

## **Developing a stroke-vision care pathway: a consensus study.**

Fiona J Rowe, PhD<sup>1</sup>, Lauren R Hepworth, PhD<sup>1</sup>, Claire Howard, MMedSci<sup>1</sup>, Kerry L Hanna, BSc(Hons)<sup>1</sup>, Brinton Helliwell, BSc(Hons)<sup>2</sup>

1, Department of Health Services Research, University of Liverpool, UK

2, Patient and public involvement representative

### **Address for correspondence:**

Prof Fiona Rowe

Department of Health Services Research

Waterhouse Building Block B, 2<sup>nd</sup> floor,

University of Liverpool,

1-5 Brownlow Street,

Liverpool L69 3GL

E: [rowef@liverpool.ac.uk](mailto:rowef@liverpool.ac.uk)

T: 0151 7944956

**Running title:** Stroke-vision care pathway

Word count: 3958

Number of tables: 5 + supplementary file (stroke-vision care pathway)

Number of figures: 1

Article category:

**Declarations:**

**Ethics:** This study had institutional ethical approval and was undertaken in accordance with the Tenets of Helsinki. Informed consent was obtained if the participants attended and participated in the focus group meetings.

**Consent for publication:** Not applicable.

**Data access;** Data can be accessed via direct contact with the lead author on reasonable request.

**Competing interests;** Nil to declare.

**Funding:** Professor Fiona Rowe was funded by a National Institute for Health Research (NIHR) Career Development Fellowship for this research project. This paper presents independent research funded by NIHR. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care

All authors declare: no financial relationships with any organisations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

**Author contributions:** FR provided oversight for the study and led the writing of the paper. FR, LH, CH, BH and KH contributed to data collection, reviewing the draft paper and approving the final version.

**Acknowledgements;** We thank the stroke survivors, carers and clinicians who contributed to the development of this care pathway.

**Keywords**

Care pathway; Stroke; Vision; Service provision; Referral; Detection

## **Abstract**

**Purpose:** We aimed to develop a stroke-vision care pathway for stroke survivors with visual impairment.

**Methods:** A literature review searched key electronic bibliographic databases for care pathways related to stroke/vision. Two focus group meetings using semi-structured/nominal group technique reached consensus on items relevant for inclusion in a stroke-vision care pathway. Following development of the pathway we obtained feedback through consultation with patient and professional groups.

**Results:** The literature review identified two care pathways relevant to acute stroke and generic vision disorders. Outputs from focus groups related to: how stroke survivors present with vision problems; the time points at which stroke survivors present with vision symptoms; the relevance of different types of visual condition to different vision services; the importance of support services supplementary to hospital services and; the importance of key resources to promote awareness of vision problems in stroke survivors. Refinement of the pathway considered time duration from stroke onset, reporting of symptoms to services, and signposting/referrals required dependent on visual condition type.

**Conclusions:** This new stroke-vision care pathway is a process pathway describing potential options for stroke survivors with visual impairment to access health care and obtain appropriate referral(s) to vision services relevant to their specific vision problem(s).

## Introduction

Visual impairment occurs frequently following stroke with a reported incidence of 60% in stroke survivors [1]. It constitutes a considerable comorbidity of stroke. Visual impairment, on its own or in addition to other stroke-related disabilities, can cause significant impact to quality of life [2]. For many, it results in inability or altered ability to undertake many aspects of daily activities with impact on return to work, participation in hobbies and family life, and can lead to social isolation, altered mood and depression [3-5].

Visual impairment may be the sole presenting sign of stroke – approximately 90% of occipital lobe stroke lesions have no other neurological signs [6]. More commonly, however, visual impairment is one of a number of presenting signs and symptoms of stroke [7]. Visual impairment can be complex encompassing many types of visual condition with a wide range of impacts. Visual impairment may give rise to symptoms that are noted immediately on occurrence of the stroke or, indeed, visual symptoms may only become apparent some weeks or months after stroke onset. Thus, presentation of visual symptoms by stroke survivors can be expected at any stage from stroke onset through to chronic post stroke stages. Furthermore, transient visual impairment is also recognised as a precursor symptom of stroke with such symptoms being hallmarks of transient ischaemic attack (TIA) [8].

Recognition of visual impairment as a common sequelae of stroke is slowly increasing [1,9]. However, it remains under reported and poorly identified in stroke survivors because many visual conditions cannot be detected by merely observing the eyes [10]. Careful questioning alongside specific testing of visual function is required for the accurate and reliable detection of visual impairment [9,11].

There are issues with how best to identify the presence of visual impairment through stroke team vision screening and specialist vision assessment [10]. Even with screening measures in place there are also issues reported with provision of care and access to vision services for stroke survivors who have been identified as having vision problems [11]. One way of improving access to appropriate vision services is to implement the use of care pathways. A care pathway has been defined as “a complex intervention for the mutual decision-making and organisation of care processes for a well-defined group of patients during a well-defined period...The aim of a care pathway is to enhance the quality of care across the continuum by improving risk-adjusted patient outcomes, promoting patient safety, increasing patient satisfaction, and optimising the use of resources” [12].

