

**The Save Your Sight Leaflet and visual impairment in the UK:
can people accurately self-assess and self -refer?**

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This project has been submitted in partial fulfilment of the requirements for the award of an Intercalated Degree in International Health. The examiners cannot, however, be held responsible for the views expressed, nor the factual accuracy of the contents

Project B includes a draft paper for publication to be submitted to Eye, the official journal for The Royal Collage of Ophthalmologists. In accordance of submission criteria for an original article in this journal, Paper A will follow the following format:

- Introduction, Materials and Methods, Results and Discussion
- Word limit: 3,500 words maximum excluding abstract, references, figures and tables

Abstract and acknowledgements are included in the main body of project B.

Abstract

Introduction

Over 4 million people in the UK are thought to have undiagnosed eye disease. The majority of these are elderly or from ethnic minorities. Although primary care is available, the problem lies in designing strategies to reach these groups and encourage them to seek treatment when necessary. With this aim the Save Your Sight (SYS) leaflet has been designed as a case finding and health promotion tool. This study determines whether the visual acuity assessment part of the leaflet can reliably detect those with poor visual acuity.

Method

Participants chosen from those attending community health centres self-assessed their vision using the SYS leaflet and decided themselves whether or not they “passed” the SYS sight test (visual acuity of 6/9 or better in both eyes). Their vision was then tested by a mentor using the SYS leaflet and then by a nurse using a formal Snellen chart at 6 metres. Cross analysis for self-assessed and assisted-assessed results was then performed using the formal Snellen acuity measurement as the gold standard.

Results

The study was carried out with 188 participants. The self-assessment visual acuity produced 17.4% sensitivity and 92.4% specificity compared to formal Snellen acuity interpretation of ‘passing’ and ‘failing’. In the assisted-assessment test, the sensitivity improved to 94.2% but the specificity dropped to 78.2%.

In the self-assessment process only 27 participants followed the instructions and appropriately assessed their visual acuity, accounting for the low sensitivity and higher specificity. The older the participants were, the more frequently they ‘gave themselves’ false negatives and used incorrect self-testing methodology.

Conclusion

The high rate of unidentified eye disease in the UK shows there is a need to reach out into the community to help identify visual problems. The assisted-assessment results indicate that the SYS leaflet offers a case finding tool that can be used to assess visual acuity when used in a mentored setting, correctly identifying those in need of care. Further studies are required to improve the SYS leaflet as a self-assessment tool.

Word Count: 321

Table of Contents

1.0 Introduction and Background	Page 5
2.0 Aims and Objectives	Page 11
3.0 Materials and Methods	Page 12
4.0 Results	Page 12
5.0 Discussion	Page 12
6.0 Further Discussion	Page 12
7.0 Conclusion	Page 17
8.0 References	Page 18
9.0 Appendices	Page 20

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(of which the paper is 3407)

1.0 Introduction and Background

1.1 Context of Topic

In 2002 it was estimated that there were over 161 million people worldwide with visual impairment, 37 million of whom were estimated to be blind [1]. An overwhelming two-thirds of these cases were preventable or treatable [2]. In many instances this relies on the availability of primary care services, which is itself a clear priority. However, a key factor is also the failure in both developed and developing countries to identify eye disease and, therefore, to initiate treatment in good time [3].

The problem of unidentified and untreated visual impairment is nowhere truer than in the UK. The North London Eye Study identified 52% unilateral and 30% bilateral visual impairment (visual acuity $<6/12$) in the over 65s in a “typical metropolitan area”. Of these cases over 70% were estimated to be potentially treatable by surgery or glasses [4]. In the same sample population there was a 30% prevalence of visually impairing cataracts with 88% of these cases not being in contact with eye services. Similarly, 75% of those with definite glaucoma were not known to the eye care services [4]. In a study in Fife, at their first appointment in an eye clinic, a significant proportion of elderly patients were adjudged to have moderate to severe visual field loss with 23% eligible to register as blind [5].

In the UK, and in many other countries with developed healthcare systems, the key issue is therefore not the availability of care but increasing the identification of those in need of treatment. The Save Your Sight (SYS) leaflet is an active health promotion and case finding tool in its third phase of development. This study, part of a wider investigation, will look at one specific aspect of the SYS leaflet in a community setting in Leeds, UK. The study will assess if it is possible to accurately measure visual acuity using the SYS leaflet.

