Children and Young People's Health Outcomes Strategy – Feedback Form

The Children and Young People's Forum has been set up to inform the development of a Children and Young People's Health Outcomes Strategy. The Strategy will be a plan for action, which will help the different parts of the health system work better together to improve the quality of healthcare services for children and young people.

We want to hear your views and key messages to help us shape the plan of action and make sure we focus on the issues that matter to you. We are holding a number of events around the country to get input from clinicians, children, young people, parents, carers and the general public. We have also created this feedback form, as we are keen to hear from as many individuals as possible.

Please respond to our four questions (should not take longer than 30minutes!), complete your details at the end of the form, and email it to: childrensoutcomesforum@dh.gsi.gov.uk

Please send your response by **31 May 2012.**

Thank you for your time and support to advise the Children and Young Peoples
Forum. You can keep up to date with the developments of the **Children and Young People's Health Outcomes Strategy,** at **http://healthandcare.dh.gov.uk/category/children/**

Before you begin, please put an **X** before the relevant category:

Patient Parent/ Carer Health Service User
Doctor Nurse

X Other (please specify) The College of Optometrists and the Optical Confederation.

The College of Optometrists is the Professional, Scientific and Examining Body for Optometry in the UK with over 13,000 members working for the public benefit.

The Optical Confederation represents the 12,000 optometrists, 6,000 dispensing opticians, 7,000 optical businesses and 45,000 ancillary staff in the UK, who provide high quality and accessible eye care services to the whole population. The Confederation is a coalition of five optical representative bodies: the Association of British Dispensing Opticians (ABDO), the Association of Contact Lens Manufacturers (ACLM), the Association of Optometrists (AOP), the Federation of Manufacturing Opticians (FMO) and the Federation of Opticians (FODO). As a Confederation, we work with others to improve eye health for the public good

The College of Optometrists and the Optical Confederation are both members of the UK Vision Strategy Action Group on Children's Screening.

Region

North West North East Yorks&Humber West Midlands
East Midlands South West South East East of England

Could you also provide details of the issue(s) that your comments are in relation to by putting a **X** in front of the relevant topic(s)

X Primary care (GP practices, community health centres, dental practices, community pharmacies…)
X Children with long term conditions
X Children with complex health needs
Children with poor mental health
Urgent care for children with acute illness (starts very quickly and lasts for a short time)
X Health promotion and improvement
Palliative care (life threatening illnesses)
X Children with disabilities
X Looked after children
Safeguarding children
Medicines for children
Mother's physical & mental health in pregnancy
Transition to adult life

Question 1
In your view, where is the health service falling short for children and young people, what is our weakest link and what can we do to improve things to make sure it makes a real difference to the lives of children and young people?

Eye health is an overlooked weak link in the care of our children and young people. There are worrying inequalities in children's eye heath and unjustifiable variation in the care and support they are offered, particularly amongst children with learning difficulties who have a much higher level of visual impairment.

So often overlooked, the right eye care at the right time can be the key to unlocking a child's potential and freeing them from a life of dependence.

Children's eye health is important for the following reasons:

- Visual impairment hinders children's emotional, social and personal development and puts great strain on their families.
- Children with poor vision can find it harder to study at school, to be physically active and to interact with other children.
- Children with learning difficulties are ten times more likely to have problems with their vision[1]. However they are less likely to have their visual problems detected and treated.
- Children with visual impairment need a complex mix of primary, secondary and social care and often rely on significant support from the third sector.
- Eye health problems often need to be treated as early as possible to get the best outcomes.
- Children's eye health problems are all too often overlooked.

The two fundamental changes that could most improve children's eye health are:

- Universally implementing the recommended visual screening services; and
- Tackling inequalities in service provision, particularly for children with learning difficulties.

Screening

The Healthy Child Programme, the National Screening Committee and the Health for All Children Report all call for children's vision to be screened when they are infants and also when they enter school at age 4-5 to detect and treat amblyopia (lazy eye).

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1 Emerson, E. & Robertson, R. (2011) *The estimated prevalence of visual impairment among people with learning disabilities in the UK*. RNIB and SeeAbility Learning Disabilities Observatory.

However, provision of screening at age 4-5 is patchy and too many children slip though the net. A recent survey by *Which?* reported that a fifth of PCTs had no screening programme for visual problems whatsoever[2]. This is particularly worrying as amblyopia becomes much harder to treat after age 7.

