Care provision and unmet need for post stroke visual impairment

Final report

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Contents

Acknowledgements 2

Executive summary 4-8

Introduction 9-11

Methodology 12-17

Results 18-34

Discussion 35-41

Conclusions 42-43

References 44-48
Executive Summary

Why is post-stroke visual impairment important?

Visual impairment is a common consequence of stroke. It is estimated that 60% of stroke survivors have visual impairment immediately after their stroke and this reduces to about 20% by three months post stroke onset. There are different types of visual impairment that occur more or less commonly than each other. Visual impairment may include impaired central vision occurring in up to 70% of stroke survivors or impaired peripheral vision occurring in up to 51%. Visual impairment may also include eye movement abnormalities in up to 68% and visual inattention and visual perceptual disorders in up to 80%. Visual impairment causes added impact to daily life over that already incurred by general problems due to the stroke. The impact includes loss of confidence, impaired mobility, reading difficulty, increased collisions and accidents, and fear of falling. There is a care issue in relation to visual impairment. National guidelines across the UK (Royal College of Physicians National Clinical Guidelines for Stroke 2012, Scottish Intercollegiate Guidelines Network Guidance 118, 2010) recommend specialist vision assessment for stroke survivors who are suspected of having a visual problem. However, vision assessment is not routinely undertaken and there are considerable variations across the UK in access to eye care services for specialist assessment and treatment. Working collaboratively, the Stroke Association and the Thomas Pocklington Trust identified a number of strategic questions relating to unmet need and the provision of vision services after stroke – namely:

1. How much unmet need is there in post-stroke vision services?
2. Is there a clear care pathway for vision care in stroke survivors?
3. What are the variations in post stroke vision care, and how might they be addressed?
4. What is best practice in post stroke vision care, and where are examples of where such care is implemented?

To answer these questions, we undertook a systematic literature review, a survey of UK-based professionals from both stroke teams and eye teams, an organisation scoping exercise to identify previous surveys which incorporated questions about vision, narrative interviews with stroke survivors and interviews with best practice services defined as those with integrated stroke and vision care.

**How much unmet need is there in post-stroke vision services?**
A number of previous surveys report clear unmet need for visual impairment post stroke. A Stroke Association survey found 47.5% of stroke survivors to have vision problems and 26% of these had unmet needs in relation to their vision. A survey of Scottish occupational therapists in stroke units reported only 9% with access to a protocol for post-stroke visual impairments. A similar survey of Scottish orthoptists reported only 12% with access to a protocol or management plan specific to stroke patients. A UK-wide survey of Orthoptists found that 45% of stroke services provided no formal vision assessment for stroke patients with poor accuracy of referrals because of low sensitivity and specificity in detecting ocular signs.

In this study we have found that screening tools for detecting visual problems were used by only 22% of the 548 professionals surveyed. A variety of vision tests were used ranging from 36-58.5% dependent on type of test. Stroke survivors, carers and clinicians have all reported the need for vision information.
Is there a clear care pathway for vision care in stroke survivors?
Yes, but it is not routinely used. Only 46% of our survey respondents reported using a care pathway. There is a national pathway for vision care in stroke survivors which is freely available. Furthermore some local departments design their own care pathway to consider local needs and allocation of services.

What are the variations in post stroke vision care, and how might they be addressed?
There was considerable variation across services as to who takes responsibility for vision screening. Where Orthoptists undertook vision screening on the stroke unit, this was identified by our best practice interviews as the gold standard. Orthoptic-led training for stroke teams on screening and referral for vision problems along with use of validated screening protocols and tools were considered to improve accuracy of detection and referrals.

Despite vision information leaflets being widely available, 33.5% of our survey respondents did not provide these to patients or carers. This was a recurrent theme from interviews with stroke survivors.

Twenty percent of respondents reported their knowledge of visual problems as fairly poor or very poor. When asked about the existing evidence base, up to 40% did not feel, or only slightly felt, this influenced their assessment or management of visual problems. A recommendation coming from stroke survivors, their carers and clinicians was for improvement of education to promote knowledge and increased awareness of post-stroke visual impairment.
What is best practice in post stroke vision care, and where are examples of where such care is implemented?

A survey of best practice for vision care in stroke survivors was undertaken in Scotland with release of a best practice statement and a number of recommendations in relation to screening, assessment, management and referral. In our UK-wide interviews with best-practice units we identified a number of recommendations to promote best practice across all stroke units. Recommendations that were considered essential included a minimum of two designated orthoptic sessions per week, flexible appointments, formal stroke team training, formal support from stroke physicians, provision of lay summaries, open communication between eye care and stroke teams, orthoptic assessment within one week of stroke onset, having the orthoptist named on the core stroke team, provision of visual information leaflets, use of standardised referral form and use of a vision care pathway. Recommendations that were considered desirable included maintenance of a database of stroke referrals to the eye clinic, follow-up designated session in the eye clinic, orthoptist attendance at MDT meetings, referrals to ECLOs, vision testing equipment available on the stroke unit and a rota of orthoptic staff.

