

**AMD Alliance
International:
Campaign Report
2005**

**Awareness of
Age-related Macular
Degeneration and
Associated Risk
Factors**

United Kingdom



“I used to smoke up to 60 cigarettes a day. Now I have wet AMD, am partially sighted in one eye and am likely to lose my sight. When you smoke you cannot imagine what it is like to have lung cancer and especially when you are young the risk of dying earlier doesn’t come into it. I am a nurse, I saw people die from smoking-related diseases and that did not make me kick the habit. But if I had been told that I could lose my sight because of smoking I am sure I would have given up earlier. I stopped the day I found out.”

Pauline M Edwards
UK, aged 50

“We have made considerable progress in identifying the risk factors linked with AMD in the past few years. While smoking remains the main modifiable risk factor growing evidence suggests that many of the aspects that we associate with a healthy life-style – a balanced diet, exercise, low cholesterol levels, etc. – also help to keep our eyes healthy. We cannot (and do not want to) escape the fact that we grow older but we can try to minimise the risk of developing AMD by taking preventative measures.”

Dr. Johanna Seddon, Director, Epidemiology Unit, Massachusetts Eye and Ear Infirmary, Boston, USA and Member of the Scientific Advisory Board of the AMD Alliance International

Acknowledgements

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AMD Alliance International: 2005 Country Report UK

Awareness of Age-related Macular Degeneration and Associated Risk Factors



Table of Contents

Survey Results: Headline Figures	5
Summary of Main Findings and Call for Action	6
Section 1: General Awareness of AMD	8
Section 2: Risk Factors and Prevention	11
2.1. Unavoidable Risk Factors	11
2.2. Avoidable Risk Factors	14
2.3. Recommendations for Preventative Actions	16
2.4. Measuring Global Awareness of Risk Factors	17
Section 3: Smoking habits in the UK	20
Section 4: Prevention in the UK	22
Section 5: Call for Action	25
References	27
Annexes	
Annex 1: About the AMD Alliance International	31
Annex 2: Quit smoking helplines	31
Useful Addresses and Links	32



Survey Results UK – the Headline Figures

- Just 16 per cent of UK respondents stated that they were very or somewhat familiar with AMD.
- 49 per cent of respondents identified age as a risk factor for AMD followed by lack of vitamins/nutrients (41 per cent). The only modifiable risk factor that has been proven beyond doubt – smoking – was named by merely 39 per cent of respondents.
- 49 per cent of respondents thought that smoking may harm their eyes, 41 per cent did not think so and 10 per cent did not know or did not say.
- 29 per cent of respondents were smokers with 20 per cent smoking regularly, 6 per cent sometimes and 3 per cent rarely.
- 23 per cent used to smoke but have now stopped and 47 per cent have never smoked.
- Young people (57 per cent of those aged between 18-24) and women (53 per cent) are most likely to have never smoked.
- 62 per cent of respondents would change their diet or take more exercise and 43 per cent would reduce their alcohol consumption to avoid blindness in later life.
- Of current smokers 69 per cent would change their smoking habits by either stopping smoking permanently (41 per cent) or by reducing their consumption of cigarettes and tobacco (28 per cent). In the group of people aged 25-39 years as many as 81 per cent would take this action (46 per cent would give up and 35 per cent would smoke less).

Summary of Main Findings and Call for Action

According to the World Health Organisation age-related macular degeneration (AMD) is the leading cause of blindness in developed countries worldwide [1]. Yet general awareness of AMD is alarmingly low. In the UK a mere 16 per cent of respondents to a major cross-national survey stated that they were familiar with the condition.

The UK results need to be seen against the background of major efforts made by the UK members of the AMD Alliance to ensure that patients with wet AMD (the more aggressive type of the disease that can lead to rapid vision loss) receive prompt treatment regardless of where they live. This campaign has resulted in considerable media coverage and has taken the issue to the highest levels of decision-taking. Nonetheless, awareness is low, particularly in comparison with other major eye conditions such as cataracts and glaucoma.