Surveys of clinical practice in the UK report minimal use or knowledge of vision and stroke specific care pathways. A survey of Scottish occupational therapists in stroke units reported only 9% with access to a protocol for post-stroke visual impairments [13]. A similar survey of Scottish orthoptists reported only 12% with access to a protocol or management plan specific to stroke patients [14]. A UK-wide survey of Orthoptists found that 46% of respondents reported using a care pathway [15], with some local departments designing their own care pathway to consider local needs and allocation of services.

Care pathways can improve patient care through better integration and referrals between services. Currently there is no overall prescriptive stroke/vision care pathway and with this in mind, the aim of our study was to develop a stroke-vision care pathway for stroke survivors with visual impairment.

## **Methods**

In the development of a stroke/vision care pathway we followed guidance on development of care pathways; steps 1-4 of the Vanhaecht 7-phase method [16]. This method can be used in hospital and community healthcare studies and its seven phases include a screening phase, project management phase, diagnostic- and objectification phase, development phase, implementation phase, evaluation phase and continuous follow-up phase. The Vanhaecht method is used internationally and is validated by a team of international experts. It forms part of the complex intervention in the European Quality of Care pathway study [16]. We report our development process in accordance with AGREE guidelines [17] which are the accepted standard for evaluation of the methodological quality of clinical practice guidelines.

### ***Steering committee***

In the development of this study we established a steering committee to oversee the conduct of the study. The committee comprised three research and clinically active orthoptists, one neuro-ophthalmologist, one orthoptic professional society representative and three stroke survivors.

### ***Literature review***

Our literature review comprised a broad review with the primary goal being to identify care pathways related to stroke and vision. We used systematic search strategies (Appendix 1) 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 2018);
- EMBASE (1980 to 2018);
- CINAHL (1982 to 2018);
- AMED (1985 to 2018);
- PsycINFO (1967 to 2018);
- British Nursing Index (1985 to 2018);
- PsycBITE (Psychological Database for Brain Impairment Treatment Efficacy, [www.psycbite.com](http://www.psycbite.com)).

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

1. searched the following registers of ongoing trials:

- i) ClinicalTrials.gov (<http://clinicaltrials.gov/>);
- ii) Current Controlled Trials (<http://www.controlled-trials.com/>);
- iii) Trials Central ([www.trialscentral.org](http://www.trialscentral.org));
- iv) Health Service Research Projects in Progress ([www.cf.nlm.nih.gov/hsr\\_project/home\\_proj.cfm](http://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](http://www.liverpool.ac.uk/orthoptics/research/search.htm)) and proceedings of Association for Research in Vision and Ophthalmology ([www.arvo.org](http://www.arvo.org));
3. contacted experts in the field,
4. individually approached the regional stroke networks, Collaborations for Leadership in Applied Health Research and Care (CLAHRCs), the Stroke Association and other UK-wide stakeholder groups and organisations to elicit whether they had developed stroke-vision care pathways.

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

Two authors (FR and LH) independently assessed study titles identified from the electronic and manual searches to identify those potentially relevant to this review. Study titles were assessed separately by the authors against criteria for this review using a data extraction form. The abstracts for these studies were then assessed to identify those meeting the criteria for this review.

### ***Focus groups***

We sought a consensus approach using focus groups in which information was collected through a semi-structured group interview process. The target populations for the focus groups were stroke survivors with visual impairment and clinicians primarily responsible for providing vision care. In order to recruit to focus groups we engaged with patient and public forums such as Connect, Different Strokes, Speakability, Stroke club consultation group, the



Stroke Association, RNIB, North West People In Research forum, local patient involvement groups and professional organisations. These groups circulated a recruitment advert to stroke survivors, carers and clinicians. Interested individuals contacted the lead investigator directly, by telephone or email. All individuals who registered interest were invited to participate.

Representation at each focus group included hospital and community clinicians (orthoptists, occupational therapists, physiotherapists, optometrists, ophthalmologists) and stroke survivors. We aimed for 6-12 participants per focus group meeting. Consensus was defined as a majority ( $\geq 70\%$ ) group agreement to support a decision in the best interest of the whole, in which the decision was an acceptable resolution that each individual could support, even if not his or her favourite.

In the planning stage, consideration was given to the structure of the meetings and whether stroke survivors and clinicians should attend the same meeting or be separated. There is potential for bias in having stroke survivors and clinicians in the same focus group, which could influence the responses from the stroke survivors, or clinicians. When planning the focus groups, we sought input from a national stroke survivor vision patient and public involvement group (VISable). Stroke survivors and carers within VISable were strongly against separate focus groups but advised that a process be put in place to ensure all voices would be heard during focus group discussions without interruption. On that basis, a nominal group technique was chosen. The technique reduces external influences that can affect group dynamics, such as hierarchical relations. The ethos of a nominal group process is that each participant is given an equal voice and individual input is encouraged. With this in mind, a decision was made to combine all groups of clinicians and stroke survivors within the same meeting.