Equally a number of weaknesses or threats to vision services were identified during our interviews and these included a lack of funding, lack of orthoptic cover during annual/sickness/maternity leave, frequent staff retraining due to rotation, lack of stroke physician buy-in, misinformation from stroke teams about visual problems. Where only one dedicated session was available per week there was a risk of missing some patients with delayed vision screening and limited time for assessments.
Key issues
Across the UK there is inequality in care provision for stroke survivors who have visual problems. Stroke survivors continue to have unmet needs in relation to their visual problems. When providing care for this population, it is evident that there are variances in how vision screening is undertaken, in which vision tests are used, in how stroke survivors with visual problems are referred to eye care services, in how the visual problems are managed and in what vision information is provided to stroke survivors and their carers. Existent screening protocols, vision tests and care pathways should be adopted and implemented widely, whether locally or nationally agreed. Education is required at many levels to ensure awareness and knowledge of the visual problems that may occur after stroke and with provision of vision information leaflets as early as is appropriate for the individual but always before discharge.
Introduction

Stroke affects 150,000 individuals per annum in the UK and is estimated to cost the NHS almost £3bn a year (CQC 2011, the Stroke Association 2013). Stroke is the main cause of disability in a community setting (NAO 2010). Visual impairment is a deficit of visual function and includes abnormalities of central and/or peripheral vision, eye movements and a variety of visual perception problems (how we interpret what we see) such as inattention and agnosia. Stroke survivors may or may not have visual symptoms, i.e. they report the effect of their visual impairment. The prevalence of visual impairment amongst stroke survivors with visual symptoms is reported as up to 68%, and up to 92% whether with or without visual symptoms (Rowe et al 2009). The visual problems (types of visual impairment) can be complex including ocular as well as cortical damage. A care issue exists in relation to visual impairment due to stroke. Vision is not routinely assessed in acute stroke settings and therefore a good understanding of the nature and extent of visual impairment is unknown in order to be able to plan care.

We know from past research the types of visual impairment that may occur after stroke. Unfortunately many previous attempts to establish prevalence in a general stroke cohort have lacked robust methodology and have included a cross section approach and case note review. Thus it remains unknown what the prevalence of visual impairment is for stroke survivors. It has not been possible to calculate incidence of visual impairment following stroke as this requires capture of visual information for all stroke survivors in a defined geographical area inclusive of all medical services from community, primary and secondary care services. Furthermore, it is recognised that some stroke survivors may
never seek medical attention, for example those who only have visual deficits due to an occipital lobe stroke. Determination of prevalence of visual impairment in a stroke unit is, however, important as this is a population that typically requires intervention (Rowe et al 2011a,b).

There are few large scale prospective studies. In recent years the Vision In Stroke (VIS) study recruited a large cohort of stroke survivors with visual impairment from across the UK using standardised protocols (Rowe et al 2009). This work confirmed that although some visual problems are easily identified, most visual problems are not detected by simply observing the individual and require questioning and assessment in order to detect their presence and subsequently make an accurate diagnosis (Rowe et al 2011a). Thus, visual impairment following stroke may be missed or misdiagnosed (Macintosh 2003). Visual symptoms can be poorly defined by patients and particularly where individuals have coexistent communication problems and cognitive impairments. Visual symptoms are wide ranging including blurred vision, hallucinations, diplopia and reading impairment and reported in 87% of stroke survivors with visual problems (Rowe et al 2013a). It is unknown what symptoms are perceived to be most problematic to stroke survivors, causing impact to everyday life. It is important to ascertain this information as specific types of visual symptoms could be targeted in the future if known to be particularly problematic for patients.

Visual impairment can impact on quality of life through loss of confidence, impaired mobility, inability to judge distances and increased risk of falls (Gall et al 2010, Rowe et al 2011a). Visual impairment may impact on a patient’s ability to participate in rehabilitation, to return to independent living and with an increased risk of falling (Jones
& Shinton 2006, Wolter & Preda 2006). There is a link between poor vision, quality of life and depression in older persons (Jones & Shinton 2006, Lynch et al 2008, Ramrattan et al 2001). Visual impairment may exacerbate the effects of other impairments, leading to increased anxiety and reliance on others (Jones & Shinton 2006). This in turn adds strain to relationships and limits social and leisure activities of both the patient and carer (Buschenfeld et al 2009). Many activities of daily living are hampered after acquiring a visual deficit, leading to increased dependence on others and long term morbidity (Jones & Shinton 2006, Saka et al 2009). Long-term, visual impairment may result in considerable financial burdens placed on individuals, carers and the wider community placing a large economic cost on society (Access Economics 2009).

Working collaboratively, the Stroke Association and the Thomas Pocklington Trust identified a number of strategic questions relating to unmet need and the provision of vision services after stroke – namely:

1. How much unmet need is there in post-stroke vision services?
2. Is there a clear care pathway for vision care in stroke survivors?
3. What are the variations in post stroke vision care, and how might they be addressed?
4. What is best practice in post stroke vision care, and where are examples of where such care is implemented?

This project seeks to bring together existing evidence of current provision in post stroke vision services, examples of best practice, case studies, statistics around visual problems after stroke and evidence of unmet service need.
Methods and materials

**Literature review**

Our literature review comprised a broad scoping review, aiming to provide a comprehensive accessible synthesis of current evidence relating visual problems after stroke. We used systematic search strategies to search key electronic databases and contacted known experts in the field.

We searched the Cochrane Stroke Group Trials Register, the Cochrane Eyes and Vision Group Trials Register, and the following electronic bibliographic databases:

- The Cochrane Central Register of Controlled Trials (CENTRAL) (*The Cochrane Library*, latest issue);
- MEDLINE (1950 to 2013);
- EMBASE (1980 to 2013);
- CINAHL (1982 to 2013);
- AMED (1985 to 2013);
- PsycINFO (1967 to 2013);
- British Nursing Index (1985 to 2013);

In an effort to identify further published, unpublished and ongoing trials, we:

1. searched the following registers of ongoing trials:
iii) Trials Central (www.trialscentral.org);

iv) Health Service Research Projects in Progress (www.cf.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) (www.liverpool.ac.uk/orthoptics/research/search.htm) and proceedings of Association for Research in Vision and Ophthalmology (www.arvo.org);

3. searched the reference lists of included trials and review articles about vision after acquired brain injury;

4. contacted experts in the field (including authors of included trials, and excluded studies identified as possible preliminary or pilot work).