In line with this low level of general awareness a large majority of people are also unaware of the risk factors that trigger AMD and are therefore unable to take targeted preventative action. This applies even to the most important modifiable risk factor: smoking. In the UK only 40 per cent of respondents who were somewhat or very familiar with AMD were aware of this risk factor. Out of all respondents only 49 per cent thought that smoking can harm their sight.

Yet, the survey shows that fear of blindness is a powerful incentive to stop smoking or smoke less. Out of the respondents who had stated that they were current smokers 69 per cent would either stop smoking permanently (41 per cent) or smoke less (28 per cent). In the group of people aged 25-39 as many as 81 per cent would take this action with 46 per cent stating that they would stop smoking permanently and 35 per cent saying they would smoke less. These figures, as well as experiences in Australia and New Zealand, lend considerable support to the assertion that a focus on the link between smoking and blindness would considerably increase the effectiveness of anti-smoking campaigns.

The Consequences of Inaction!

It is an established fact that the global number of people who will lose their sight because of AMD will increase, if only because of our ageing population. The costs of vision loss, both to individuals and their families and to society are therefore likely to increase. For the UK the costs of blindness have been estimated at £4.9 billion per annum. Given that AMD is the leading cause of



vision loss in the UK, a significant part of these costs is likely to be attributable to AMD. Prevention, early detection and treatment are keys to reducing these costs.

Urgent Action Needed Now!

Increased awareness of AMD is essential. Increased awareness of AMD will allow individuals to make informed life-style choices (particularly in relation to smoking) to reduce the risk of vision loss from AMD. Preventing blindness and helping visually impaired people lead independent lives is a moral imperative that makes strong economic sense. We must educate the general public and health care professionals about the factors that increase the risk of developing AMD, but the AMD Alliance and its members cannot do this alone.

We are therefore calling on the UK Government and interested stakeholders to:

- Fund a large scale public awareness campaign on AMD focusing on prevention and early detection;
- Support the introduction of warnings about the link between smoking and blindness on tobacco products.

Immediate action is required: Partner with us now to ensure that AMD does not remain the unknown cause – and cost - of blindness and severe vision loss.

