

Commissioning Guidance

Strabismus surgery for adults in the United Kingdom: indications, evidence base and benefits

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1 Summary

Strabismus (squint) is a misalignment of the two eyes affecting 4% of adults. Uncorrected this may cause functional visual problems including double vision, visual confusion, loss of stereopsis (3D vision) and binocularity (the coordinated use of the two eyes together), asthenopia (eye strain) and headaches and the requirement to adopt an abnormal head posture for vision. There are negative effects in terms of reduced ability to drive and independence, and increased risk of falls. Even in the absence of functional visual issues, strabismus in adults is associated with psychosocial difficulties including low self-esteem, abnormal mood, reduced quality of life, reduced employment opportunities, discrimination and psychiatric issues.

Non-surgical management options include prism lenses, eye exercise and botulinum toxin procedures in a small percentage but many cases will require surgery to achieve significant improvement. There is good evidence that surgery is very safe and highly effective in addressing these issues in clinically suitable cases. Current evidence shows that even patients with longstanding strabismus without diplopia demonstrate measurable benefits in binocularity, function, quality of life and psychosocial interactions after strabismus surgery. There is excellent cost-utility for strabismus surgery at between approximately £1,000-1600 dollars/QALY (NICE cut off for cost effectiveness is less than £20,000 per QALY). Strabismus surgery in adults should not be rationed on non-clinical grounds and ppatients with strabismus should be considered as candidates for surgical treatment whether or not they experience double vision.

2 Introduction

What is strabismus?

Strabismus, or squint, is defined as a misalignment of the two eyes. It may be present from birth or arise at any time in life. In many cases, no clear cause is identified. However, it is more common in those with a family history of the condition, refractive errors and some syndromic or neurological conditions. A smaller number arise from a range of identifiable pathologies including orbital, neurological and muscular conditions affecting ocular muscle control. Strabismus can be constant or intermittent, whereby the eyes are straight some of the time. The most common types of strabismus are horizontal and can be classified as esotropia (convergent, the eye turns in) and exotropia (divergent, the eye turns out); vertical strabismus includes hypertropia (upward turn) and hypotropia (downward turn). Less commonly, eyes can be rotated (torsional strabismus).

Epidemiology

Strabismus affects approximately 4% of adults and 2% of all children 1,2. In the UK, the overall rate of strabismus surgery has declined over the last few decades 3-6.

Between 1994-2000, the total number of squint procedures decreased by 41.2% in England and Wales 4 but between 2000-2014, the overall rate of strabismus surgery in the UK stabilised 6,7. In these more recent years there has been some continued reduction in surgery in children, probably due to improved early management and surgical planning; in adults, there has been a small increase (24%) in overall surgical rates, reflecting a heightened awareness of the functional and psychosocial consequences of strabismus and the benefits of correction 7.

Effects of strabismus

What are the effects of strabismus on patients' health and well-being?

Uncorrected strabismus poses significant medical, psychosocial and cost implications for patients with related resource implications for healthcare systems and governments as detailed below.

Medical impact of strabismus:

Diplopia: Strabismus can cause diplopia (double vision) when patients (older children and adults) are unable to suppress the image from the squinting eye. Children below the age of 7 years do not usually experience double vision as the brain tends to suppress the image from the squinting eye.

Amblyopia: Amblyopia, also known as lazy eye, is a vision development disorder in which an eye fails to achieve normal visual acuity, despite glasses or contact lenses, due to a failure of adequate stimulation of the nerve pathways between the brain and eye in early childhood. Once established, amblyopia will persist for life.

Loss of 3-dimensional vision: The ability to perceive 3-dimensional objects is known as stereopsis and requires the brain to use the slightly differing images from the two eyes looking at the same point to reconstruct a perception of a 3-D world. 3-D vision assists in our ability to navigate and mobilise, coordinate fine movements and judge depth. People who develop a squint in early life either fail to develop or may lose stereopsis. In later onset strabismus, whilst the eyes are misaligned, sufferers will usually see two objects and lose the ability to appreciate 3-D. However, this is often reversible if the squint is corrected 8,9.

Visual confusion: Adults with strabismus may experience visual confusion, where they perceive two different images superimposed onto the same space. This can be due to a new-onset squint or a deterioration of a long-standing squint 10. Visual confusion is particularly debilitating when driving and patients often feel as if cars are coming towards them.