Recommendations:

- To tackle these failures, we support the submission of the UK Vision Strategy Action Group on Children's Screening in calling for visual screening at age 4-5 to be incorporated in to the National Screening Programme.
- We also urge the Forum to include visual screening in the indicators being developed for the 'school readiness' outcome measure.

Health inequalities in children, particularly those with learning difficulties

The most common problems affecting children's vision are:

- Refractive error (being long or short sighted)
- Amblyopia and strabismus (lazy eye and squints)

Undiagnosed these can hold back children's educational and personal development. Less common, but potential causes of blindness, are glaucoma and cataracts and a number of rare conditions.

There are significant health inequalities in how these different conditions affect different populations:

- As noted above, children with learning difficulties are ten times more likely to have problems with their vision and these are not as easy to spot as for other children.
- Certain ethnic groups are more likely to suffer problems with their vision[3].
- Children in lower socio-economic groups are less likely to access healthcare services[4].

Of each of these groups, it is children with learning difficulties where we feel the biggest improvements in care could be made as:

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[2] Which? (2011) One in five PCTs do not offer school sight tests, 31 August 2011, available from http://www.which.co.uk/news/2011/08/one-in-five-pcts-do-not-offer-school-sight-tests-264291/

[3] Rahi JS, Cable N, on behalf of the British Childhood Visual Impairment Study Group (BCVIS).Severe visual impairment and blindness in children in the UK. *Lancet* 2003;362:1359–65

[4] Saxena S, Eliahoo J, Majeed A. Socioeconomic and ethnic differences in self-reported health status and use of health services by children and young people in England: cross sectional study.*BMJ* 2002;325:520–3

- Children with learning difficulties find it hard to recognise that they are having problems with their vision, and parents and carers find any problems much harder to spot[5].
- Testing and treating the vision of a child with learning difficulties requires particular skills from optometrists and can need a longer appointment than a routine test would.
- Care pathways can be particularly complex but the outcomes especially rewarding.

Case study – sight tests and learning disabilities
Craig was raised in care, he was performing poorly at school and his behaviour to pupils and teachers was very challenging. He was wrongly diagnosed as having learning difficulties. At age 10, his carers were under considerable stress and took Craig for his first ever sight test. The optometrist, who had the expertise and time to properly examine Craig's eyes found in fact that his problems had been caused by undetected poor vision.

With his sight corrected by spectacles and having regular sight tests, Craig behaviour began to turn around and his performance at school improved considerably. Craig recently won a place at university and is working to improve care services for children.

In response to the huge eye health inequalities amongst adults with learning difficulties suffer, the patient groups SeeAbility and Mencap have launched a bespoke pathway in partnership with LOCSU[6]. It enables those aged 16 and up with learning disabilities to access the tailored NHS eye care services they need in the most cost-effective way for commissioners and serves as ideal example of what could be achieved were a similar service developed for younger people.

Recommendation

We recommend:

- Public health commissioners consider implementing a specific eye health service for children and young people with learning difficulties.

Question 2

[5] Kerr, A.M (2003) Medical needs of people with intellectual disability require regular reassessment, and the provision of client- and carer-held reports, *Journal of Intellectual Disability Research*, p134-145, February 2003.
[6] http://www.locsu.co.uk/communications/news/?article=39

With so many different parts of the health system in place, what do they need to focus on and improve to make sure they each work together to deliver the best possible health service for children and young people?

The biggest barriers to delivering the best possible eye health services for young people are a lack of awareness amongst commissioners and the wider health workforce about eye health (in particular the needs of young people with learning disabilities) and poor IT connections that prevent integration of primary and secondary care.

Working together

Working through the new health and wellbeing boards we would like to see greater awareness amongst GPs, health visitors, community nurses and the teaching profession of potential visual problems amongst children – especially in looked-after, disadvantaged and deprived groups. This would help them to detect early warning signs of visual impairment and poor ophthalmic health that could be diagnosed and treated quickly by community optometrists.

IT issues as a barrier to integrated care

- Optometrists deliver valuable eye care in community settings, yet the communication channels between them and other healthcare providers are poor (in most cases reliant on paper-based postal referrals with limited feedback). This makes it much harder to integrate care, to provide the best possible care and to realise efficiency savings.
- For example, only a minority of optometrists have secure NHSmail email addresses, so they are not copied into correspondence about patients whom they have referred to other providers and continue to treat in the community.
- This means patients often go through unnecessary referrals which could be prevented were primary care optometrists able to consult electronically with ophthalmologists in secondary care.
- Lack of feedback hinders professional development.

