

## CONSULTATION QUESTIONS

1. The strategy outlines a care pathway (page 10).

(a) If you are a service user and/or carer, please tell us what difference you believe the implementation of the pathway will make to the services you experience.

No comment

(b) How can we best ensure that services and support meet your needs?

No comment

c) If you are a care provider, what changes will you need to make to implement the pathway?

No comment

(d) How will you make these changes?

No comment

2. The strategy identifies key factors that need to be in place to ensure the pathway is successful (Page 11 para 6.7).

(a) Which of the key factors are most important for a successful pathway?

The development of a care pathway for visual loss due to stroke is essential, but poses challenges. Visual loss due to stroke is quite different to visual loss caused by ocular conditions and those affected fall into a clear gap between stroke care and vision care services. These arise often because there is poor understanding of the visual problems caused and how they can best be supported: stroke teams include occupational, physio and speech and language therapists but no eye care professionals, eye care professionals are often unaware of the available rehabilitation and support services provided, those providing rehabilitation and support often do not know the best management methods for stroke-related impairments.

The key factors in ensuring a successfully pathway for this group are:

Screening – visual problems are often not screened for adequately and it has been common for stroke survivors with severe visual impairment to be discharged home with their problems unrecognised and undiagnosed (and therefore no support provided). A clear screening method to cover the variety of visual problems possible - visual neglect, visual field loss, eye movement disorders and visuo-perceptual problems is required.

Referral – The point of assessment and diagnosis for stroke patients is varied – it may be on a stroke ward, by a community occupational therapist or an optician – and may be either at the acute or longer-term phases post-stroke. There needs to be a clear referral pathway, that signposts the correct services for providing both accurate diagnosis and appropriate management and care. This must be communicated to all those working in stroke care and vision care, as there is often a lack of understanding of the services each can provide for stroke survivors with visual problems

Awareness – There is a lack of awareness across the board about visual impairment due to stroke. Awareness is poor in patients, family, carers, health and social care staff and at a managerial level. Increased awareness of the existence and variety of visual problems, the impact of these, and the care pathways available are essential.

(b) Which are the most challenging to put in place?

The most challenging aspect is providing joined up services: the development of clear referral routes and sensory impairment care pathways will involve a wide variety of care providers and professions. It will include primary and secondary NHS services, charities and social care services. These groups come from very different organisations with a wide variety of funding sources and in many cases will not have established links to enable communication and integration of services.

There is a clear need to develop a pathway of care for patients, as in most areas no clear pathway exists. This would allow for an improvement in service provision by making best use of existing expertise and resources.

(c) Do you think that any key factors have been missed?

The SVSN appreciates that the framework has clearly mentioned hidden sensory loss, as many visual problems after stroke go undiagnosed and can be masked or mistaken for other physical or cognitive problems. We would like the framework to identify stroke more clearly as a cause of hidden sensory loss: it can affect over 1/5 of stroke survivors but is frequently overlooked, with huge implications for those affected.

3. The strategy identifies areas for action that should be addressed going forward (Page 13-16)

(a) Which of the areas for action will be the most challenging to implement?

As noted above, the provision of an integrated care pathway for stroke survivors with visual loss may prove most challenging to implement.

This is due to

- current lack of awareness of the visual problems
- under-diagnosis of stroke-related visual problems
- unclear referral pathways once diagnosed
- huge variability in available services for management and support
- lack of information and awareness of how best to manage and support visual problems after stroke
- lack of funding to provide the support services required
- geographical variation in the method of delivery

It will also be difficult to audit the current expenditure on stroke-related visual impairment as it may be difficult to differentiate stroke funds utilised for visual difficulties from those used for other impairments.

(b) Which of the areas for action will make the biggest difference and why?

Due to the huge variability in the quality and provision of current services, improvement is needed in all areas, but the development and delivery of clear care pathways should make the biggest difference for those with visual loss due to stroke.

This must be supported by adequate training provision that is tailored to current expertise and training needs of the different groups involved.

(c) Are there any other areas for action that you would like to see included within the strategy?

As noted above, clear mention should be made of stroke-related vision impairment.

4. Please comment on the current provision of sensory impairment services as either a service provider or service user. If you have any experience of sensory impairment services, please let us know what you think of them: this should include any experience of one-stop shops.

There is huge variability in the services provided across Scotland, and levels of care can be very poor. This is dependent on the occupation of the care provider, their interest in the topic, the availability of support services (especially those services tailored to the needs of those with stroke related visual impairment) and the provision of adequate funds to maintain services. Variability is clear in the provision of services at key stages post-stroke -

1. initial screening of all stroke survivors for visual impairment (in A&E or an acute stroke ward) . **This is not routine practice across Scotland**
2. accurate assessment (and diagnosis) of visual problems in those who are identified, through screening, to have a visual impairment. **This is not routine practice across Scotland**
3. timely follow-up of those with visual impairment. Significant improvement will occur within the first 3 months – the level of remaining visual impairment must be assessed to allow proper provision of support. **This is not routine practice across Scotland**
4. referral for appropriate treatment, rehabilitation & support. There are few existing protocols to ensure appropriate assessment or referral and it is often not clear who to refer a patient to. It is also often the case the services required are not available, for example - orthoptic clinics are often not adequately funded, specialist rehab for those with visual field loss is only available in a few areas of Scotland and detailed assessment of visuo-perceptual problems is poorly provided.

There are many examples of excellent care provision; but service provision is irregular and non-standardised. There is little scope for giving service users choice in their care, as there is no choice available in the majority of instances.

5. What difference will the implementation of the strategy make to your life?

No comment

6. Does this strategy properly reflect the current climate and developments in policy and practice for children and young people particularly in relation to the Getting it Right for Every Child approach and the Doran Review?

No comment

7. Do you have anything you wish to add to the Sensory Impairment Strategy or any other general comments that have not been covered by the questions?

I wish to add some relevant details about the Scottish Vision and Stroke Network.

The Network began in 2009 and evolved out of a growing concern that:

- Visual problems after stroke have a lower profile with stroke survivors, health care professionals and policy makers.
- There are significant inequalities in the assessment and management of visual problems across Scotland.
- There is also inadequate funding for the screening and rehabilitation of patients and the appropriate training of their clinicians
- There is a lack of research into how visual problems resolve naturally and how they can be effectively treated

It is a collaboration between stroke & vision charities, health care professionals, researchers and people affected by stroke.

Our aims are:

- To improve awareness, diagnosis and treatment of visual problems after stroke within Scotland.
- To support the research needed into effective assessments and treatments