There were no date or language restrictions in the electronic searches for trials.

Two authors (FR and LH) independently assessed study titles identified from the electronic and manual searches to identify those potentially relevant to this review. The abstracts for these studies were then assessed to identify those meeting the criteria for this review. Author analysis was compared and full papers for appropriate studies were subsequently obtained. We synthesised research evidence which reported (i) incidence or prevalence data; (ii) describes or evaluates screening or assessment strategies or tools; (iii) evaluates the effectiveness of management and treatment interventions; and (iv) describes (quantitatively or qualitatively) impact and/or recovery from visual impairment.
problems. We used a critical appraisal tool (Cochrane quality appraisal tool) to assess the quality of the identified evidence.

Where there were existing systematic reviews we provided an overview of these, and did not seek to repeat searches.

**Stroke survivor interviews**

We aimed to conduct five full patient interviews of stroke survivors with long-term (greater than 1 year) visual problems.

We contacted patient and public forums such as Connect, Different Strokes, Speakability, Stroke club consultation group, the Stroke Association, North West Stroke Research Network consumer reference panel, RNIB, North West People In Research forum, local patient involvement groups. These groups circulated the recruitment announcement to stroke survivors and carers.

Biographical narrative interpretative methods were used with long-term stroke survivors. Interviews (typically 1-2 hours duration) commenced with a pre-constructed single narrative question. This was followed with additional narratives relating to the sequence of topics raised and then followed by non-narrative questions to explore the topics further.

Interviews were audio-recorded, transcribed verbatim and then assessed to extract and establish themes. The assessment was undertaken twice to ensure capture of themes. A thematic approach to analysis of the qualitative data was adopted. All transcripts were systematically coded using the NVivo10 qualitative software package.
**Professional practice survey**

Our surveys of professionals included the following stages;

Methodology and feasibility: development of survey questions involved consultation with clinicians, academics and users. Pre-coded questions addressed the types of visual problems seen, how these are identified, how these are treated and follow-up, what care pathways are used, links with other professions and referral options.

Instruments: consideration was given to self-completion and online survey options.

Sample: included ophthalmic and stroke professions to identify existing care pathways approved at national and/or local level, and how care pathways are used along with the range of vision services provided. The ophthalmic professions included orthoptists, optometrists, ophthalmologists, eye clinic liaison officers (ECLOs) and visual rehabilitation officers (VROs). The stroke professions included physicians, nurses, physiotherapists, occupational therapists. All of these ophthalmic and stroke professional groups were contacted via a variety of routes inclusive of UK-wide professional bodies, the Stroke Association, the UK Stroke Forum, the Stroke Research Network regional contacts, etc.

Conduct: release of survey to all professional groups.

Subsequent stages included analysis of data and reporting of data.

The information provided on the returned surveys was input to a database (SPSS version 20) and descriptive analysis undertaken to combine responses in relation to each of the questions.
**Organisation scoping**

We individually approached the regional stroke research networks, CLAHRCs, the Stroke Association and other UK-wide stakeholder groups and organisations to elicit whether they had conducted previous surveys that included vision-related questions and to scope knowledge of pending data from research studies.

**Best practice service interviews**

Further to the professional surveys, we reviewed the Vision In Stroke (VIS) and Visual Impairment in Stroke: Intervention Or Not (VISION) recruitment sites to identify areas of best practice across the UK. In addition, we liaised with the Scottish Stroke and Vision Network to identify areas of best practice. Best practice services were defined as those with integrated stroke and vision care provision for stroke survivors.

Health care professionals involved in these services were invited to participate in 1:1 interviews or a focus group. A ‘SWOT’ framework was used to lead the discussion in a semi-structured format. The discussion was structured by establishing the Strengths, Weaknesses, Opportunities and Threats (SWOT) of having a vision assessment on the stroke unit. A social constructionist theoretical approach was used to guide the interview/focus group; participants were encouraged to express their views and consider their own views in the light of other opinions expressed.

The data were analysed using a methodological approach compatible with a social constructionist perspective. A thematic analysis was undertaken and themes were established. The data were revisited considering the group interactions, with the aim of
establishing whether there was evidence that the interactions supported these themes.
The NVivo10 software package was used to support the data analysis.
Results

**Literature review**

Initial search of the literature obtained 109197 results. Following refinement of the search, for example removing duplicates and removing letters to editors and single case reports, 22160 search results remained. Two authors (FR and LH) reviewed the titles and abstracts independently and identified 246 papers to be obtained as full copies. Following review of full papers, 144 were found to be directly relevant. In the process of reviewing the titles, abstracts and full papers we sought to identify reports of incidence or prevalence data, screening or assessment strategies or tools, management and treatment interventions and impact and/or recovery from visual problems. We used a critical appraisal tool (Cochrane quality appraisal tool) to assess the quality of the identified evidence.