Abnormal head posture: Adults with strabismus may turn their face or tilt their head to eliminate and/or reduce their double vision. This compensatory head posture is frequently associated with neck muscle discomfort and even contractures that can be improved with eye muscle surgery 11.

Loss of independence: Diplopia and sudden loss of 3-D can cause many patients to lose their independence as it prevents them from carrying out ordinary everyday tasks. Patients with double vision often feel overwhelmed in public areas such as supermarkets due to disorientation and an inability to navigate or avoid collisions with objects. It can make cooking and even pouring hot water into a cup from a kettle hazardous. Often this can lead to social isolation, anxiety and even loss of employment in certain cases 12.

Driving: Double vision has significant implications on a patient's ability to drive. The DVLA states that patients cannot drive if they have double vision 13. While they can legally drive once they overcome their double vision (if they can have the double vision corrected using prism lens spectacles or cover over the squinting eye), many patients feel uncomfortable or unsafe doing so, partly because depth perception is poor with one eye covered. Inability to drive, both temporarily or permanently, can have negative implications on independence and the ability to work, particularly for patients who are carers or those in employment who need to drive for their livelihood.

Risk of falls: Patients with diplopia or reduced binocularity (difficulty using both eyes together) secondary to strabismus are at risk of other health problems such as falls, fractures and musculoskeletal injuries. In a study of over two million patients, it was found that adults with binocular vision disorders were 27% more likely suffer from falls, fractures and injuries than those without 14.

Asthenopia and functional visual difficulties: Eye strain, also known as asthenopia, is a common complaint amongst adults with strabismus and can cause significant discomfort and distress. Symptoms include headaches, blurred vision and pain around the eyes, which limits the ability of patients to perform important visual tasks such as reading and using computer screens. Patients' performance in the workplace can decline because of asthenopia 9.

Psychosocial and economic impact of strabismus:

Strabismus is a functional disability, regardless of whether it is associated with double vision and visual issues. The WHO recognises that disability is "a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives" 15. Uncorrected strabismus has negative and far-reaching implications on individuals and withholding surgery from patients with strabismus could be considered discriminatory.

Strabismus is known to have debilitating effects on a person's quality of life, mood, independence and livelihood 16–24. Many patients with strabismus suffer from severe anxiety and depression due to their ocular deviation. Negative social effects include difficulties in socialising and impaired employment prospects. Adults with strabismus often belong to lower socioeconomic groups, hypothesised to be due to limited job prospects and perceived employer prejudice 20. Coats et al 21 performed a study in which they provided employers with photographs of prospective employees with similar resumes. Respondents were asked to rate the prospective candidates based on their photos and resumes, without understanding the purpose of the study. The authors revealed that patients with straight

eyes were ranked higher on the employability scale than those with a squint, despite having similar resumes.

Patients with strabismus also have lower self-esteem. Many patients adopt adaptive techniques to disguise their squint, such as placing their hair over the squinting eye or avoiding eye contact 17. Others withdraw from society for fear of being stigmatised. There is a wealth of literature that directly links strabismus with lower quality of life indices. Patients with a squint often find it more difficult to find life partners and develop close relationships 22.

The psychological impact of having an uncorrected squint can have lifelong negative implications. Children can identify squints in themselves or others by 4 years of age and by age 6, they begin to adopt negative attitudes towards squints which continue into adulthood 25-28. Squint can lead to mental illness in adult life: a retrospective study of 407 young adults with a history of strabismus revealed that 41% had a diagnosable mental health disorder compared with a 30% rate in control subjects and children diagnosed with some forms of strabismus are reported to have a three-fold higher likelihood of developing mental illness by early adulthood compared with controls 29-31. Patients with intermittent exotropia seemed to be particularly prone to developing significant psychiatric diseases by the third decade of life 29.

3 Case studies

Case study 1 - Sophie: a 33-year-old photographer who underwent squint surgery in 2016

"I have had a squint since I was born. Growing up, my mum was a nurse she took me regularly to an eye doctor, who advised patching. My mum was really persistent with patching but it never fully corrected my squint.

Being a healthy and generally happy child, no one contemplated how this squint would affect me. It did not seem justifiable to operate. However, the perception of myself changed when I started to get bullied as a teenager. It was not for that long, but it was enough to change how I saw myself. I am naturally an outgoing and sociable person, even with a slight squint, but I always tried to hide it and that really limited me. I enjoyed acting and theatre as a child but once the bullying had started, I never pursued anything that would put me in the spotlight. In fact, I avoided all of it.