1.2 The Global Prevalence of Visual Impairment and Blindness

In 2002 the World Health Organisation (WHO) reported that there were over 161 million people globally who were either blind or visually impaired. The primary cause of blindness was cataract, accounting for 47.8% of blindness. Glaucoma (12.3%) and age related macular degeneration (AMD) (8.7%) were cited as the second and third commonest causes of blindness respectively (figure 1) [6]. These age related conditions are largely preventable or treatable, especially if identified at an early stage [1].

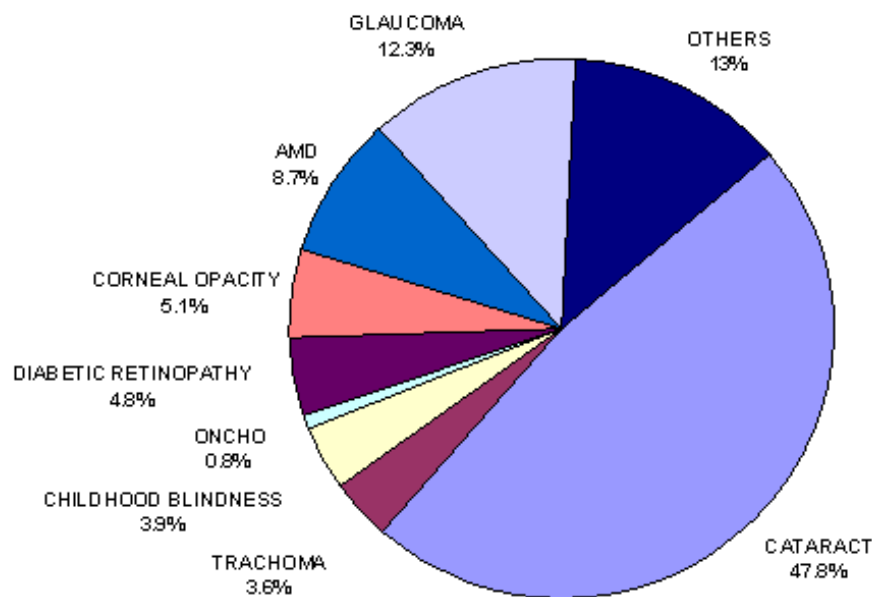


Figure 1: Global causes of blindness as a proportion of total blindness in 2002)[2]

Global causes of blindness as a proportion of total blindness in 2002

Frick et al.[7] predict that at present rates, the global prevalence of blindness will rise from 0.72% in 2002 to over 1% by the year 2020. Using the WHO statistics for the same time period there is a predicted doubling of visual impairment cases to over 300 million [8].

Communicable eye diseases, such as trachoma, remain an undoubted problem in less economically developed countries[6]. However, as economic development and its attendant social, economic and health care changes take place, an increase in non-communicable disease, such as cataracts and AMD, is expected [9]. As global life expectancy increases, the growth in non-communicable age related disease is estimated to account for much of the predicted global increase in the prevalence of visual impairment and blindness [10]. The WHO has identified these age related degenerative conditions as priorities for treatment [6].

1.3 The UK prevalence of visual impairment and blindness

According to the Government Disability Survey conducted by the Department of Social Security (DSS) in 1997, there were approximately 2 million cases of self-defined sight problems in the UK [11]. Cataracts, glaucoma, AMD and diabetic retinopathy are the four major causes of blindness in the UK accountable for over 90% of blindness [6]. In the UK visual impairment and blindness is more prevalent in elderly populations as these age related diseases, self evidently, mainly develop later in life [4] [12] [13] [14] [15].

Fifty percent of all sight problems in the over 65s are due to untreated cataracts or refractive error; both of which are relatively easy to treat [14]. Indeed treatment of these conditions is seen as one of the most cost effective health-care interventions available, comparable to immunization [16].

With an aging population in the UK, the prevalence of visual impairment and blindness, particularly from eye diseases, is expected to rise. The number of cases of glaucoma alone is expected to increase by approximately 30% between 2000-2020 [17].