We found a small number of randomised controlled trials but studies were mostly of longitudinal observation design and many lacked robust methodology. There were a small number of large cohort studies but most had small sample sizes of less than 100 subjects. Overall incidence of visual impairment after stroke could not be determined. On the basis of combined information of presence of visual impairment in stroke study populations from prospective clinical studies and clinical trial data, an estimation of prevalence is approximately 60% at baseline assessment and reducing to about 20% by 3 months post stroke onset (Ali et al 2013, Freeman and Rudge 1988, Gall et al 2010, Giroud et al 1994, Macintosh 2003, Rowe et al 2009, Rowe et al 2011a). We reviewed further studies that only included stroke survivors with particular types of visual
impairment but not inclusive of all types of visual impairment. Based on these studies, for visual field loss the estimated prevalence is up to 51% at baseline reducing to 21% by 3 months post stroke onset, for eye movements it is up to 68% at baseline, for impaired central vision it is up to 70% at baseline and for visual perceptual impairment it is up to 80% at baseline, particularly for right hemisphere strokes (Agrell et al 1997, Ali et al 2013, Ciuffreda et al 2007, Crews et al 2006, Kissel et al 1983, Rowe et al 2009, 2013b,c, Stone et al 1993). Full recovery of visual function by 3 months was reported in up to 17% for visual field loss, in up to 71% for visual acuity deficit and up to 34% for visual perceptual impairment including visual inattention (Ali et al 2013, Beaudoin et al 2013, Cassidy et al 1998, Cassidy et al 2001, Freeman & Rudge 1988, Gray et al 1989, Kedar et al 2007, Schmielan & Wong 2007, Zhang et al 2006).


Four Cochrane systematic reviews were identified relating to intervention studies for visual impairment post stroke (Bowen et al 2013, Pollock et al 2011a,b, 2012). We found further articles reporting interventions but these were non-randomised study designs. Hence we did not review this literature further but have opted to report the Cochrane review findings in the discussion.
Impact of visual impairment post stroke was reported to include poor quality of life, particularly aspects of mobility, self-care, activities of daily living, pain/discomfort, anxiety or depression, social functioning, dependency, driving, confidence and reading (Bois-Wollner & Diamond 1976, Chen et al 2009, Fisk et al 2002, Langelaan et al 2007, Papageorgiou et al 2007).

**Stroke survivor interviews**

We interviewed five stroke survivors who had ischaemic infarcts (blockage of blood supply). There were three females and two males aged from 34 to 75 years (two in their 30’s, one in their 50’s and two in their 70’s) at stroke onset. Interviews were conducted in England and Scotland. A number of themes emerged.

The stroke was diagnosed immediately in both people in their 70’s. There was a delayed diagnosis of greater than 3 days in the younger three people. Where visual problems existed, they were attributed to other causes such as migraine. General problems due to the stroke are shown in table 1. Of these, fatigue, limb weakness/hemiplegia and communication problems were most frequent. Visual problems due to the stroke are shown in table 2. Of these, homonymous hemianopia visual field loss was the most common impairment with additional problems with reading, glare/photophobia, blurred vision and perceptual problems.

Impact of the visual problems typically included a loss in confidence, increased collisions/accidents, fear of crowded places and fear of falling (table 3). These individuals reported a number of adaptations that they had made or used to compensate for their visual problem(s) and commonly including magnifiers, large print,
taking extra care/caution, de-cluttering their environment, increased lighting and use of a white stick (table 4).

**Table 1  Stroke-related general impairments**

<table>
<thead>
<tr>
<th>General impairments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Balance</td>
</tr>
<tr>
<td>Limb weakness: hemi/quadriplegia</td>
</tr>
<tr>
<td>Fatigue</td>
</tr>
<tr>
<td>Dysarthria</td>
</tr>
<tr>
<td>Memory issues</td>
</tr>
<tr>
<td>Expressive/receptive aphasia</td>
</tr>
<tr>
<td>Dizziness</td>
</tr>
<tr>
<td>Facial palsy</td>
</tr>
<tr>
<td>Elevated emotional responses</td>
</tr>
<tr>
<td>Depression</td>
</tr>
</tbody>
</table>

Two individuals had no recovery of their visual problems, two had partial recovery and one had full recovery. Two individuals never received any vision assessment and three never received any treatment for their visual problems.

**Table 2  Visual problems after stroke**

<table>
<thead>
<tr>
<th>Visual impairments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Homonymous hemianopia</td>
</tr>
<tr>
<td>Reading difficulty</td>
</tr>
<tr>
<td>Glare sensitivity/photophobia</td>
</tr>
<tr>
<td>Anosognosia</td>
</tr>
<tr>
<td>Visual inattention</td>
</tr>
<tr>
<td>Prosopagnosia</td>
</tr>
<tr>
<td>Diplopia</td>
</tr>
<tr>
<td>Nystagmus</td>
</tr>
<tr>
<td>Blurred vision</td>
</tr>
<tr>
<td>Corneal dryness</td>
</tr>
</tbody>
</table>
When considering post-stroke support, two received a 1-month community support after discharge for their general problems, two received information from local vision rehabilitation officers and one received no support and sought private medical care. Only one received information about visual problems whilst in hospital. Stroke survivors and their carers felt there was a need for improvement of education to promote knowledge and increased awareness of post-stroke visual impairment.