In retrospect, I now know that a lot of interactions and discomforts I have experienced throughout my life were because of how I felt about myself and the way I saw myself. I even lost a job because of shyness and my personal insecurity in a situation that anyone would have mastered easily. A few years ago, I started to see a therapist for a number of reasons. It was only once year into therapy that I told her that my squint was something that bothered me. It still surprises me, but also shows that it takes a lot to address real and deep insecurities. My therapist supported and encouraged me to go to Moorfields, where I underwent surgery.

After the surgery, I went back home and called my mother. Looking at the mirror my eye

was red and sore, but straight. I could not even speak to her properly because I cried and could not find the words. She knew what it meant to me and how happy I was.

To look straight into a photo camera and genuinely smile and not worry is still a novelty to me. It is a novelty to me to go dancing or do sports and look people straight in the eyes, even when I am tired. It is also a novelty to be more confident in meetings and look at my seniors. I will turn 33 this year. A long time to run around unhappy when it is something so easy to fix. This surgery has really changed my life and given me so much happiness that only people with the same experience can truly understand.

I am absolutely aware that there a many people out there with different conditions and different, maybe more visible sufferings, but therapy has taught me that every emotion is valid. I have looked at the mirror so many times with so much hatred. I am sure people would be surprised. I wanted to scratch my eyes out. I remember that, as a teenager, I told my best friends back home if I had one wish I would want my eyes to be "normal". We communicate with our eyes and we express ourselves and our inner world.

Today I work in the photography and film world and my career has nonetheless taken me onto a creative path, but only now I feel that I can really express myself and be the way I want to be. I do not take this for granted."

Case study 2 - Lee: a 45-year-old single parent with a convergent squint who wishes to have strabismus surgery

"As a child, I found social interaction difficult, awkward and I was consistently teased. This has also been a problem for many years as an adult. Professionally, it can be extremely difficult, especially when it's important to maintain eye contact with colleagues or friends.

I am a single parent and currently not working due to child-care issues. I volunteer at the children's school, and some children have made various (embarrassing) public comments about my eye. People cannot always understand where I am looking and who I'm looking at. Also, meetings and discussions with teachers can be difficult, not to mention any other social interaction. The likelihood of rejection in relationships and more importantly, future employment opportunities is also a concern for me."

Case study 3 - Alice, a 23 year old law student awaiting squint surgery

Since before I could remember, my life has revolved around my eyes. Family and people close had been carefully cautioned to avoid making me feel aware of the fact that when I looked at them, I wasn't actually looking at them. But children pick up when something is different and the children at my school were no different. Being called ugly, a googly-eyed monster and asked if my parents were cousins was only the start of what I would have to accept as the norm.

As I got older, I realised that I would have to live with an elephant in the room. I don't assume that everyone's attention was sorely focused on the direction of my eyes, but after a while of living with a squint, I learned to hide it. You never look people in the eye, you focus on their nose, or their cheek. You make your eyes small and always glance away every few seconds. You distract yourself, play with your nails, pick some lint off your clothes. I was told to never pin my hopes on correcting my eyes, that a part of me would have to accept that maybe I would always live like this. I use to beg my parents to get it fixed for my birthdays, for Christmas'. It was the only thing I ever truly wanted.

But as I became a young woman I realised just how much my life was hindered by such a small thing. Romantically speaking, I was grateful to anyone who could look at me when I couldn't look back. I have never been able to look someone in the eye and tell them I love them, nor when I have ever been intimate have I been able to open my eyes. I live in absolute fear of what they would see, that it was disgust them, that they would change their mind about me.

Since a child I would cry at night, most nights, asking why so many people had two working eyes and I didn't. I would worry that no one would ever love me, ever be able to see past my squint. There is so much to be grateful for - I am healthy, driven and have a lot to look forward to in life. But I am mentally and emotionally exhausted of waking up every morning and wondering which way my eyes will go. I hate looking in the mirror, I use to avoid it at all costs. I shied away from photos taken by others - since I couldn't control what I looked like.

Career wise, I have so many hopes and dreams. I aim to be a qualified solicitor (once I can afford the LPC fees) and have been working in a law firm since graduating. But my confidence holds me back. I have noticed that people associate squints with mental capability. People have often spoken to me in a manner that made me question my own intellect. Clients would struggle to take me seriously - whether by the squint or my own inability to look at them in the eye. I dread mentioning it because people then become embarrassed, guilty like they are caught out pitying me or otherwise making me feel different.