We used a nominal group technique consisting of five stages:

1. Introduction and explanation of the study was provided by the facilitator.
2. Silent generation of ideas by each participant was sought where each participant was asked to write down their ideas and views for each key question. They were asked not to consult or discuss their ideas with others.
3. Sharing ideas between participants was requested. The facilitator recorded each idea on a flipchart as each participant outlined their ideas in turn, but still without group discussion of these ideas such that each participant had opportunity to express their individual ideas without interruption.
4. Group discussion between participants took place as the next step. Each idea was discussed with explanations provided where required for any idea lacking clarity. The facilitator ensured that each idea was discussed in turn with contribution from all participants. At this stage, new ideas could be added and ideas could be combined.
5. Voting and consensus formed the concluding stage of the focus groups. Participants discussed the ideas and prioritised them in relation to the key questions. Ideas achieving  $\geq 70\%$  consensus from the participants remained.

Following the focus groups, all items reaching consensus through both meetings were collated. These were taken forwards and developed into a care pathway process framework alongside an executive summary (Figure 1). This was circulated to the focus group participants for their comments and revised via an iterative process through email discussion.

### ***Consultation***

After agreement of the care pathway content we sought further peer review of the care pathway. We circulated the care pathway and its explanatory document to a stroke/vision patient and public involvement group (VISable) and to professionals encompassing orthoptists, general practitioners, occupational therapists, paramedics, stroke physicians, stroke facilitators and physiotherapists in a range of settings from pre-hospital through acute and community health care and within the charity sector.

### ***Ethical approval***

This study had institutional ethical approval and was undertaken in accordance with the Tenets of Helsinki. Informed consent was obtained if the participants attended and participated in the focus group meetings.

## **Results**

### ***Literature review***

Initial search of the literature obtained 109,197 results. Following refinement of the search, for example removing duplicates and removing letters to editors and single case reports, 22,160 search results remained. Two authors (FR and LH) reviewed the titles and abstracts independently using separate data extraction forms and identified four papers to be obtained as full copies. None of these full papers were found to be relevant to care pathways for stroke and vision. A search of web-based information identified two care pathways meeting the search criteria.

The British and Irish Orthoptic Society (BIOS) propose a vision care pathway for referral of acute-stage stroke survivors who have been identified as having possible visual impairment [18]. A further generic pathway exists for adult onset sight loss [19] with its purpose being to enable people with sight loss to get the right support at the right time and from the right person. It clarifies the pathway across health and social care and so enables better partnership working and a smooth transition for the person with sight loss.

Two papers were identified from the literature search that discussed stroke/sight loss research prioritisation processes [20,21]. These papers reported the top ten research priorities established through a robust consensus process overseen by the National Institute for Health Research James Lind Alliance (Table 1). Key questions arising from these process studies and two existent care pathways relating to stroke and vision, based on absence of information, included:

1. How do stroke survivors present with vision problems?
2. What are the time points at which stroke survivors present with vision symptoms?
3. What is the relevance of different types of visual condition with regard to different vision services?
4. What is the importance of support services in providing information supplementary to hospital services?
5. What is the importance of key resources to promote awareness of potential for vision problems in stroke survivors?

### ***Focus groups***

Two focus groups were conducted. The first comprised 15 participants including two optometrists, six stroke survivors, three occupational therapists and four orthoptists. The second comprised 11 participants including one optometrist, four stroke survivors, three occupational therapists, one physiotherapist and two orthoptists. In each focus group, one orthoptist (FR) acted as the facilitator. All stroke survivors had experienced visual problems as a consequence of their stroke; some had recovered their visual function whilst others had no recovery of their visual deficit. None had co-existent cognitive problems and one had mild dysphasia that did not interfere with contribution to the discussion. Throughout the focus groups, the primary attention was on stroke survivors with visual impairment, with or without other neurological signs and symptoms related to their stroke.

The five key questions identified in the literature review formed the basis of the semi-structured process.

#### *How do stroke survivors present with vision problems?*

Discussion started with how stroke survivors might present with vision problems in terms of who they might report their vision symptoms to. The groups recognised a number of contributing factors including:

- patient recognition that visual symptoms were new and not related to 'natural ageing process',
- recognition that visual symptoms alone would most likely not be seen as being caused by stroke,

- recognition that patients might be more likely to present to eye care professions with visual symptoms alone (particularly if symptoms were noted at home),
- patient reliance on stroke teams to help with eye service referrals where reporting of visual symptoms was made when under the care of hospital stroke and rehabilitation teams.

Consensus from participants was that a stroke-vision care pathway should start with likely presentation modes/services (Table 2).