**Table 3  Impact of visual problems**

<table>
<thead>
<tr>
<th>Impact issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loss of confidence</td>
</tr>
<tr>
<td>Assistance required when outside</td>
</tr>
<tr>
<td>Panic attacks</td>
</tr>
<tr>
<td>Unable to pursue hobbies</td>
</tr>
<tr>
<td>Fear of falling</td>
</tr>
<tr>
<td>Unable to return to work</td>
</tr>
<tr>
<td>Startled by sudden appearances from blind side</td>
</tr>
<tr>
<td>Fear of dark evenings/ nights – worse in winter time</td>
</tr>
<tr>
<td>Loss of driving licence</td>
</tr>
<tr>
<td>Fear of crowded places</td>
</tr>
<tr>
<td>Increases bumps/collisions</td>
</tr>
<tr>
<td>Misjudged distances</td>
</tr>
</tbody>
</table>

**Professional survey**

The survey was circulated to organisations whose members would contribute to stroke and eye care. Stroke professions included stroke physicians, neurologists, occupational therapists, physiotherapists, stroke nurses, speech and language therapists, dieticians, radiographers and others. Eye professions included ophthalmologists, orthoptists, hospital optometrists, ophthalmic nurses and eye clinic liaison officers.
Table 4  Adaptations to visual problems

<table>
<thead>
<tr>
<th>Visual adaptations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Magnifiers</td>
</tr>
<tr>
<td>Narrow columns for reading</td>
</tr>
<tr>
<td>De-clutter</td>
</tr>
<tr>
<td>Companion when going out</td>
</tr>
<tr>
<td>Positions things to non-affected side</td>
</tr>
</tbody>
</table>

Completed surveys were obtained from 548 individuals. It is unknown what the total number of individuals are represented by these professional groups, hence it is not possible to calculate the percentage return of surveys. Figure 1 shows the professional categories completing the survey. Stroke team responses were received from 49.5% and eye team responses were received from 42.5%. 'Other' responses received from 8% included A&E staff, assistant practitioners, charity executives, clinical and neuropsychologists, dieticians, GPs, orthotists, paramedics, administrative and support workers and visual rehabilitation staff.

Respondents were primarily based in eye clinics in 39.5%, 1.5% in general medical or neurological wards, 26.5% in stroke units, 11.5% in community stroke services, 10% in rehabilitation units and 11% in other services. Patients were seen within variable time periods but many respondents (41%) saw patients within one week (figure 2). Nineteen percent did not personally test vision in any way and 11% had a visiting clinician to test vision. Screening tools were used by 22%. These included screening forms such as the
VIS or locally modified VIS form, BIOS or locally modified BIOS form. Locally designed screening forms were used most commonly.

A common range of vision tests were used for visual acuity, visual field, eye movement and visual function by 36-58.5% of respondents. LogMAR charts were more frequently used to test visual acuity, confrontation was used most frequently to test visual field, cover test for ocular alignment and nine position testing for eye movements.

**Figure 1   Professional categories**

Most patients (57%) were assessed on the ward with 30.5% seen in the eye clinic. Figure 3 shows the frequency of visual symptoms that professionals recognised as reported by patients. Visual problems reported by family or other professionals were high at 88.5%.
Figure 2  Time period for visual screening

Figure 4 shows the frequency of visual conditions recognised by professionals as underlying their patients' visual symptoms. Figure 5 shows the various treatment options offered and whether provided personally by the professional or referred. If patients had no visual symptoms but had an eye condition, 20.5% stated they would always treat, 46.5% would sometimes treat, 11% would not treat and 22% stated 'don't know'. The typical overall follow-up period was less than 3 months.

Many referred direct to members of the eye care team including ECLOs (19.5%), low vision clinics (38%), ophthalmologists (57%), optometrists (37%) and orthoptists (46.5%). A designated care pathway for stroke survivors with visual problems (whether a national care pathway or locally designed) was used by 46% of respondents. Visual information sheets related to patient’s visual problems were not given to patients by 33.5% of respondents. Twenty percent rated their knowledge of visual problems as
fairly poor or very poor and would request information on types of visual problems (39%), assessment options (47%), management options (60%), who to refer to (37%) and information resources for patients (59%). When asked about the existing evidence base, 40.5% felt this did not influence, or only slightly influenced, their assessment of visual problems, and 36.5% felt the evidence base did not influence, or only slightly influenced, their management.

**Figure 3**  **Frequency of visual symptoms**

![Graph showing frequency of visual symptoms](image)

**Organisation scoping**

We contacted a broad range of country-specific organisations (including Chest Heart Stroke Scotland, All Wales stroke group, the Stroke Association, Northern Ireland NIMAST, etc.), charities (including Visibility, Different Strokes, Seeability, Headway, RNIB, etc.), health organisations (including CLAHRCs, Stroke Research Network, James Lind Alliance, etc.) and independent researchers in the UK. Responses were
received from all the organisations that we contacted and from the responses, we identified a small number of previous scoping exercises or surveys.

**Figure 4  Frequency of visual conditions**

![Frequency of visual conditions graph]

**Figure 5  Options for therapy**

![Options for therapy graph]
The Stroke Association (Coleman 2013) conducted a needs survey in 2010. They asked the question “Since your stroke, have you had enough help with sight difficulties?” Most respondents (52.5%) had not had a problem, 37.5% had experienced a visual problem and 10.3% had experienced a problem but did not want help. Of those with a problem, 26% reported that their need was unmet, 35% stated their need had been met to some extent and 39% reported their need had been fully met.

The GM-SAT (Greater Manchester Stroke Assessment Tool) is a descriptive post stroke assessment tool to provide a structured, systematic needs assessment at 6 months post hospital discharge (Rothwell et al 2012). It covers 34 patient and one carer related common long-term post stroke problem areas. This tool was assessed in a study of 137 stroke survivors across ten community stroke services in England. Unmet need was defined as “a problem that was not being addressed or one that was being addressed but insufficiently”. A total of 464 unmet needs were identified with 8% of people having no unmet needs. There were a mean of three (SD2.5) unmet needs ranging from 0 to 14 per person. Vision was identified as an unmet need by eight people (5.8%) and one person (0.7%) was referred to a visual impairment service.