I could write all the things that my squint has done to me - diminished my self-worth and confidence, made me ashamed and embarrassed of myself, held me back when I could have otherwise taken a chance or opportunity. But the biggest impact I have ever experienced was being told that I could have it fixed. The first thing I thought of was 'I can finally be normal'. I began to envision what I could do with two eyes that looked where I

wanted them to.

Small things, little things that everyone takes for granted. Those were the things that ran through my head. In that moment I realised just how little of my life I had been living and the prospect of being able to finally live it - it was beyond real to me.

4 Detection and Management of Squints

How is a squint detected?

Adults can present with strabismus at any age. Patients may have a squint that began in childhood and present for care later or after unsuccessful earlier therapy. Patients may present to their GP or optician after noticing that their eye deviates or that they have double vision or headaches. Some adults describe psychosocial implications, such as uncertainty in where to look, and that other people are confused as to whether the patient is looking at them or elsewhere. They should be referred to an ophthalmologist urgently if there is any suspicion of an underlying serious pathology in the eye or brain, which is causing their squint. Others can be seen routinely.

At the hospital eye clinic, patients are initially assessed by an orthoptist (an allied health professional who assesses how the eyes work together). This is followed by a review by an ophthalmologist. More than one orthoptic assessment may be necessary before a decision is made regarding surgical management.

What are the aims of management of strabismus in adults?

The aims of management are:

- To promote, maintain or restore binocular vision.
- To restore the alignment of the eyes.
- To correct significant abnormal (compensatory) head posture.
- To alleviate debilitating functional symptoms including asthenopia
- To minimise any psychological or social problems that arise as a consequence of having a squint.

How is adult strabismus managed?

Correction of refractive error (glasses prescription): Unlike in children, in most adults with significant strabismus, there is very limited benefit to be gained from correction of the refractive error. However, attempts will be made to optimise the vision and binocular function with the best possible refractive correction where possible.

Eye exercises: These may be appropriate for some intermittent squints, particularly if there is poor convergence (ability to bring the eyes together). However, they are not effective for most adult squints.

Prisms: A prism is a wedge-shaped lens that bends light rays. It can be used to correct double vision by placing the second image back onto the central retina (fovea) even when the eye is deviated. Prisms can be temporary (stuck onto a glasses lens) or incorporated permanently into the glasses prescription. Many patients require use of temporary prisms with frequent adjustment before a stable prescription can be found and incorporated into the glasses lens more permanently. In some cases, patients may not be suitable for prism wear (e.g. large angle or fluctuating strabismus), may not tolerate prisms or prisms alone may not fully correct double vision, thus necessitating further treatment.

Botulinum toxic: An injection of botulinum toxin into an extraocular muscle, usually given to awake patients in a suitably adapted eye clinic, can cause weakening of the muscle for up to three months and help to correct a squint. There are several indications for the use of botulinum and some of these are listed below.

- Acute onset squints with previous binocularity
- Consecutive convergent squint following over-correction of intermittent divergent squint with diplopia
- Nerve palsies
- Investigation of potential for permanent postoperative double vision
- Double vision following retinal detachment surgery
- Situations in which surgery is not possible or contraindicated

Botulinum is not suitable for patients who cannot tolerate the injection. It has a temporary and fluctuating effect and should be used only in specific clinical situations and conditions.

Strabismus Surgery

What are the benefits of squint surgery?

Strabismus surgery can restore or optimise ocular alignment, binocular vision and minimise the adverse effects of strabismus and can improve quality of life and function, by reducing eye strain, improving self-image and thus reducing social anxiety. Surgery is to reduce the degree of the squint, (rather than to completely correct it), can still be successful and has the potential to offer a long lasting or permanent solution. Several studies have demonstrated long-term gains from strabismus surgery beyond cosmesis, including significant psychological and functional improvements. 32-36 Notably, even adult patients with longstanding strabismus can display binocular vision (e.g. fusion of images of the two eyes) and stereopsis after successful strabismus surgery with up to 86% patients demonstrating fusion after surgery 8, 9. Restoration of binocular vision after strabismus surgery has been linked to heightened quality of life and greater ease with performing everyday tasks 37.

