	Retired Senior Manager - Pharmaceutical Industry	Yes	
Dr Tim S Sprosen (Meeting Chair)	Epidemiologist	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Ms Rachel Katzenellenbogen	REC Assistant

Appendix 2: IVIS Clinical Assessment Report Form

IVIS STUDY

Version 2, 08/02/2015

PATIENT DETAILS

Centre ID:

Patient ID:

Date of birth:

Ethnicity:

Postcode:

Orthoptist:

Date:

Baseline screening ○ Baseline full ○

1 month visit ○ 3 month visit ○

6 month visit ○ 9 month visit ○

12 month visit ○ Unscheduled visit ☐

DETAILS OF CONDITION

Date of stroke onset: ☐

Number of whole days post stroke: ☐

MRI / MRA / CT date and report: ☐

(attach ○ copy if available) ○

OCULAR SYMPTOMS

Patient reported symptoms: ☐

Unable to report ○ Asymptomatic ○

Family/Carer reported symptoms: ☐

Recovery of symptoms

Date of cessation of symptoms: ☐

OCULAR SIGNS

None ○

Squint / turn of eyes ○ Ptosis (lid droop) ○

Defective eye movements ○ Abnormal pupils ○

Nystagmus (wobbling eyes) ○ Head turn ○

Visual inattention / neglect ○ Family concerns ○

Closing one eye ○ Mis-judging distance ○

Suspected visual problem ☐

OCULAR HISTORY

e.g. cataract, glaucoma, retinopathy, macular degeneration, sight impaired registration, childhood squint?

☐

GLASSES

Does the patient usually wear glasses? Y / N / U

Does the patient need glasses? Y / N / U

Does the patient have their glasses with them? Y / N

Optometry visit within past 18 months? Y / N / U

Myopic ○ Hypermetropic ○ Astigmatism ○

Type of glasses ☐

GENERAL INFORMATION

Indicate the presence of communication and general physical difficulties.

☐

Barthel score: ☐

COGNITIVE SCREEN

OCS: Picture Naming: ☐ Semantics: ☐ Orientation: ☐ Visual Field: ☐

Sentence: ☐ Number & Calculation: ☐ Broken Heart: ☐

Gesture: ☐ Recall & Recognition: ☐ Executive task: ☐

Comments: ☐

MoCA: Visuospatial/Executive: ☐ Naming: ☐ Attention: ☐ Language: ☐

DRIVING

Does the patient drive? Y / N / U

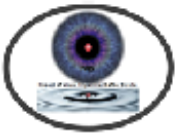
Did the patient drive before their stroke? Y / N / U

Yes?: Specify any self-imposed driving restrictions: ☐

Tick ○ as relevant or if test is abnormal. Enter details ☐ for (e.g. numerical results or

IVIS STUDY

Version 2, 08/02/2015



PATIENT DETAILS

Centre ID:

Patient ID:

Date of birth:

Ethnicity:

Postcode:

Orthoptist:

Date:

Baseline screening ○ Baseline full ○

1 month visit ○ 3 month visit ○

6 month visit ○ 9 month visit ○

12 month visit ○ Unscheduled visit ☐

DETAILS OF CONDITION

Date of stroke onset: ☐ MRI / MRA / CT date and report: ☐

Number of whole days post stroke: ☐ (attach ○ copy if available) ○ ☐

OCULAR SYMPTOMS

Patient reported symptoms: ☐

Unable to report ○ Asymptomatic ○

Family/Carer reported symptoms: ☐

Recovery of symptoms

Date of cessation of symptoms: ☐

OCULAR SIGNS

None ○

Squint / turn of eyes ○ Ptosis (lid droop) ○

Defective eye movements ○ Abnormal pupils ○

Nystagmus (wobbling eyes) ○ Head turn ○

Visual inattention / neglect ○ Family concerns ○

Closing one eye ○ Mis-judging distance ○

Suspected visual problem ☐

OCULAR HISTORY

e.g. cataract, glaucoma, retinopathy, macular degeneration, sight impaired registration, childhood squint?

☐

GLASSES

Does the patient usually wear glasses? Y / N / U

Does the patient need glasses? Y / N / U

Does the patient have their glasses with them? Y / N

Optometry visit within past 18 months? Y / N / U

Myopic ○ Hypermetropic ○ Astigmatism ○

Type of glasses ☐

GENERAL INFORMATION

Indicate the presence of communication and general physical difficulties.