*What are the time points at which stroke survivors present with vision symptoms?*

Table 3 outlines consensus views relating to the timing at which patients might present with their visual symptoms. Participants noted that visual symptoms are a common presentation of TIA or mini stroke and acknowledged that more could be done to raise awareness of visual symptoms as a possible presenting symptom of stroke and TIA. There was discussion of the issue that visual symptoms alone are a potential risk for delayed diagnosis of stroke whereas visual symptoms in association with more commonly recognised features of stroke as depicted in the Face-Arm-Speech-Time (FAST) campaign would not usually delay diagnosis of stroke. In addition, participants discussed the late reporting of visual symptoms with possible explanations that the patient might not have been aware of their visual problems in the early acute stages of stroke, their belief that visual symptoms might not be related to their stroke but due to problems with their eyes rather than their brain, or being unable to report their visual symptoms earlier because of communication or cognitive difficulties. For stroke survivors with visual symptoms who present within 4 hours of onset

of symptoms, participants were unanimous that patients be sign-posted direct to the emergency department A&E where as those presenting more than 4 hours but within 24 hours of stroke be sign-posted to urgent medical/stroke team including services such as emergency department A&E, rapid referral centre / equivalent, TIA hospital clinic and stroke hospital clinic. Those presenting longer than 24 hours following onset could be directed to general practice, early support discharge team, community stroke team, hospital stroke unit, or Optometrist dependent on whether symptoms were purely visual or in addition to other neurological symptoms, ensuring appropriate investigation and preventative treatment for further strokes with appropriate referrals to specialist eye and/or stroke services as indicated for the individual. The need for appropriate vision screening by these services was raised as highly important with screening undertaken at as early a time point as possible. For example, in the absence of access to specialist eye assessment, stroke/vision screening tools may be used such as the Vision Assessment Screening (VISA) tool [22] or StrokeVision app [23] with assessment of visual acuity, visual fields, visual attention and eye movements. Special consideration was recommended for those wishing to return to driving. Specific attention was given to the discussion of non-stroke related visual symptoms due to other ocular causes or stroke mimics and migraine. There was overall agreement that the referral options and timescales should still apply on the basis that ocular causes of acute vision loss such as angle closure glaucoma or retinal detachment also require rapid ophthalmic referral, symptoms of diplopia and oscillopsia require neurological referral and stroke mimics, including atypical migraine, still warrant appropriate medical referral for differential diagnosis.

*What is the relevance of different types of visual condition with regard to different vision services?*

Following detection of visual impairment, discussion then centred on the relevance of different types of visual condition as to where the onward referral should be made. Where referrals were being made for stroke survivors within the hospital service, consensus from participants was that referral could be made to orthoptists for visual conditions affecting eye position, eye movements and/or visual fields. Where impaired visual acuity was the issue, referral could be made to the hospital optometrist, ophthalmologist or low vision service. Where visual inattention was the issue, it was likely that stroke team occupational therapists would care for these stroke survivors but with the added option of referrals to orthoptists and/or neuro-psychologists where appropriate and dependent on local policies and procedures. Where referrals were being made for stroke survivors in the care of community services, referrals could be made to community optometry and low vision, occupational therapy and neuro-psychology services respectively for issues relating to visual acuity and visual inattention. For visual conditions affecting eye position, eye movement and visual fields, referral was recommended back to hospital or community orthoptic services.

Equitable access to specific vision services was discussed and noted that not all local areas would have all vision services nearby. Not only would this consideration apply within the UK but other countries could have similar issues where eye service provision differed. However, referral to neighbouring areas offering the requisite vision services was recommended and this was specifically endorsed by stroke survivors to reduce the health inequality incurred by post-code lottery.



*What is the importance of support services in providing information supplementary to hospital services?*

There was unanimous participant consensus as to the importance of support services in providing information supplementary to hospital services. Support services were considered to be those based both within hospitals as well as within those based in the community and included NHS services, social services, charity and professional organisations (Table 4).

*What is the importance of key resources to promote awareness of potential for vision problems in stroke survivors?*

Key advantages of these support services were the provision of information targeted through an individual needs assessment. Participants acknowledged the importance of key resources and provision of information to promote awareness of potential for vision problems in stroke survivors.

### *Barriers*

Throughout the focus group discussions a number of barriers were considered within the current care of stroke survivors with visual impairment, many of which could be negated by the adoption of a standardised care pathway. Key barriers included poor communication, issues with access to appointments, funding and issues with training and education (Table 5).

## ***Consultation***

Feedback on the pathway was received from stroke survivors, carers, eye teams (orthoptists, optometrists and ophthalmologists), stroke teams (stroke physicians, occupational therapists and physiotherapists from acute and community services) and the charity sector (eye and stroke). Refinement of the pathway was required to clarify time points at which stroke survivors might present with visual symptoms to ensure appropriate referral and care was provided at critical time points; thus facilitating hyperacute (e.g. thrombolysis pathway) and acute care versus sign-posting to TIA and stroke clinic care. Clarification was sought from explanatory notes for the pathway sections.

## **Discussion**

We have developed a care pathway for stroke-related visual impairment through a consensus process with eye care professionals, stroke team professionals and stroke survivors (Figure 1; Supplementary table 1). This care pathway is specific to stroke survivors with visual impairment and not to stroke onset generally. The care pathway considers the process through which stroke survivors with visual impairment may present with their visual symptoms in relation to the timing after stroke onset and who they might present to with their vision symptoms. At this stage, appropriate vision screening is required to target the service to which they should be referred to dependent on the duration of time since first onset of symptoms with/without other neurological symptoms of stroke, and the specific

referrals within eye services dependent on the type of visual impairment identified by vision screening.