In 2003 there were 157,000 blind people registered in England, a 40% increase from 1982. In the same period the partially blind register doubled to 155,000 and the proportion of the registered blind and partially blind aged over 75 years rose from 59% and 55% to 67% and 68% respectively [11]. Similarly, the proportion of registered partially sighted aged over 75 increased from 55% to 68%. These increases are at least partially attributable to an aging UK population [11]. However, in 1998 only 51% of outpatients attending eye clinics who were eligible for a blind disability certificate had requested one [18]. Despite efforts to improve these rates, in 2005 there was little evidence of improved registration of partially sighted and blind people, underlining that under reporting of visual impairment is still very much an issue [19].

See Appendix 1 (paper) 'Introduction' for further discussion of disease prevalence and unidentified visual impairment in the UK.

1.4 Implications of visual impairment

Visual impairment and blindness have severe implications upon health and well-being [20], and may also impact negatively on family, friends, social networks and the wider community [21] [22] [23]. Education, employment and independence may all be compromised if the consequences of visual impairment are managed incorrectly [24]. Once independence and self-confidence are lost, they can prove extremely difficult to rebuild [23]. A community survey in Italy highlights the significant link between sensory impairment, detected through examination, and a decreased quality of life. Visual dysfunction is associated with erratic mood levels and fewer social relationships, two factors the article defines as determining quality of life [25]. A consistent relationship has also been found between falls, fractures, increased mortality and declining visual function [20] [26] [27].

There are also financial implications at a national level with the global annual economic loss as a result of visual impairment and blindness is estimated to be in excess of \$131 billion [7] [28] [29].

1.5 Self-assessment tools

Knowledge has been shown to be an important predictor in programmes aimed at altering unhealthy behaviour and changing health service utilization patterns [30] [31]. There is little understanding about eye disease in the UK population and the elderly know the least about visual impairment and, as a result, place minimal priority on its treatment [32] [33]. The problem lies in reaching this group and stimulating them to seek care when necessary.

“The Save Your Vision Month” in America, the nearest equivalent programme to the SYS leaflet, has been relatively effective in imparting knowledge but has focused on identifying visual impairment cases in children. These results cannot be extrapolated to those most at risk, the elderly.

In other health areas it has been found that media programmes linked to personal communication yield significant behavioural changes, in particular in addictive subtractive behaviour. However, poorly focused education programmes have been shown to yield unspectacular results [34].

It has been found that knowledge transfer is a careful balance between raising awareness and raising anxiety [35]. However, it has also been shown that fear of blindness is a reason why people visit the optometrist [36]. Testicular [37] and breast self-examination [38] form the largest bulk of literature in leaflet lead self directed self-referral. The varying referral success rates were shown to be closely linked with anxiety levels and understanding of the related disease [39]. Leaflet education on self-examination and self-referral was shown to significantly increase referral rates in subjects who read these leaflets [37] [38]. Whilst leaflet distribution is not necessarily the most effective method of education, it is a viable and cost effective option [40].

1.6 Justification for the research

Vision 2020: “The Right to Sight” is a global initiative aimed at eliminating avoidable blindness by the year 2020 [41]. Early detection is a key aspect of this programme. It allows for prompt delivery of effective treatment, potentially halting the progression of eye disease before its latter stages, reducing the possible extent of visual impairment. This is both cost-effective and beneficial to the individual and the wider community [42] [43] [44] [30].

Appropriate early referral and treatment can therefore ensure that patients remain integrated and fully functional members of society. Timely treatment has the potential to eliminate or reduce the negative implications of visual impairment and blindness discussed above.

In the UK only one quarter of those with visual impairment are in contact with eye services [15]. A large proportion of these unidentified cases are in the elderly population, with at least 4 million people over the age of 65 not having regular sight tests [15]. It is therefore important to carry out research into methods of raising awareness of eye health, particularly for this age group.

1.7 The Save Your Sight Campaign

The Save Your Sight (SYS) Leaflet [Appendix 1] is part of an existing public health programme, The Save Your Sight Campaign, supported by North Leeds Primary Care Trust. The leaflet uses a health promotion initiative as a vehicle for a case detection tool designed to increase primary eye health care usage in the over 60s in the UK. The current SYS leaflet is the third version. Feedback from previous pilot studies has assisted in the development of the present format. Present distribution includes Neighbourhood Network Schemes - community groups for the over 60s, sheltered accommodation and community eye centres.

The two parts of the leaflet, health promotion and case detection are centred on a simple self-assessment process. Instructed self-assessment of visual acuity, and a series of questions, are used as a method of identifying subjects who should seek further attention. The leaflet also provides relevant information on accessing primary care services (figure 2 and appendix 2).