On behalf of AMD Alliance International

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Section 1

General Awareness of AMD

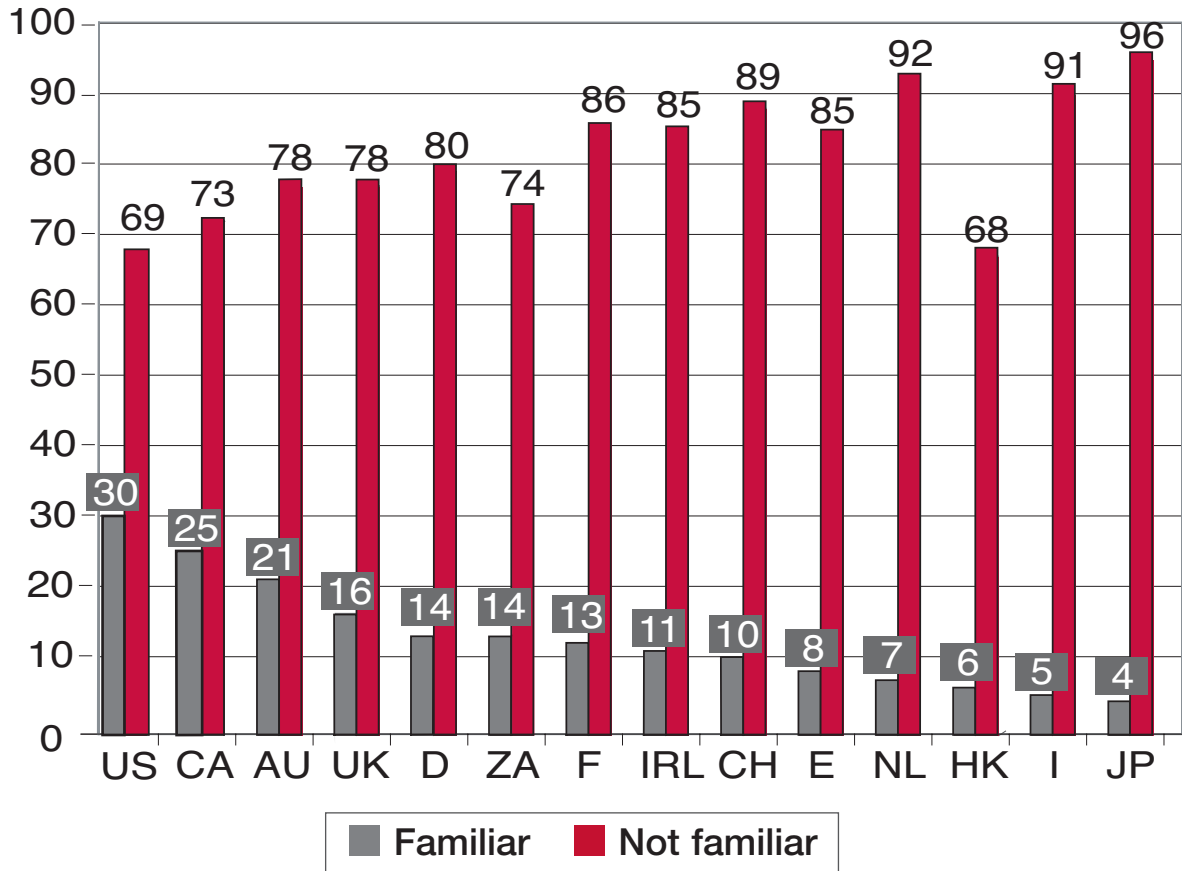
According to the World Health Organisation age-related macular degeneration (AMD) is the leading cause of vision loss in developed countries [1]. AMD is a degenerative retinal eye disease that causes progressive loss of central vision. AMD affects the macula – the central part of the retina responsible for clear, central vision needed for daily activities such as reading, driving or watching TV. As light-sensing cells in the macula called photoreceptors begin to deteriorate, so does the individual's central vision. It usually starts in one eye and is highly likely to affect the other eye at a later stage. Common symptoms are blurred or distorted vision but there are often no signs of vision loss in the early stages. We distinguish between two types of AMD. Dry AMD is the most common form of the condition and develops slowly, eventually leading to a loss of central vision. Currently, there are no treatments for dry AMD. Leaking blood vessels inside the eye cause wet AMD. It is less common (10 to 15 per cent of the total) than dry AMD but it can cause more rapid loss of vision. If detected in time, treatments for some forms of wet AMD are effective in reducing or delaying sight loss. The extent of vision loss varies widely and is related to the type of AMD, its severity and other individual characteristics. Whilst individuals with AMD usually retain some residual vision, vision loss can be so severe that it is classed as “legal blindness” in most countries.

In 2005 the AMD Alliance International commissioned EOS Gallup Europe to conduct a global survey to assess awareness of AMD and the risk factors associated with the disease. The survey covered Australia, Canada, France, Germany, Hong Kong, Ireland, Italy, Japan, the Netherlands, South Africa, Spain, Switzerland, the UK and the United States of America. In the UK total of 1023 people were interviewed by telephone.

To establish awareness levels respondents were asked whether they were very, somewhat, not too familiar or not at all familiar with the medical condition known as age-related macular degeneration or AMD. They also had the option to answer “don't know” or give no answer.