There is good evidence that even patients without double vision demonstrate significant improvement in their quality of life and function after strabismus surgery 38-40. Liebermann and colleagues 9 assessed function in adult patients without diplopia who underwent strabismus surgery. They utilised the adult strabismus- 20 questionnaire (AS-20), a strabismus-specific questionnaire that assesses ten psychosocial aspects and ten functional aspects of strabismus surgery. In all patients surveyed, there was notable improvement in nine of the functional domains postoperatively with all reporting improvement in concentration, depth perception, hobbies, strain, reading, stress, and worry. Overall mean scores in reading and general function were much better and asthenopia symptoms reduced significantly in this cohort. Patient responses to the AS-20 questions can be seen in figure 1.

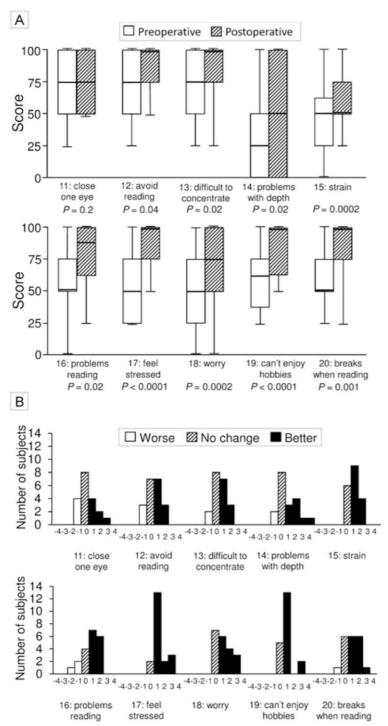


Figure 1: Improvement in score (A) and change in response category (B) preoperatively to postoperatively for each function-related item of the Adult Strabismus 20 questionnaire. Taken from Liebermann et al (2014)

How is strabismus surgery undertaken?

Strabismus surgery is performed as a day case procedure under general anaesthetic in most cases and takes up to 1 hour of surgical time. By altering the point of the insertion of an extra-ocular muscle into the sclera, or by shortening an extra-ocular muscle, the misalignment of a squinting eye can be corrected. There are various techniques, and the muscle(s) operated on depend on the type of squint. Surgery may be performed on one or both eyes. Sometimes two or more operations are required to achieve a successful alignment of the eyes.

What are the risks of squint surgery?

Squint surgery is a very safe procedure. Common risks include minor redness, allergy to stitches, scarring and mild infection. Patients are informed that they may have double vision or under/over correction necessitating further surgery. The incidence of serious adverse events and complications is 1 in 400 operations. According to a BOSU study which looked at 24,000 squint surgeries performed across the UK between September 2008, and August 2010, the most common reported serious complication was perforation of the globe (19 [0.08%]), followed by a suspected slipped muscle (16 [0.067%]), severe infection (14 [0.06%]), scleritis (6 [0.02%]), and lost muscle (5 [0.02%]). A poor or very poor clinical outcome was recorded as 1 operation per 2,400 41. This makes the surgery extremely safe, with much less risk of a serious complication than, for instance, cataract surgery.

How many adult squint surgeries are performed nationally and in Moorfields Eye Hospital each year?

Between March 2015 and March 2016, 520 adult strabismus operations were performed in Moorfields Eye Hospital. Hospital episode statistics (HES) show that between 2015-16, 11955 strabismus procedures (operations on the eye muscles) were undertaken in England. Of this number, 5549 were performed on adults 42.

How much does squint surgery cost?

In Moorfields Eye Hospital, given that the average tariff for an ocular motility procedure is £1,343, strabismus surgery for all Moorfields patients costs £16,048,921 annually (42).

What is not well known is the cost of not treating strabismus. As stated by The Royal College of Ophthalmologists, strabismus is a "disfiguring condition... and should not be classified as a low priority treatment for funding." 43. The treatment costs to the NHS, social services and to society as a whole must be taken into account when considering the overall cost of strabismus surgery. This is not insignificant given the visual effects, increased anxiety and depression, psychosocial effects, difficulty in driving, working and retaining independence

and reduced job prospects. This presents a significant societal opportunity cost which is likely to offset the cost of strabismus surgery to the NHS.

The Royal College of Ophthalmologists' notes that "restoration of ocular alignment is a reconstructive procedure and is thus not a cosmetic procedure" as defined by the General Medical Council's guidelines on cosmetic procedures 44. As such, strabismus surgery is a vital restorative procedure and decisions to operate should not be subject to exceptions panel funding nor considered a low priority treatment.

What is the cost utility/cost benefit of squint surgery?