As clearly outlined within the leaflet (see figure 2 and appendix 2), the reader is advised to “make an appointment with their local optician” if they fulfil one of the following criteria:

- Fail the self-assessment sight test chart.
- Identify any day-to-day problems with their vision
- Have not had their vision assessed within the last 2 years (or recommended time for specific conditions, e.g. 1 year for known diabetics)

The SYS Leaflet

Front Page: Scaled down Snellen chart to assess acuity from 2-metres



Inside Page: Questions about day-to-day visual function and its implication on daily living.



SYS leaflet instructions on seeking professional help from a local optometrist.

What to do next

If you have not been to the optician in the last two years or have identified any problems with your eyesight during the test, please make an appointment with your optician.

Inside Page: Information on how to make an appointment with a local optometrist



Back Page: Additional information about eye disease



Figure 2: The functional aspects of the SYS leaflet

2.0 Aims and Objectives

2.1 Aims

This pilot study will specifically explore the development of an acuity-testing tool to be used inside and outside the clinical setting. The results will feed into the wider assessment of the SYS leaflet which is considering if it is suitable for community wide distribution as a case finding and health promotion tool.

2.2 Objectives

Primary Objectives:

- Identify if the SYS leaflet accurately measures visual acuity from 2 metres, as compared to formal Snellen acuity at 6 metres.
- Explore the concept of self-assessment and see if participants appropriately “self-refer” themselves according to their self-assessed visual acuity results.

Secondary Objectives:

Ascertain if:

- Assessment of acuity using the SYS leaflet is more accurate if carried out by a mentor
- There is a correlation between ability to self-assess and age
- There is a correlation between the ability to self-refer and age
- Participants can follow instructions and, if not, how the leaflet can be modified and improved
- 2 metres can be judged accurately and whether this is age related

3.0 Materials and Methods

See paper for materials and methods (Appendix 1).

The paper is part of a wider health promotion and case detection service development programme with appropriate ethical approval. The study received ethical approval from the University of Leeds; see paper for more information.

4.0 Results

See paper for results (Appendix 1).

5.0 Discussion

See paper for discussion (Appendix 1).

6.0 Further Discussion

6.1 Methodology

Although neither a formal part of the study, nor systematically completed for every patient, JPL recorded the nature of problems participants encountered when self-assessing their vision. This further discussion explores the finer aspects of these difficulties, which are also discussed in the paper (appendix 1).

These methodology problems were largely due to a failure to understand or act upon the instructions in the leaflet. Improved instruction compliance was shown to increase the SYS leaflet sensitivity and maintain a high specificity, even if only within a relatively small sample size (appendix 1 tables 5 and 6). Improvements in the leaflet format, including carrying out the vision testing at arms length, may improve the proportion of participants who use the correct methodology. This will therefore increase the self-assessment of visual acuity sensitivity rates and make the SYS leaflet a more effective self-assessment case finding tool. However, due to the inherent nature of self-assessment and the self-judging of passing and failing (see paper appendix 1), the sensitivity rates are unlikely to reach the same level as in the assisted-assessment process.

Even though the instructions in the leaflet are font size 12, newspaper print is size 10 in comparison, those with more severe visual acuity problems struggled to read the instructions and therefore to test their acuity. This underlines an innate problem with any leaflet used to identify visual impairment since it excludes those most in need.

6.2 Aspects of current knowledge and the SYS leaflet

The high prevalence of visual impairment and blindness in the elderly has led to suggestions for a screening programme for the over 60s [45]. However, trials of these programmes have failed to successfully reduce the prevalence of visual impairment and blindness [46]. Furthermore, given the high prevalence of visual impairment in the elderly, the value of screening has been questioned [47]. Cost effectiveness of healthcare interventions is the key to their integration into the health service. Whilst there is a specific retinal-screening programme in the UK for known diabetics, a national vision screening programme for the over 60s is simply not a cost effective option.

'Prevention is better than cure' is as much a healthcare statement as it is a financial one. The economic benefits of early detection and treatment must be weighed against more expensive treatment if the disease is allowed to progress [7] [28] [29]. Poor vision and health, including falls and fractures [20] [26] [27], as well as lack of independence and a lower quality of life [21] [22] [23] may all be avoidable with timely intervention [42] [43] [44], giving very great benefits at the individual patient level.