☐

Barthel score: ☐

COGNITIVE SCREEN

OCS: Picture Naming: ☐ Semantics: ☐ Orientation: ☐ Visual Field: ☐

Sentence: ☐ Number & Calculation: ☐ Broken Heart: ☐ Comments: ☐

Gesture: ☐ Recall & Recognition: ☐ Executive task: ☐

MoCA: Visuospatial/Executive: ☐ Naming: ☐ Attention: ☐ Language: ☐

DRIVING

Does the patient drive? Y / N / U Did the patient drive before their stroke? Y / N / U

Yes?: Specify any self-imposed driving restrictions: ☐

Tick ○ as relevant or if test is abnormal. Enter details ☐ for (e.g. numerical results or

Appendix 3: Attendance CRF, Version 2

ID: **Date of call:**

DOB: **Spoke with:** **Patient** **Y**
Partner **Y**
Career **Y**

1. Are you having any eye/ vision problems? If so, what problems?

2. If symptoms recovered post hospital discharge, can you remember when they recovered?

3. Would you like another eye appointment sent out?

4. Do you have any difficulty in getting to the hospital for your appointment? If so, what problems? E.g. ambulance transport/ nursing home/ disability.

5. Do you regularly attend your own optician/ eye clinic?

6. Other comments

Appendix 4: Codes for Attendance CRF

DNA/cancelled/discharged without follow-up, due to:

1. Discharged to nursing home and orthoptic decision that patient is not suitable for follow-up: **DNA1**
2. Too unwell to attend: **DNA2**
3. Transport difficulty getting to clinic: **DNA3**
4. Does not wish to attend as patient having no vision problems: **DNA4**
5. Already attends an eye clinic/optometrist regularly and does not want another orthoptic appointment: **DNA5**
6. Forgot about appointment: **DNA6**
7. Did not attend; unknown reason: **DNA7**
8. Does not wish to attend: no reason given: **DNA8**
9. Does not wish to attend: other reason **DNA9**

    → Comment

Appendix 5: BIOS confirmation letter of approval for the orthoptic professional body survey

01/12/2018

Dear Dr Rowe

I am writing to confirm that Ms Kerry Hanna carried out a survey on home visits in conjunction with the British and Irish Orthoptic Society between 2015 and 2016. The results of this survey were reported directly to the steering committee at the annual meeting. Following this work, a report on the survey findings was circulated to all the special interest group members via email.

In addition, Ms Hanna was invited to present her findings at the 2016 SIG annual study day to a group of around 80 orthoptists with a special interest in working with stroke survivors.

Kind regards

Ms Claire Howard

BIOS Stroke and Neurological rehabilitation SIG Lead

Appendix 6: Focus groups/interviews ethics approval letter from University of Liverpool

Health and Life Sciences Committee on Research Ethics

(Psychology, Health and Society) 18 August 2016

Dear Dr Rowe,

I am pleased to inform you that your application for research ethics approval has been approved. Details and conditions of the approval can be found below:

Reference: 0418
Project Title: Health inequalities associated with post-stroke visual impairment
Principal Investigator: Dr Fiona Rowe
Co-Investigator(s): Miss Kerry Hanna
Student Investigator(s): -
Department:
Reviewers: Dr Freya O'Brien, Prof Rumona Dickson
Approval Date: 18/08/2016
Approval Expiry Date: 16/12/2016

The application was **APPROVED** subject to the following conditions:

Conditions

- All serious adverse events must be reported to the Subcommittee within 24 hours of their occurrence, via the Research Integrity and Ethics Officer (ethics@liv.ac.uk).
- If it is proposed to extend the duration of the study beyond the expiry date listed above, the Subcommittee should be notified.
- If it is proposed to make an amendment to the research, you should notify the Subcommittee by following the Notice of Amendment procedure.
- If the named Principal Investigator or Supervisor leaves the employment of the University during the course of this approval, the approval will lapse. Therefore please contact the Committee (details below) in order to notify them of a change in Principal Investigator or Supervisor.

Kind regards,

Health and Life Sciences Committee on Research Ethics (Psychology, Health and Society) iphsrec@liverpool.ac.uk

0151 795 5420

Appendix 7: Patient information sheet for focus groups and interviews

Health inequalities associated with post-stroke visual impairment

Patient information sheet

You are being invited to take part in a research study.

Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve.

Please take time to read the following information carefully and feel free to ask us if you would like more information or if there is anything that you do not understand.

Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

Part 1

What is the purpose of the study?

In this study we propose to hold a focus group in which to investigate the potential health inequalities and difficulties experienced by stroke survivors with visual impairment.

Why have I been chosen to take part?

Up to 10 individuals are being asked to take part in a focus group. You are being invited to take part because you have been identified as having had a visual impairment as a result of a stroke.

Do I have to take part and can I change my mind?

Your involvement is entirely voluntary and you are free to withdraw at any time without providing explanation.

What will happen if I take part?

You will be asked to sign a consent form.

A focus group will be arranged and you will be provided with details of the date, time and venue.

Part 2

What happens during the focus group?

During the focus group, you will be introduced to other stroke survivors who are taking part in the focus group. The focus group will be facilitated so that every participant has full opportunity to provide their opinions on the testing options. Written notes and an audio recording will be made throughout the session.