Figure 1. Awareness of AMD



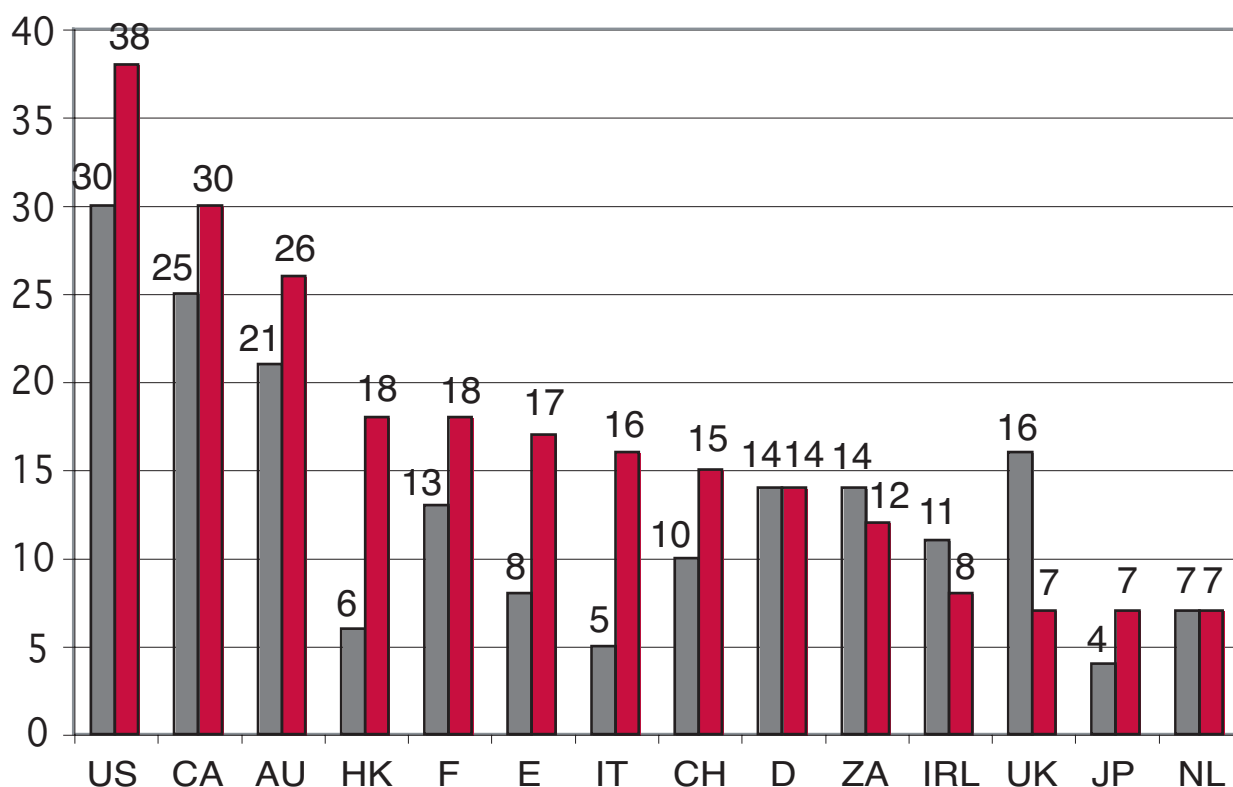
The results show the US, Australia and Canada at the top of the table with 30 per cent, 25 per cent and 21 per cent of respondents respectively stating that they were very familiar or somewhat familiar with AMD. The UK (16 per cent), South Africa and Germany (14 per cent), France (13 per cent), Ireland (11 per cent) and Switzerland (10 per cent) occupy the middle ground whereas in Spain, the Netherlands, Hong Kong, Italy, and Japan less than one in ten respondents were aware of the condition.

Because individuals will have different views of what it means to be “somewhat” or “very familiar” with a condition, we used a control question, asking all respondents, whether they were familiar with AMD or not, what body part they thought was affected by the condition. Respondents were able to choose from a list of organs including the eyes.

The responses to this question show that in the majority of countries the percentage of people linking AMD with the eyes is greater than the percentage

of people stating that they are familiar with AMD (see figure 2 below). However, in some countries (UK, Ireland, and South Africa) respondents appear to have overstated their knowledge of the condition since the percentage of people claiming familiarity with AMD was higher than the percentage of people linking AMD with the eyes. This raises the challenge of ensuring that awareness campaigns are successful in going beyond the “have you heard of” aspect of familiarity and generate awareness linked with factual knowledge and action. The UK results have to be seen against the background of a major campaign led by the AMD Alliance UK to secure access to treatment for wet AMD across the country. This generated wide-spread media coverage, particularly following questions about failure to provide the treatment being raised by the Leader of the Opposition in the House of Commons. We were therefore expecting higher awareness levels even though the campaign had targeted decision-makers and not the general public. With 16 per cent awareness in the general population we clearly have a long way to go to achieve a level of awareness that is similar to the awareness of other major eye conditions such as cataracts (95 per cent) and glaucoma (92 per cent) [2]. Given the new treatment options and the increased knowledge about prevention this is the level of awareness we should aim for with age-related macular degeneration.