The SYS leaflet is not part of a screening programme but is a sight assessment process embedded in a health promotion campaign [48]. Whilst not fully developed for self-assessment, the leaflet is appropriate for distribution as an assisted assessment case finding tool. The proposed policy and action plans assume that the remainder of the SYS leaflet which deals with health promotion and awareness have also been positively assessed.

The presence of a trained mentor was shown to increase the SYS leaflet sensitivity. Since a high proportion of the unidentified visually impaired are regular users of general medical services, the assisted-assessment mentors could potentially work within any healthcare field or profession [49]. Indeed, the training of mentors from a diverse spectrum of the voluntary sector, social services and healthcare field is key in ensuring that the best results are obtained when using the leaflet. Where relevant and appropriate, integration of the SYS leaflet into both graduate and postgraduate education is a simple way of promoting prevention in general, and the SYS leaflet in particular. The normal monthly and annual meetings of potential mentors who are already trained professionals or volunteers is an ideal opportunity to train a large number quickly, as was seen when sheltered accommodation wardens were successfully trained (see discussion in paper, appendix 1).

The SYS leaflet is designed as a catalyst to stimulate users to have their vision tested by an optometrist. It is therefore crucial to integrate the development and distribution of the SYS leaflet with primary care services. Local ophthalmic services are integral to the success of the leaflet and must become fully involved and drive the SYS leaflet programme in their local communities.

For further discussion see paper, Appendix 1.

6.3 Policy Recommendations

Ultimately the target must be for all those over the age of 60 to visit an optician at least every 2 years. Distribution and use of the SYS leaflet by health and social services is vital in the increased identification of the visually impaired. Collaboration and coordination of these services with opticians would ensure greater referral using the SYS leaflet.

A driving force behind identifying those unidentified cases of visual impairment in the community could be the development of a target led system whereby optometrists are required to examine an appropriate and defined number of new patients over the age of 60 every year. The introduction and structuring of such targets should maintain the focus on improving treatment for the elderly without impacting on the health care of other patients.

The SYS leaflet can be used by opticians as a means of reaching these targets by working with other health professionals, residential homes, neighbourhood schemes and age related charities to identify and then examine the elderly in the community. This approach is cheap and cost effective since it builds on established care frameworks.

This programme could also be integrated into other public health initiatives for the elderly, for example, the SYS leaflet could be used in tandem at community centres when the over 60s receive their flu inoculation.

Sight tests are free for those over the age of 60 and coupon schemes supplement payment of spectacles for those on low incomes. There are therefore no financial disincentives to regular visits to the optician. There should be greater emphasis of these facts in the SYS leaflet. Research into developing strategies for improving patient understanding of the coupon system may also improve optician attendance.

The emphasis on early detection and the prevention of disease progression is also a cost-effective measure in terms of the total care framework since money can be saved elsewhere by the reduction in costly treatment and social services support.

6.3 Suggested Policies

- Integrate a revised and improved SYS leaflet into the NHS and ophthalmic services as a functional and recognised assisted-assessment and referral tool.
- Plan for an expected increased volume of patients visiting opticians and requiring hospital care.
- Provide greater equality in eye health care provision.
 - Develop SYS leaflet in conjunction with other health promotion initiatives to focus on communities most in need and at risk - the elderly, ethnic minorities and the financially deprived.
 - Develop translated SYS leaflets for major ethnic minority groups.
- Develop financial initiatives for to emphasize prevention and early detection.
- Develop target scheme for the percentage of over 60s who should have their sight tested at least every 2 years.
- Develop a community specific minimum percentage of the optometrist patient load that should be over the age of 60.
- Incorporate “mentor training” within the broader training of appropriate members of the social services, health care professionals and the voluntary sector.
- Build partnerships and promote the SYS leaflet with the Royal National Institute for the Blind (RNIB), Help the Aged, Age Concern and other vision or age related charities.

6.4 Suggested Further Research

Short term

- Develop an arm’s length acuity test in the SYS leaflet.
- Complete research on the health promotional aspects of the SYS leaflet.
- Use focus groups taken from those most at risk, such as the elderly, to help with leaflet design.

Long term

- Consolidate data on the prevalence of visual impairment and blindness, including unidentified cases, in the UK.
- Gain further understanding of barriers to sight testing, especially when free for the over 60s in England.
- Research the option for SYS leaflet usage in different countries and cultures.