In Wales, a recent survey has been undertaken (Djiallis 2013) to determine what vision screening services are available for stroke patients across Wales. No results were available at the time of writing this report.

In Scotland, the University of Glasgow best practice statement was recently released (Best Practice Statement 2013). This resulted from a Scottish collaboration and provides guidance for the screening, assessment and management of stroke survivors in the first month after stroke. The statement recommends:
• Vision screening as part of the initial general stroke screen – for example using the STARs tool – to identify pre-existing visual problems plus new visual problems with the latter being referred to orthoptic services,

• Full assessment of people with visual field loss with explanation of the possibility of visual hallucinations, risks of visual field loss and treatment options such as prisms and scanning training plus referral for formal visual field assessment,

• Assessment of eye movement disorders with referral to orthoptists if problems are detected and management of double vision as appropriate,

• Screening for visual inattention with a combination of appropriate tests, full assessment if detected with an appropriate test battery and behavioural assessment with management and re-assessment as required,

• Clear care pathways with appointments for follow-up made prior to discharge, consideration of cognitive, physical and communication problems during assessment, training of staff, appropriate communication between staff, awareness of visual problems by patients and caregivers and access to appropriate information in a variety of formats and driving checks.

A review of stroke units across Scotland was conducted by Pollock et al (2011c). They aimed to scope current practice by occupational therapists working in Scottish stroke in-patient services in relation to assessments, protocols, referrals and treatments for post-stroke visual impairment. They obtained a 90% response to their questionnaire and of the total respondents, only 9% reported access to a protocol for post stroke visual impairment. Assessment of visual attention and visual scanning was undertaken with every patient or regularly by 89% of respondents. Treatment was provided for visual
neglect by 82%, for visual field loss by 69% and for eye movement problems by 11%. Choice of treatment was similar regardless of the type of visual impairment present.

In a second survey Pollock et al (2011d) aimed to scope the current assessment and management strategies used by Scottish Orthoptists for post stroke visual impairment. A 100% response rate was obtained and of the respondents, only 12% reported access to a protocol or management plan specific to stroke patients. Commonly employed treatment options for eye movement disorders included prisms, advice on head posture and convergence exercises. For visual neglect and visual field loss, advice was most commonly provided. Orthoptists identified lack of a management plan and lack of funding as the main barriers to effective eye care.

A survey of Orthoptists across the UK was undertaken in 2007 (Rowe 2009). The survey showed that 45% of stroke services provided no formal vision assessment for stroke patients. The conclusions stated that enquiries about a patient’s last visit to their optometrist were of little information when so many visual impairments occur subsequent to the stroke. Furthermore basic screening by nursing, doctor or therapy staff were reported to miss more subtle ocular motility and visual field deficits which are known to impact on general rehabilitation with a recommendation for formal vision screening by Orthoptists and eye care teams.

**Best practice service interviews**

Interviews were conducted with 14 UK NHS Trusts offering an integrated stroke and vision service. Interviewees included eye clinic managers, nurses, orthoptists, occupational therapists and physiotherapists. Distribution of these Trusts is outlined in
Discussions during the interviews centred on perceived strengths, weaknesses, opportunities and threats to this specialist service.

Strengths

All services considered communications to be key to their success, all provided training for stroke team staff, all provided ‘open access’ for referrals (i.e. stroke staff could contact the Orthoptist at any time to discuss query referrals if unsure), all saw patients on the stroke unit with follow-up arranged in the eye clinic and all aimed to undertake initial visual assessments within one week of stroke onset. All but one service used a standardised screening/referral form – either the VIS (Rowe et al 2009), BIOS (British and Irish Orthoptic Society 2013) or locally designed form. These services had an average of 2 dedicated sessions per week for this service ranging from 1-4 sessions per week. Cost analysis for providing these orthoptic sessions are outlined in table 5. These were calculated based on the 2013 agenda for change mid-point salary scales for band 6 and 7 with 20% on-costs.

**Figure 6  Location of NHS Trusts**
The Orthoptists in one service screened all stroke survivors whereas the remainder had initial vision screening by stroke staff who had been trained by the Orthoptist and secondary screening by the Orthoptists. Half of services provided lay summaries to the stroke teams plus patients and carers in addition to providing vision-specific information to patients and carers. Individualised patient summaries (patient passport) were provided by four services in which patients were provided with details of when they had their vision assessment, the results, any treatment planned and any follow-up planned. Half of services were able to provide flexible appointments throughout the week and of variable durations. Half of the Orthoptists reported being an integral part and a named member of the core stroke team. A number of Orthoptic services (n=6) maintained a database of all referrals to ensure all received assessment and follow-up. This proved useful where patients were discharged early before vision assessment and ensured patients did not get ‘lost’ to the service. Four services reported supportive stroke physicians as being vital to their success and four services reported being able to provide a rota of Orthoptist staff as essential to ensure coverage of the service despite annual leave or sick leave.
**Weaknesses**

Lack of funding was raised as a major weakness by twelve services. In addition, lack of Orthoptic cover during annual leave was an issue. Orthoptists identified that retraining of stroke staff on a regular basis because of staff rotation and changes could be time consuming. Services were reported as more likely to fail where stroke physicians did not ‘buy into’ or fully support the service. Where services could only provide one dedicated session per week, there was a risk of missing patients and not being able to screen all patients as quickly as would be preferred with limited time for assessments. Occasional misinformation from stroke teams about visual problems proved problematic to resolve and added to patient confusion.