This care pathway differs to other care pathways in stroke and vision. Our stroke-vision care pathway considers the access points and wider referral streams where the BIOS stroke and neuro-rehabilitation care pathway is primarily for acute stroke survivors requiring referral to outpatient eye services following vision screen or other medical referral [18]. Our care pathway also differs to the Vision2020 eye health and sight loss pathway [19] whose purpose is “to offer commissioners and practitioners a unique tool to enable people with sight loss to get the right support at the right time and from the right person” and seeks to facilitate working partnerships across health and social care. Our care pathway is specific to post-stroke visual impairment rather than any form of adult sight loss such as that due to trauma, ocular disease, hereditary disease, etc.

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 [24]. In a series of UK-wide interviews with integrated stroke-vision services a number of recommendations were made to promote best practice across all stroke units including use of standardised referral forms and use of a vision care pathway [25].

Use of our stroke-vision care pathway is recommended alongside appropriate vision screening. Key visual functions affected by stroke are impaired central vision, peripheral visual field loss, eye position/movement disorders and visual inattention. Vision screening tools show promise in improving detection accuracy of visual impairment in stroke survivors, with potential to lead to more prompt referral with fewer false positives and

negatives [22,23]. Furthermore, they can be used in a variety of settings including primary care, acute stroke units, community, and rehabilitation units. Identification of visual impairment with access to early vision rehabilitation has impact to quality of life and activities of daily living with potential cost savings to the NHS by enhancing rehabilitation and supporting early discharge [22]. Thus, improving knowledge and awareness of post-stroke visual impairment is also important such that the potential for hidden visual problems is remembered and identification of visual impairment is specifically targeted.

Development of the stroke-vision care pathway was in response to priority research calls from clinicians and patients as a need to improve the screening, assessment and access to treatment for stroke survivors with visual impairment [20,21]. It is known that significant delays can occur where stroke survivors only have visual problems as a result of their stroke which places them at high risk of falling outside the treatment window for IV thrombolysis [26]. Potential benefits of this pathway are that it is specific to stroke and vision, it considers many potential entry points, through different health and social care services, on to the pathway dependent on the timing of onset of stroke and the time point of recognition of visual problems. Development of this care pathway involved a variety of key stakeholders with active participation and consensus agreement of pathway content.

There are some limitations to acknowledge for this study. Participants were predominantly from the North West region of the UK although a national BIOS representative was present during one of the focus groups. Further, the focus groups comprised clinicians that provide eye care for stroke survivors but not clinicians involved in primary care and stroke care such as General Practitioners, stroke physicians and emergency department staff. The target population for the focus groups was chosen specifically to consider visual impairment.

However, during the final consultation phase, the draft care pathway was circulated to national vision, stroke, neuro-rehabilitation and primary care professionals for wider review and feedback. The pathway represents vision services available in the UK NHS. Thus, for use in other countries, mapping to equivalent professions and services is required. Referrals and time scales in such a process pathway as this are broad-scale. Thus, stroke mimics and other ocular causes of acute onset vision symptoms still have to be considered with the differential diagnosis for stroke-related visual impairment.

## **Conclusions**

It is imperative that those who care for stroke survivors (clinicians, carers, charity groups, etc.) have an awareness of the visual consequences of stroke and make the appropriate referrals for vision and support services.

The stroke-vision care pathway is a process pathway that describes the potential options for stroke survivors with visual impairment to access health care and obtain the appropriate referral(s) to vision services relevant to their specific vision problem(s). Identification of visual impairment with access to early vision rehabilitation has impact to quality of life and activities of daily living with potential cost savings to the NHS by enhancing rehabilitation and supporting early discharge. This paper explains the components of the stroke-vision care pathway.

The stroke-vision care pathway has been developed collaboratively with stroke survivors, clinicians and researchers (including stroke professionals and eye professionals). We

encourage anyone working with stroke survivors to implement the use of this care pathway to improve detection of visual impairment and access to eye care.

The stroke-vision care pathway now requires implementation, evaluation and follow-up appraisal in clinical practice to determine its usefulness in streamlining referrals such that there is greater accuracy and reliability in accessing correct care dependent on the nature of the visual impairment.

The stroke and vision care pathway is available (free to download) from the VISION research unit (University of Liverpool) website.

## References

1. Rowe FJ, Hepworth LR, Howard C, Hanna KL, Cheyne CP, Currie J. High incidence and prevalence of visual problems after acute stroke: an epidemiology study with implications for service delivery. *PLoS One* 2019;14(3).
2. Jones SA, Shinton RA. Improving outcome in stroke patients with visual problems. *Age and Ageing* 2006;35(6):560-5.
3. Hepworth LR, Rowe FJ. Visual impairment following stroke - the impact on quality of life: a systematic review. *Ophthalmology Research* 2016;5(2):1-15.
4. Tsai S-Y, Cheng C-Y, Hsu W-M, Su T-PT, Liu J-H, Chou P. Association between visual impairment and depression in the elderly. *Journal of Formosan Medical Association* 2003;102(2):86-90.
5. Chia E-M, Wang JJ, Rochtchina E, Smith W, Cumming RR, Mitchell P. Impact of bilateral visual impairment on health-related quality of life: The Blue Mountain Study. *Investigative Ophthalmology and Vision Science* 2004;45(1):71-6.