6.5 Relevance to International Health

As in the UK, the implementation of a case finding tool is only justified if treatment is available for those identified with visual impairment and blindness. This practical and ethical consideration is true in both developed and developing countries. The SYS leaflet should be used differently in countries with developed national health service coverage than in those with poorly established health provision.

Developed countries with relatively similar visual impairment disease profiles and identification rates to the UK [1] [50] [51] [52] will use the SYS leaflet in much the same way as outlined in 6.3 above.

However, an estimated 90% of the global disease burden due to visual impairment and blindness is in developing countries [1]. In these countries the visual impairment prevalence is significantly higher than in the UK and those most at risk are not necessarily the elderly, with communicable diseases potentially affecting all ages.

Vision 2020: 'the right to sight' is a global initiative aiming to reduce avoidable blindness by 2020 [8]. The SYS leaflet fit with the programme ideals of treating the 70% of visual impairment and blindness that is avoidable in the world today [2].

Identification and subsequent diagnosis of these cases of visual impairment is the first step in the treatment process. However, the SYS leaflet should only be used in those countries where care is directly available to the target populations. This is not a country specific issue since in urban areas in most developing countries there are care services and, equally, those who are able to access them. In this instance the leaflet should be specifically targeted at those population groups living in appropriate areas with the financial or political status to access care. It should be noted that this leaves aside the ethics of whether care should only be available for the few, a judgement that must be made by each country's care providers.

In developing countries the SYS leaflet could be used more as a screening programme by non-governmental organisations (NGOs), such as Mercy Ships and Vision Africa, identifying those who require the medical care that they are able to provide.

6.6 Suggested International Policies

- Targeted implementation of the SYS leaflet in developed countries with sufficient treatment availability.
- Targeted implementation of the SYS leaflet in specific communities and populations in developing countries where treatment is available.
- Incorporate SYS leaflet into case finding and educational programmes with NGOs providing effective care.
- Use the SYS leaflet as a screening tool for treatment by NGOs such as Mercy Ships and Vision Africa.

7.0 Conclusion

The UK has a well-developed healthcare system providing effective and appropriate eye care for those who seek it. However, there is a high level of unidentified visual impairment and blindness, particularly in the elderly and ethnic minority communities. The problem lies in identifying the estimated 4.2 million people with undiagnosed visual impairment in the UK today, and those countless others globally. The development of a case finding tool, which would facilitate the identification of visual impairment blindness, could drastically reduce their negative social and economic impact. There is a necessity to bridge the gap between these unidentified cases and primary care. The SYS leaflet can provide a stepping-stone towards timely treatment by testing vision and raising awareness in the community.

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9.0 Appendixes

Appendix 1: Draft paper for publication in Eye

Appendix 2:



Front page of SYS leaflet

Have you had your eyes tested in the last 2 years ?

T
V H
X U A
H T Y O
V U A X T

H A Y O U X
Y U X T H A

Test yourself now, see inside...



Test yourself below

1 Do the Sight Test chart:

- Put on your distance glasses
- Stand 2 large paces away from the chart
- With one eye at a time can you read below the black line?

2 Now ask yourself:

With your best glasses on, do you struggle:

- To look up phone numbers and dial them?
- To read the words on the television or in the newspaper?
- To get around without the fear of falling?

What to do next

If you have not been to the optician in the last two years or have identified any problems with your eyesight during the test, please make an appointment with your optician.

▶ How to make an appointment with the optician

- Call in or phone your local optician (optometrist)
- Contact your GP practice or health centre
- Contact NHS Direct on 0845 46 47

To arrange a home visit:

- Contact the Patient Advice and Liaison Service (PALS) on 0800 0525 270

Please give this form to the optician when you see them and mention the Save Your Sight campaign

Optometrists - please return this form to WYCSA

Please enter your postcode here

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“ I only discovered I had eye disease when I visited my optometrist. I’m really pleased it was discovered early. ”



Are you at risk of losing your sight?

You are more at risk of losing your sight if:

- you are over 60
- you have diabetes or glaucoma
- you smoke

NHS sight tests are **FREE** if:

- You are over 60 (go every 2 years)
- You are a diabetic (go every 12 months)
- You are over 40 and have glaucoma in the immediate family (go every 12 months)
- You are on certain low income benefits
- You are under 16 or aged 17-18 in full time education

Additional information

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