Figure 2. Awareness of AMD v. knowledge that AMD affects the eyes



■ Awareness of AMD
 ■ Knowledge: AMD affects the eyes

Section 2

Risk Factors and Prevention

The survey results discussed above illustrate how difficult it is to raise general awareness of AMD, yet this is the prerequisite for any work on prevention. If people are unaware of a condition that may affect them in later life, they are unable to take targeted preventative action.

Before discussing the results of our survey questions on risk factors, we would like to present the current understanding of factors that increase the risk of developing AMD and recommendations for preventative measures.

2.1. Unavoidable or non-modifiable risk factors

So why should we be aware of the unavoidable risk factors of AMD? Some people may think that there is not much point knowing of a higher risk if you cannot do anything about it.

We feel that it is important to take a more positive, pro-active approach. People need to know if they are at a higher risk of developing AMD so they can focus on avoiding the environmental risk factors that could increase this risk even further. They also need to be made aware of their increased risk to ensure that they take early detection particularly seriously. The recommendation from the AMD Alliance's Scientific Advisory Board is that people aged 55 or older should have regular eye examinations every two years. This should consist of a dilated fundus examination performed by a qualified eye health professional. However, people who experience loss of vision or distorted vision should immediately consult a qualified eye health professional and should follow his or her advice regarding follow up. By following this advice people who develop AMD increase their chances of accessing the growing number of treatment options and rehabilitation services available in most countries.



The unavoidable factors that increase the risk of developing AMD discussed below are:

- Ageing
- Family History/Genetics
- Gender
- Ocular factors such as hyperopia and lower disc/cup ratio
- Ethnic group and iris colour

Ageing and family history or genetics are unavoidable risk factors whose link with AMD is firmly established.

Ageing

As the name of the condition suggests age-related macular degeneration is a condition that is clearly linked to the ageing process. Even though figures on the prevalence of AMD vary greatly depending on the definition used, it is clear that the likelihood of developing the condition increases considerably with age. Prevalence increases from 12.2 per cent in people aged 55-64 years to 18.3 per cent in those aged 65-74 years and 29.7 per cent in people aged over 74. It is important to note that not all of these will be cases of advanced AMD resulting in vision loss. In fact the figure for those with advanced AMD above the age of 75 is 7.8 per cent. [3]

Because of this age profile, the vision loss associated with AMD was for a long time considered to be an inevitable consequence of ageing. Even today, when there is treatment available to halt the progression of the most aggressive form of the disease and low vision rehabilitation helps many patients to continue autonomous lives, many people still believe that they just have to “put up” with their deteriorating sight rather than exploring treatment and low vision rehabilitation options.

Family History / Genetics

Twin studies and evidence that first degree relatives of people with AMD are more likely to develop the condition themselves, suggest that genetic predisposition is one of the risk factors for AMD. However, it is only in the past five years that significant progress has been made in identifying the genes that are involved in the disease process. Four research papers published in 2005 [4,5,6,7], now report identifying a gene on chromosome 1 which is responsible for the production of the so called “complement factor H” (or CFH) protein. In



people with AMD changes to the DNA lead to a change in the sequence of amino acids that form this protein. The CFH protein is involved in the control of inflammatory processes. Scientists therefore believe that the variant protein may be associated with inflammation within the retina. However, more research is required to define more accurately the role of the abnormal CFH protein in the development of AMD. Current data suggests that people who have inherited the variant CFH gene from one parent have a 2-4 times increased risk of developing AMD. If both parents carry the variant CFH gene the increased risk is 5-7 fold. Putting it another way, the current data suggests that the change to the sequence of the CFH protein possibly accounts for 20-50 per cent of the overall risk of developing AMD. These findings are significant because people, and in particular those with a family history, may be able to undergo screening for the variant CFH gene to assess their risk of developing AMD well before they develop any symptoms. More importantly, powerful technologies are being developed to manipulate the process that transforms genetic information into proteins. This means that it may be possible to suppress the “misinformation” contained on the variant CFH gene to avoid the increased risk of developing AMD. [For a more detailed discussion of the role of genetics in the development of AMD, written by Prof. Peter Humphries, member of the AMD Alliance International Scientific Advisory Board, please go to: www.amdalliance.org.]