6. Brandt T, Steinke W, Thie A, Pessin MS, Caplan LR. Posterior cerebral artery territory infarcts: clinical features, infarct topography, causes and outcome. Multicenter results and a review of the literature. *Cerebrovascular Diseases* 2000;10(3):170-82.
7. Rowe F, VIS Group UK. Symptoms of stroke-related visual impairment. *Strabismus* 2013;21(2):150-4.
8. Eisenberg RL, Mani RL. Clinical and arteriographic comparison of amaurosis fugax with hemispheric transient ischemic attacks. *Stroke* 1978;9(3):254-5.
9. Rowe FJ, VIS Group UK. Accuracy of referrals for visual assessment in a stroke population. *Eye* 2011;25(2):161-7.
10. Hanna KL, Hepworth LR, Rowe FJ. Screening methods for post-stroke visual impairment: a systematic review. *Disability and Rehabilitation* 2017;39(25):2531-43.
11. Rowe FJ, Walker M, Rockliffe J, et al. Care provision for poststroke visual impairment. *Journal of Stroke and Cerebrovascular Diseases* 2015;24(6):1131-44.
12. Schrijvers G, van Hoorn A, Huiskes N. The Care Pathway Concept: concepts and theories: an introduction. *International Journal of Integrated Care* 2012;12(6) e192.
13. Pollock A, Hazelton C, Brady M. Visual problems after stroke: a survey of current practice by occupational therapists working in UK stroke inpatient settings. *Topics in Stroke Rehabilitation* 2011;18(Suppl 1):643-53.
14. Pollock A, Hazelton C, Brady M. Orthoptic assessment and management of patients with stroke in Scotland. *British and Irish Orthoptic Journal* 2011;8:36-42.
15. Rowe FJ. Who sees visual impairment following stroke? *Strabismus* 2010;18(2):37-40.
16. Vanhaecht K, Van Gerven E, Deneckere S, et al. The 7-phase method to design, implement and evaluate care pathways. *International Journal of Person Centered Medicine* 2012;2(3):341-51.
17. Brouwers MC, Kerkvliet K, Spithoff K, AGREE Next Steps Consortium. The AGREE Reporting Checklist: a tool to improve reporting of clinical practice guidelines. *British Medical Journal* 2016;352.

18. British and Irish Orthoptic Society. Orthoptic Stroke and Neuro-rehabilitation Care Pathway. 2018 [updated 2018; cited]; Available from: <https://www.orthoptics.org.uk/resources/clinical-advisory-group/stroke-and-neuro-rehabilitation/>.
19. Vision UK. Adult UK eye health and sight loss pathway. 2015 [updated 2015; cited]; Available from: [www.visionuk.org.uk/adult-uk-eye-health-and-sight-loss-pathway-revised-january-2015/](http://www.visionuk.org.uk/adult-uk-eye-health-and-sight-loss-pathway-revised-january-2015/).
20. Rowe FJ, Wormald R, Cable R, et al. The Sight Loss and Vision Priority Setting Partnership (SLV-PSP): overview and results of the research prioritisation survey process. *BMJ Open* 2014;4(e004905).
21. Pollock A, St George B, Fenton M, Firkins L. Top 10 research priorities relating to life after stroke - consensus from stroke survivors, caregivers and health professionals. *International Journal of Stroke* 2014;9(3):313-20.
22. Rowe FJ, Hepworth LR, Hanna KL, Howard C. Visual Impairment Screening Assessment (VISA) tool: pilot validation. *BMJ Open* 2018.
23. Quinn TJ, Livingstone I, Weir A, et al. Accuracy and feasibility of an android-based digital assessment tool for post stroke visual disorders - the StrokeVision app. *Front Neurology* 2018;9(146).
24. Tolmie E, Stanley J, Cowey E, et al. Quick reference guide, best practice statement for screening, assessment and management of vision problems in the first 30 days after an acute stroke. Glasgow: University of Glasgow; 2013 Contract No.: Document Number |.
25. Rowe F, Walker M, Rockliffe J, et al. Delivery of high quality stroke and vision care: experiences of UK services. *Disability and Rehabilitation* 2016;38(8):813-7.
26. Rätty S, Silvennoinen K, Tatlisumak T. Prehospital pathways of occipital stroke patients with mainly visual symptoms. *Acta Neurologica Scandinavica* 2018;137(1):51-8.



**Table 1      Priority setting partnership questions [20,21]**

<b>Life after stroke</b>	<b>Sight loss and vision</b>
<p>Priority question:</p> <p>What is the best way to treat vision problems after stroke?</p> <p>Sub-level questions/statements:</p> <p>Does a neuro-vision technology rehabilitation package improve functional ability and quality of life for people with stroke in the longer term?</p> <p>What are the best ways of helping people come to terms with the long-term consequences of stroke?</p> <p>Do prisms improve visual field loss after stroke?</p> <p>Does visual feedback improve movement during rehabilitation exercises following a stroke?</p> <p>What are the best treatments for visual inattention (neglect) following a stroke</p> <p>What is the best way to treat visual problems after stroke?</p> <p>More research into visual problems.</p> <p>Interventions for visual field defects, treatment of eye movement disorders, visual neglect</p>	<p>Priority questions:</p> <p>What rehabilitation or treatment methods are most effective for vision loss following brain damage due to stroke, brain injury, cerebral vision impairment, tumours and dementias?</p> <p>What is the most effective way to assess vision in patients with neurological visual impairment i.e. stroke, dementia and cerebral/cortical visual impairment?</p> <p>Can treatments be developed for visual field and ocular motility manifestations following stroke?</p>