Expenses and / or payments

Standard travel expenses are payable for this study.

Are there any risks in taking part?

It is unlikely that there will be any risks to taking part in this study.

Are there any benefits in taking part?

There is no personal benefit to the individual for taking part in the study. Some participants may believe there is benefit in being part of the process towards identifying and tackling health inequalities for stroke survivors with visual problems.

What if I am unhappy or if there is a problem?

If you are unhappy, or if there is a problem, please feel free to let us know by
[*Contact information removed from thesis to protect confidentiality*]
and we will try to help.

If you remain unhappy or have a complaint which you feel you cannot come to us with then you should the Research Governance Officer at the University of Liverpool on 0151 794 8290 (ethics@liv.ac.uk).

Please provide details of the name or description of the study (so that it can be identified), the researcher(s) involved, and the details of the complaint you wish to make.

Will my participation be kept confidential?

All information will be kept private, confidential and secure.

Will my taking part be covered by an insurance scheme?

There are no special compensation arrangements in place for this study.

What will happen to the results of the study?

The focus group information (all anonymous information) will be made available to people who took part should they specifically request this information. The results will be published when the study is completed and the details can be accessed via medline search using the author's surname as a search code (Hanna):
http://www.ncbi.nlm.nih.gov/pubmed
People taking part cannot be identified from the data taken from the focus group information.

What will happen if I want to stop taking part?

Anybody taking part can withdraw at any time, without explanation. Results up to the time of withdrawal may be used, if you are happy for this to be done. Otherwise you may request that they are destroyed and no further use is made of them.

Who can I contact if I have further questions?

You may contact the **Chief Investigator.**

[*Contact information removed from thesis to protect confidentiality*]

Appendix 8: Patient consent form for focus groups and interviews

Title of Project: Health inequalities associated with post-stroke visual impairment

Researcher (s): Dr Fiona Rowe and Ms Kerry Hanna

Participant Identification Number for this study: _____

	Please initial box
1. I confirm I understood the information provided for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2. I understand my involvement is voluntary and I am free to withdraw at any time without giving any reason, without my rights being affected.	☐
3. I agree to take part in the above study.	☐

Participant Name	**Date**	**Signature**
Name of Person taking consent	Date	Signature

Contact details of lead Researcher (Chief Investigator) are:
[*Contact information removed from thesis to protect confidentiality*]

Appendix 9: Topic guide for focus groups and interviews

Introduction

- Who I am – orthoptist (eye specialist with an interest in stroke) form the University of Liverpool
- What the research is about (brief layman's)/their participation in the day/the conduct of the focus groups/tape recorders/consent forms
- "Has anyone come across the term health inequality?"
- Outline the plan for the session:

"*Through the current research being done in the IVIS study and from what has been identified in previous studies, we are aware of a few issues that prevent patients from being able to attend hospital clinics for their outpatient appointments.*
Likewise, some hospitals and patients have identified ways of attending hospital despite their impairments, or have no bother from them at all. If they do not attend two consecutive appointments they are routinely discharged."

"Today, *I would like you to discuss…*"

1. What changes to your vision did you have after the stroke?
2. Your experiences following stroke/diagnosis of visual impairment and your attendance of hospital appointments/post-stroke care.
3. Were there any particular aids/support/coping strategies that you have found helpful?
4. Or did you never experience any impact (change to your normal lived) due to your visual impairments?

Discussion topics:

Keep questions neutral – do not lead with negative connotation, to try to counteract the term "health inequalities" and possible researcher bias

1. <u>Transport/area of residence/cost</u>

- Driving/ driving license
- Cost of taxis/buses/any other adaptations required – cheap/free/expensive?

- Using public transport – is this new (due to disability) or did you use public transport before?
- Good/poor transport links? Confidence in using public transport or going out alone? Do you travel alone or do others help to take you to appointments?

2. Occupation

- How was it returning to work after stroke/vision impairment?
- Use of support or aids at work?
- Getting time off work to go to appointments

3. Age

- Memory (due to separate age-related conditions or stroke?) - Remembering/forgetting appointments/volume of appointments.
- Did anyone receive an automated voicemail message or text message or reminder letter when appointment is coming up? If so, what was your experience of those? If not, is this something you think might have been helpful/unhelpful?

4. Information/education

- Did you have a previous knowledge about stroke/vision impairment?
- Were all appointments valuable/what did you like and dislike about them?
- What was your outpatient attendance like?
- Contacting clinics for unwanted appointments (awareness that you would be discharged if you do not attend? Feelings about that?)
- Verbal and written information (in hospital, when you were discharged, or not at all?)
- When would be the best time to receive information post-stroke?

5. Race/ethnicity

    - Language barriers/ability to read letters or have them translated
    - Can someone attend appointment to help with communication?
    - Cultural differences?