**Opportunities**

Services believed opportunities to be present for increased Orthoptic sessions and training of stroke staff. Many Orthoptists were invited to speak at stroke meetings which was seen as an opportunity to highlight visual problems, what to look for and who to refer to. Orthoptists had used audits of service to demonstrate the continued increase in referrals and wide benefits to patients and staff. Further opportunities were identified for dual assessments with occupational therapists and physiotherapists plus wider involvement with visual rehabilitation officers from sensory support teams.

**Threats**

Funding was again identified as a threat to provision of these services along with increased waiting times for appointments because of increased numbers of referrals and insufficient dedicated sessions or insufficient Orthoptic staff. Lack of support from stroke physicians and from eye clinic managers and/or ophthalmologists were reported.
Through integration of all responses several key factors could be identified that were considered integral to provision of a ‘best practice’ specialist service. Essential recommendations were determined where greater than 50% of services had stated that they had this in place or it was detrimental if not in place. Desirable recommendations were determined where less than 50% of services had stated that they had this in place or would wish to have this in place. Table 6 outlines these recommendations.

### Table 6  Essential and Desirable recommendations for stroke/vision service

<table>
<thead>
<tr>
<th>Essential recommendations</th>
<th>Desirable recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 designated orthoptic sessions per week (minimum)</td>
<td>Database maintained of stroke referrals to eye clinic</td>
</tr>
<tr>
<td>Flexible appointments</td>
<td>Follow-up designated session in eye clinic</td>
</tr>
<tr>
<td>Formal stroke team training</td>
<td>Orthoptist attendance at MDT meetings</td>
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<tr>
<td>Formal support from stroke physicians</td>
<td>Referral to ECLO</td>
</tr>
<tr>
<td>Lay summaries</td>
<td>Vision testing equipment on stroke unit</td>
</tr>
<tr>
<td>Open communication</td>
<td>Rota of orthoptic staff</td>
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<tr>
<td>Orthoptic assessment within one week of stroke onset</td>
<td></td>
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<tr>
<td>Orthoptist named on core stroke team</td>
<td></td>
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<tr>
<td>Provision of visual information leaflets</td>
<td></td>
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<tr>
<td>Standardised referral form</td>
<td></td>
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<tr>
<td>Vision care pathway</td>
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</table>
Discussion

Literature review

We were unable to identify a precise incidence rate for visual impairment post stroke. We reviewed a variety of articles, a few of which were randomised controlled trials but many which were retrospective or prospective observation studies. Robust methodologies could not be identified in many studies. We have therefore estimated prevalence/incidence of visual impairment after stroke as a figure of approximately 60% at baseline assessment (Ali et al 2013, Freeman and Rudge 1988, Gall et al 2010, Giroud et al 1994, Macintosh 2003, Rowe et al 2009, 2011a). This reduces to approximately 20% by 3 months post stroke onset due to factors such recovery, adaptation or death. Recovery of function was best reported for visual acuity deficit. The prevalence is highest for eye movement problems, visual field loss and visual inattention. However, accurate figures regarding incidence of visual impairment after stroke remain unknown and is required so that appropriate services can be commissioned, further developed and implemented. This is the subject of current ongoing research (Rowe 2013).

Accuracy of referrals by the stroke multidisciplinary team were reported to have a low sensitivity and specificity when evaluating the identification of presence or absence of ocular signs (Rowe 2010). Such results raised concerns for patients unable to communicate their visual symptoms and for patients in units without specified eye care liaison. Recommendations were made to provide education promoting knowledge and heightened awareness of visual impairment. In addition, vision screening protocols and
tools were recommended to identify potential visual deficits in stroke survivors with clear care pathways for their onward referral to eye services.

Four Cochrane systematic reviews were identified relating to intervention studies for visual impairment post stroke. These included interventions for age-related visual problems, for visual field loss, for eye movement problems and visual inattention (Bowen et al 2013, Pollock et al 2011a,b, 2012). Implications for research were reported as requiring further high quality randomised controlled trials to determine the effect of interventions in addition to considering the impact of interventions such as environment modifications and activities of daily living training plus including outcomes relevant to activities of daily, visual function and vision-related quality of life.

The impact of visual impairment post stroke was wide ranging across various vision-related and health-related quality of life measures. This must be considered in future studies and as evidence for provision of specialist vision services.

**Stroke survivor interviews**

Given the short time-scale of this project, interviews were conducted with five stroke survivors only. However, a large scale study of stroke survivor interviews is on-going in a separate study (Rowe 2013). From our small study, issues were evident with prompt diagnosis in younger stroke survivors particularly where visual problems occurred. Diagnosis was quicker when general problems emerged such as hemiparesis and aphasia. The visual problems experienced by these people were quite varied but included hemianopic visual field loss, double vision and nystagmus, facial palsy with dry eye, reading difficulty, glare, blurred vision and perceptual problems.
Vision was affected from the onset of their strokes but attention from medical staff was always directed to any mobility issues first. This is understandable but also a problem as a lack of visual information resulted in more bumps and collisions for some people as they mobilised. Both issues need to be addressed together so that people are successfully and safely mobilised.

The impact of visual impairment reported by these people included fear of falling and increased bumps or accidents, missing things, being startled by people suddenly appearing from their affected side, loss of driving licence, a dislike of crowded places and loss of confidence. Adaptations made to compensate for the visual impairment included having someone with them when out, leaving lights on all the time and use of a white stick. Other adaptations included use of magnifiers, large print, reading with narrow columns, increased caution and de-clutter. There was no consistency for provision of visual assessment and treatment early after stroke and no visual information was provided to any person. Post discharge support was also lacking which is disappointing given that many local services can provide considerable support and assistance. Misinformation such as “hemianopia will recover over a few years” or “hemianopia due to migraine” angered people.