Table 2

Possible places for presentation with vision symptoms

Reporting of symptoms	Possible presenting services	Notes
Start – at onset of symptoms	A&E/Emergency department Care homes Eye clinics General practitioner GP NHS telephone service Optometry Paramedics/999 Pharmacists Schools and HEIs Screening centres / specialist centres, e.g. diabetes Sports fixtures TIA clinics Walk-in centres and GPs Workplace	Report of visual symptoms may be by the patients themselves or reported by family/friends/carers. Those with visual symptoms alone as a result of stroke may be more likely to present to community services such as their high street optometrist, their GP. Patients might also report their visual symptoms as ‘incidental’ whilst attending another community or hospital service.
Early – at hyper- and acute stages	Acute units – stroke, ICU, neuro, etc. Charities Community health service Community stroke team Eye clinics	

	<p>Medical / health students</p> <p>Neuro rehab</p> <p>Therapists</p>	
<p>Late</p> <p>– at sub-acute and chronic stages</p>	<p>Care homes</p> <p>Charities</p> <p>Community health service</p> <p>Community stroke team</p> <p>District nurses / visiting carers</p> <p>Eye clinics</p> <p>General practitioner GP</p> <p>Medical / health students</p> <p>Optometry</p> <p>Social services</p> <p>Therapists</p>	
<p>Throughout</p>	<p>Charities</p> <p>Community health service</p> <p>Community stroke team</p> <p>District nurses</p> <p>Eye clinics</p> <p>Family / friends</p> <p>General practitioner GP</p> <p>Medical / health students</p> <p>NHS telephone service</p>	

	Optometry Pharmacists Social services Specialist services Workplace occupational health	
--	---	--

**Table 3**                      **Timing of presentation**

<b>Time of onset of visual symptoms</b>	<b>Notes</b>
Within 4 hours of onset	Emergency department A&E
More than 4 hours but within 24 hours of onset	Emergency department A&E Rapid referral centre / equivalent Stroke hospital clinic TIA hospital clinic
More than 24 hours after onset	Community stroke team Early support discharge team GP general practice Hospital stroke unit Optometrist – high street
Note: ensure appropriate preventative measures for further stroke risk	

**Table 4**

**Support services**

Potential support services	Notes
CVI (Certificate of Visual Impairment)	<p>Can only be signed by an ophthalmologist so requires a hospital eye service referral to ophthalmology. The CVI form is issued to a patient assessed by a consultant ophthalmologist as being visually impaired. The form is then sent to social services who work with the person to assess what help and advice they need.</p>
RVI (Referral of Visual Impairment)	<p>Used where registration is not appropriate or where the patient has declined registration but wants advice and information about the difficulties caused by loss of vision.</p> <p>Being registered as partially sighted or blind enables a person to access a range of benefits to help them manage their condition and the impact it may have on their lives. Registration is voluntary, and access to benefits and social services is not dependent on registration.</p>
Low vision service	

<p>Dependent on local services, this may be provided in the hospital eye service or in community eye practices</p> <p>ECLO (Eye Clinic Liaison Officer)</p>	<p>The assessment aims to discuss your eyesight condition and the difficulties this may present in your day-to-day life. It considers what you would most like help with, such as reading cooking instructions, paying bills, watching television, dealing with medicines or tablets, completing schoolwork or even working on hobbies. You can try out a number of different low vision aids such as handheld or stand magnifiers, typoscopes, task lights, electronic magnifiers, shields and/or reading stands etc. specific to your requirements.</p> <p>Also known as Sight Loss Adviser or Vision Support Officer. ECLOs are key in helping patients understand the impact of their diagnosis and providing them with emotional and practical support for their next steps. They work closely with medical and nursing staff in the hospital eye clinic, and the sensory team in social services.</p> <p>They provide those recently diagnosed with an eye condition with the practical and emotional support which they need to understand their diagnosis,</p>
---	--

<p>VRO (Visual Rehabilitation Officer)</p>	<p>deal with their sight loss and maintain their independence.</p> <p>Works in an adult social services team with those who are sighted impaired (partially-sighted) or severely sight impaired (blind). Their aim is to provide high quality specialist assessment and support to adults who are considered to have a visual impairment and/or dual sensory loss, maximising their independence, safety and dignity. They provide expertise and support to teams across Adult Services to assist in the development of knowledge in relation to visual impairment and/or dual sensory loss.</p>
<p>Charity Organisations</p> <p>e.g. RNIB, the Stroke Association, Henshaw's, ESME's umbrella, Headway, Brain Charity (list not exhaustive)</p>	<p>These charities and professional organisations provide specific support with regard to vision impairment, stroke and brain injury information resources and practical information, for example relating to return to work, activities of daily living and driving.</p>
<p>Professional organisations</p> <p>e.g. Royal College of Ophthalmology, British &amp; Irish Orthoptic Society,</p>	