Recommendation

- Community eye care is of course not the only part of the NHS with limited connectivity to NHS IT. We would welcome recognition that improved IT connectivity would lead to better outcomes for patients, in this case children and young people.
- In order to achieve improved and appropriate connectivity, the NHS IT systems need to engage fully with end users under a clearly defined national project to deliver a seamless, cost-effective and workable electronic interface between community eye care and the rest of the NHS.

Question 3

The NHS and Public Health Outcomes Frameworks both propose key areas of focus: making sure everyone lives healthy lives for longer, addressing inequalities, enhancing quality of life for people with long term conditions, helping people recover from ill health or following an injury, ensuring people have a positive experience of care, treating and caring for people in a safe environment and protecting them from harm. (Details of the current outcomes specific to children and young people within these frameworks are at http://healthandcare.dh.gov.uk/outcomes-frameworks/)

Are these the right priority areas in relation to children and young people's health outcomes? Is there anything missing.

We particularly welcome the focus on addressing health inequalities.

As noted above, there is significant variation in the coverage of children's screening across the country. Failing to screen children exacerbates existing health inequalities in eye care. We have also set out the importance of tackling eye health inequalities in children in socio-deprived areas and children with learning difficulties.

Key health outcomes for children and young people must include…

Recommendation:

As noted above, we urge the Forum to include visual screening (in line with the policies of the Health Child Programme and National Screening Committee) in the indicators being developed for the 'school readiness' outcome measure.

Question 4

Is there anything else you'd like to tell us?

A study in 2005 found that children currently wearing glasses or with a history of wearing eye patches were 35-37% more likely to be victims of physical and verbal bullying[7], which asides from the great emotional strain it puts on young people, makes it harder for them to comply with treatment for eye health

[7] Horwood, J et al (2005) The Avon Longitudinal Study of Parents and Children Study Team: Common Visual Defects and Peer Victimization in *Children, Investigative Ophthalmology and visual Science*, 46 (4) pp.1177-1181

problems. We fully support efforts to stamp out bullying and would welcome the indirect benefits to young people's eye health.

In the meantime, some parents and their children are unaware of the untapped potential for contact lenses to improve the quality of life of young people. Contact lenses can now be worn safely by children from age 8 upwards, reducing the stigma of wearing glasses where that is a problem and potentially boosting self confidence and social participation e.g. in sports and physical activities[8,9]. For instance, according to the Medical Officers for Schools Associations, children should be expected to use soft contact lenses to correct vision when playing sport at school[10].

Recommendation

We would very much welcome clear recognition in the Forum's final report of the fact that contact lenses can now be worn safely by children (from age 8 upwards) and a recommendation that their benefits should be better promoted among schools and parents.

[8] Walline, J.J. et al (2007) Benefits of contact lens wear for children and teens, *Eye & Contact Lens* 33(6 Part 1) pp.317-21.
[9] Soni P, Horner D, Jimenez L, et al. (1995) Will young children comply and follow instructions to successfully wear soft contact lenses? *CLAO journal* 21(2) pp.86
[10] Medical Officers for Schools Association (2006) *Guideline for eye wear in sport* http://www.mosa.org.uk/Open%20Folders/Eye_Wear_in_Sport_feb06.pdf

Your Details

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Confidentiality of Information:

1. We manage the information you provide in response to these engagement questions in accordance with the Department of Health's Information Charter.

2. Information we receive, including personal information, may be published or disclosed in accordance with the access to information regimes (primarily the Freedom of Information Act 2000 (FOIA), the Data Protection Act 1998 (DPA) and the Environmental Information Regulations 2004).

3. If you want the information that you provide to be treated as confidential, please be aware that, under the FOIA, there is a statutory Code of Practice with which public authorities must comply and which deals, amongst other things, with obligations of confidence. In view of this, it would be helpful if you could explain to us why you regard the information, you have provided as confidential. If we receive a request for disclosure of the information, we will take full account of your explanation, but we cannot give assurance that confidentiality can be maintained in all circumstances. An automatic confidentiality disclaimer generated by your IT system will not, of itself, be regarded as binding on the Department.

4. The Department will process your personal data in accordance with the DPA and, in most circumstances; this will mean that your personal data will not be disclosed to third parties.

On behalf of the Children and Young People's Forum, we would like to thank you for taking the time to complete this feedback form.