Cost-utility analyses evaluate the cost of medical care in relation to the gain in quality-adjusted life years (QALYs). Globally, several studies have shown that strabismus surgery is a highly cost-effective intervention with high QALYs reported 45,46.

Beauchamp et al 45 conducted a cost-utility analysis of strabismus correction in 35 adult patients whose average age was 49 years. The study evaluated the cost of surgery in relation to the gain in quality of life it generated. Before surgery, patients rated their expected improvement in quality of life, known as utility, as a numerical value from 0 to 1. The average rating was 0.85. After surgery, the mean utility rating increased significantly to 0.96 (P = .00008) [Note *NICE (47) defines one QALY as equal to 1 year of life in perfect health]*. The cost-utility for strabismus surgery was \$1,632 dollars/QALY. The authors of this study also incorporated a time trade off analysis, whereby they asked participants what proportion of their life expectancy they would give up to spend without a squint. A majority of the patients interviewed would trade a significant portion of their life expectancy in return for being rid of strabismus and its associated effects.

Similarly, Fujiike et al 46 used surveys to assess the quality of life of 226 patients who were due to undergo strabismus surgery. They used Visual Function Questionnaire-25 (VFQ-25), 8-ltem Short-Form Health Survey (SF-8) and utility assessment by a time trade-off method pre and postoperatively. The authors also estimated the gains in quality-adjusted life years (QALYs) and \$/QALY that could be appreciated following strabismus surgery. They concluded that strabismus surgery resulted in a mean value gain of 0.99 QALYs and the cost-utility for strabismus surgery was \$1,303 or £1011/QALY. In general, NICE states that that interventions costing the NHS less than £20,000 per QALY gained are cost effective 47.

By comparison, the cost-utility of cataract surgery in the first eye (which is widely thought to improve quality of life and function) varies between £190 to £17,076/QALY in Western countries 48. The cost of other comparable procedures is listed in the table below.

Intervention	Cost (converted to pounds sterling) /QALY
Strabismus surgery	£1011
Cataract surgery	£190 to £17,076
Defibrillator	£543 to £17,852
Epileptic surgery	£3104 to £15,524
Hip arthroplasty	£1785 to £3725

Table 1: Comparison of cost-utility of different health interventions 48.

Given that the many patients who undergo strabismus surgery are of working age, they are likely to benefit from the effects of surgery for a longer duration, thus increasing its cost utility. As such, strabismus is a highly cost effective procedure that should not be rationed.

Opportunity costs of strabismus surgery

As described above, patients with strabismus have a higher incidence of mental health problems, discrimination in the work place and reduced employment opportunities. Given that the annual cost of treating mental health in the UK is around £2.92 billion and mental health costs the NHS approximately £13.52 billion in lost earnings, treatment of the underlying causes is widely encouraged by health bodies ⁴⁹. Uncorrected strabismus is a functional disability with preventable mental health sequelae. Addressing this disability, particularly in the working age population, could help to mitigate against the medical and socioeconomic burden of mental health in the UK.

Whilst there is sufficient evidence to support the health impacts of strabismus surgery, more work is required to quantify the costs of untreated strabismus patients and the NHS. Nevertheless, current evidence strongly supports the recommendations of the RCOphth 43 that strabismus is a disfiguring condition and that strabismus surgery should not be withheld from UK patients if they meet the current clinical criteria.

5 Conclusion

Strabismus has debilitating medical, psychological and economic implications for patients and our wider society. The effect of successful strabismus surgery has long-lasting effects both on the functional and psychological well-being of the patients and far beyond a cosmetic effect. As such, strabismus surgery should always be defined as a 'reconstructive' rather than a 'cosmetic' procedure.

As detailed above, patients with non-diplopic strabismus can suffer from lifelong psychological and functional problems if their squint remains untreated. Large scale quality

analyses including the AS-20 have demonstrated the value of strabismus surgery on an individual's functional skills, including their ability to read, concentrate at work and perform daily tasks. Patients with strabismus are often of working age and are known to suffer from diminished mental health, discrimination and reduced employment opportunities. According to NICE, strabismus surgery demonstrates excellent cost-utility, particularly in a population who are likely to reap the rewards for several years. Strabismus surgery is generally considered to be amongst the safest of ocular surgeries and is associated with few serious complications. Given the overall cost benefit, and proven effectiveness, strabismus surgery has positive societal implications and should not be rationed on non-clinical grounds.

6 Authors

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