<p>Royal College of Occupational Therapists, College of Optometry (list not exhaustive)</p> <p>Research organisations e.g. University College London, University of Durham, University of Liverpool (list not exhaustive)</p>	<p><a href="http://www.readright.ucl.ac.uk">www.readright.ucl.ac.uk</a></p> <p><a href="http://www.eyesearch.ucl.ac.uk">www.eyesearch.ucl.ac.uk</a></p> <p><a href="https://www.dur.ac.uk/psychology/research/drex/">https://www.dur.ac.uk/psychology/research/drex/</a></p> <p><a href="https://www.liverpool.ac.uk/psychology-health-and-society/departments/health-services-research/research/vision/resources/">https://www.liverpool.ac.uk/psychology-health-and-society/departments/health-services-research/research/vision/resources/</a></p> <p>**</p>
---	---

\*\* Note that these websites were functional at the time of writing of this paper (April 2019)

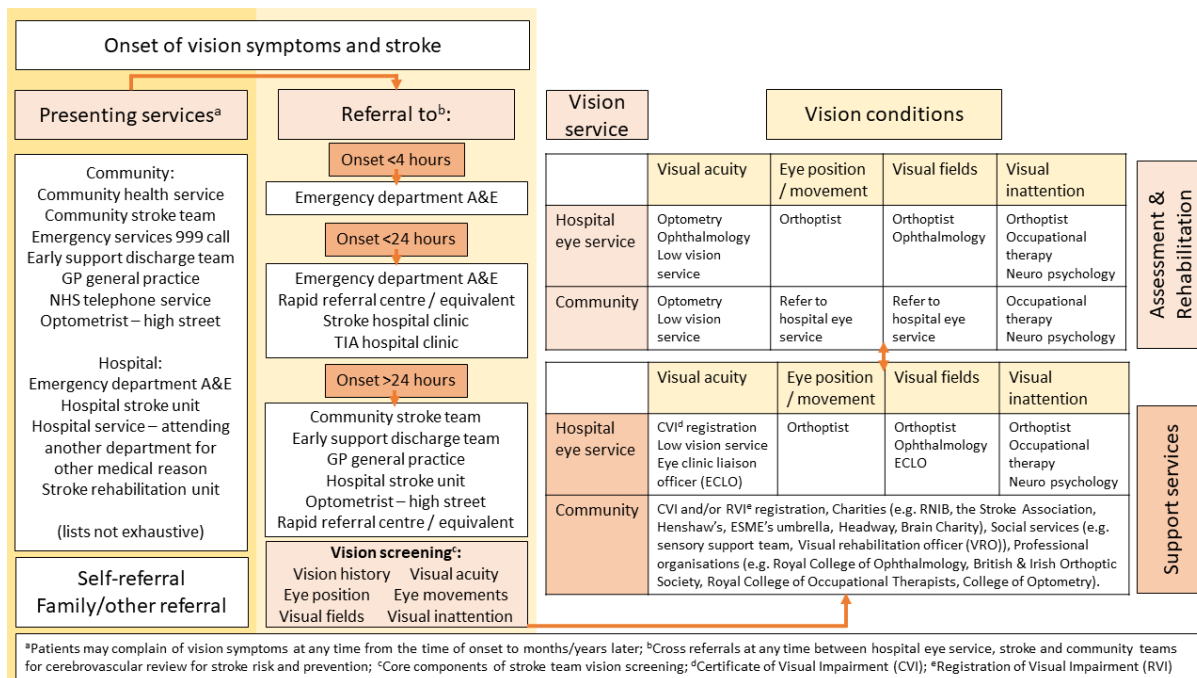
but may not remain so in future years.

**Table 5**

**Potential barriers faced by poor eye care provision**

<b>Barriers</b>	<b>Notes</b>
Poor transfer of patient information	Poor communication between teams, with patients and families, from hospital to community services
Access to appointments	Physical barriers to stop people accessing services such as rural areas, driving, memory, mobility Postcode lottery
Funding	Insufficient funding for vision screening on stroke units, Lack of awareness of need for vision services for stroke survivors from CCGs through to hospital managers and through to community services
Training and education	Lack of awareness and knowledge by: general public, reception staff, medical staff, pharmacy

Figure 1



Supplemental table 1 Search terms

Cerebrovascular disorders/	Eye Movements/
Brain ischaemia/	Eye/
Intracranial Arterial Disease	Eye Disease/
Intracranial Arteriovenous Malformations/	Visually Impaired Persons/
Intracranial Embolism and Thrombosis*/	Vision Disorders/
Stroke/	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/

	<p>Strabismus/  Smooth pursuits/  Saccades depth perception/  Stereopsis gaze disorder/  Internuclear ophthalmoplegia/  Parinaud’s syndrome/  Weber’s syndrome/  Skew deviation/  Conjugate deviation /  Oscillopsia/  Visual tracking/  Agnosia/  Hallucinations/  Care pathway/  Care process/  Pathway/  Flowchart/</p>
OR	OR
AND	