**Professional survey**

We received 548 responses to our survey. A roughly equal number of responses were received from members of the stroke team and members of the eye team. The highest number of responses was from Orthoptists and occupational therapists. Patients with vision problems were reported by respondents as being seen at greater than 4 weeks
post stroke in 27%. This delay between stroke and visual assessment potentially has an impact with lack of early treatment of eye problems and contribution of effect to general stroke problems. Where visual assessment was undertaken, a common array of tests were used for visual acuity, visual field, eye movements and visual perception but detailed vision assessment was not generally undertaken by stroke staff. The most commonly reported visual symptoms included blurred vision, changed or altered vision, field loss, facial weakness, reading difficulties and clumsiness. Notably these symptoms could be attributed to a number of different visual problems and could not be used to infer a diagnosis of a specific type of visual problem which has been reported previously (Rowe et al 2013a). Even where some people never reported visual symptoms, the survey highlighted that visual problems were frequently suspected and thus reported by family or members of the stroke team (88%). The most common treatment options that were provided personally by either members of the stroke or eye teams included functional activity training, scanning training for hemianopia and for eye movement problems plus reading strategies and general advice on adaptations. Scanning training for eye movement problems was reported as a widely used treatment option by a previous survey (Pollock et al 2011c). In our survey its use was reported by members of the stroke team but less by members of the eye team who targeted treatment specifically to the type of eye movement problem. Care pathways for visual problems were reported as not present by 44% of respondents and 31% did not provide any visual information leaflets. One fifth reported their visual knowledge as fairly poor or very poor and only one third felt the existing evidence base influenced their practice.
This raises education issues which has also been previously advocated (Pollock et al 2011c,d).

The survey highlights important gaps on how patients are cared for, who takes responsibility for their assessment and management of visual problems.

**Organisation scoping**

Six reports of previous surveys and studies were accessed. The surveys of unmet vision needs showed that people reported visual problems at various time points after stroke but did not always receive referral to the relevant eye care services. This again raises the issue of education about detection of visual problems, the impact of these and who the referrals should be sent to. The lack of care pathways for visual problems post stroke must be addressed particularly as national care pathways exist (BIOS 2013). The best practice statement in Scotland provides a number of recommendations for screening, assessment, management and referral of stroke patients in the first month after stroke.

Some issues will be addressed in on-going research. For example, a review of the UK clinical research network study and NIHR portfolio revealed four registered studies/trials:

1. Scanning training for visual field loss after stroke – pending (in set-up),
2. Visual impairment in stroke: intervention or not – in follow-up phase with no results available currently,
3. Vision and driving after stroke – in follow-up phase with no results available currently,
4. Impact of visual impairment after stroke – at year 1 of a 5-year programme of research.

**Best practice service interviews**

A SWOT analysis was undertaken in 14 service interviews across the UK. From these interviews we have identified key ‘essential’ and ‘desirable’ recommendations for provision of vision and stroke specialist services. From discussion of weaknesses and threats to services, it is recommended that consideration is given to providing sufficient orthoptic cover with appropriate funding to ensure 52 week services.

**Limitations**

We received 548 responses to our professional survey. We had hoped to receive over 1000 responses on the basis of returns of previous vision/stroke surveys. We circulated the survey to all professions involved in stroke and eye care but are unsure whether the survey was sufficiently disseminated to clinicians. However we received almost equal number of responses from eye teams and stroke teams with useful information provided. We received three criticisms about completion of the survey in which respondents found it difficult to complete the survey because many questions asked about visual assessments and treatments and staff did not necessarily have sufficient knowledge of these. This criticism had been raised in our pilot survey before the main survey was released and a ‘don’t know’ or ‘not applicable’ option had been added to most questions. Future, similar, surveys should add these options to all questions where relevant.
Results of the Wales stroke/vision survey were not available at the time of writing of this report and thus we cannot provide information about the extent of vision screening across Wales.

We conducted only five stroke survivor interviews which was not enough to reach saturation. However, a larger scale study is currently on-going to address this.
Conclusions

To our knowledge this is the first large-scale scoping study to determine the extent of unmet need and care provision for post-stroke visual impairment. There remains considerable unmet need for stroke survivors with visual problems. The precise incidence of post stroke visual problems remains unknown. Thus, on the combined basis of reviewed studies, we estimate approximately 60% overall. There are specific issues for screening and assessment of visual impairment and further evidence is required for efficacy of management options.

It is encouraging that many professionals and researchers across the UK and abroad are cognisant of the need for appropriate assessment, referral and management of stroke survivors with visual problems. It is arguably of concern that use of care pathways are lacking, that stroke survivors go without appropriate visual information and that up to 40% of professionals did not feel their practice was substantially influenced by the existing evidence base.

There have been a limited number of previous surveys but all identify unmet needs for vision after stroke. It is encouraging that there are clear recommendations as to what constitutes best practice for specialist stroke and vision services, which can be implemented with relatively little financial inputs. It is recommended that there should be increased integration of orthoptists within core stroke teams with orthoptists named within the team and local referral pathways.

Stroke survivors need early vision assessment so that this information is available to the stroke team to influence their treatment choices. Early provision of visual information is
reported as beneficial by stroke survivors as is post-discharge information about local support services.
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