Other unavoidable risk factors have been linked to AMD but some of the evidence is not consistent:

Gender

It is a common assumption that women are more likely to develop AMD. However, the evidence is not strong since the larger number of women with AMD may simply be a reflection of their greater longevity. Generally, there does not seem a significantly increased risk for women as compared to men [8]. It is also worth noting that a study in Japan has found the prevalence of AMD to be higher in men than in women [9].

Ocular factors such as hyperopia and lower cup/disk ratio

AMD has been linked to hyperopia (farsightedness) [10] and a lower cup/disc ratio [11]. People with these conditions should be made aware of the importance of regular eye tests and should be encouraged to test their vision with the Amsler Grid. This is a wise precaution even though the impact of these factors has not been quantified, and not all studies have evaluated these parameters.

Ethnic group and iris colour

It is generally assumed that Caucasians are more likely than others to develop AMD, even though some studies suggest prevalence rates of 1.1 per cent in South India to 17.4 per cent in Africa [12,13,14] (against 1.2 per cent - 1.4 per cent in the United States and Europe). In addition, people with blue or hazel eye colour [15] appear to have a higher risk and Caucasians with AMD seem to be more likely to progress to the advanced stages of AMD [16]. One of the problems with these figures is the lack of a universally accepted definition of AMD which means that it is difficult to compare different studies. It should also be noted that in Asia and Africa a more common form of age-related macular degeneration is polypoidal choroidal vasculopathy (PCV) which is not yet well understood and where accurate prevalence figures are even harder to find. This explains the difficulty of establishing to what extent ethnic groups differ in their susceptibility to AMD.

2.2. Avoidable or Modifiable Risk Factors

Avoidable risk factors are those that are open to behavioural modifications, or in other words they are environmental factors that individuals can control.

The following modifiable risk factors are discussed below:

- Smoking
- Relatively low levels of micronutrients and antioxidants
- Obesity, high blood pressure, fat intake and cholesterol levels
- Light exposure

Smoking

The only avoidable risk factor that can be regarded as proven is the link between AMD and smoking [17]. The first prospective study in 1996 definitively demonstrated an association between AMD and smoking [18]. The most recent study on smoking and AMD was published in the British Journal of Ophthalmology on 14 April 2005. A study of more than 4,000 Britons aged 75 and older showed that those who smoke were twice as likely to have age-related macular degeneration as those who did not [19]. Other studies have come to the conclusion that the risk may be as high as three to four times that of a non-smoker [20,21]. In addition, a review of the association between smoking and age-related macular degeneration that examined the results of 17 studies into the link has found that scientific evidence is sufficiently strong to prove that smoking causes age-related macular degeneration. The causality criteria used were the same as those applied to proving the link between smoking and lung cancer [22].



Studies in a number of countries confirm that people who stopped smoking 20 years ago have a similar risk of developing AMD as non-smokers and the risk starts to decrease after 10 years of not smoking. Some studies also suggest that there is a link between the number of packs smoked and the likelihood of developing AMD. [23]

In a nutshell, there is now sufficient evidence to show that smoking is the main modifiable risk factor for developing AMD. It is responsible for at least a two-fold increase in relative risk, while some studies suggest the risk could be as high as 3-4 fold.

Relatively low levels of micronutrients and antioxidants

The best known food supplement for AMD, the so-called AREDS formula is recommended only for people with intermediate or advanced AMD [24,25,26]. Anybody considering taking the AREDS formula as a supplement should discuss this with their eye care professional. They should be aware of concerns about the link between beta-carotene and cancer in smokers. They also need to realise the danger of over-supplementation if they use other supplements in addition to the AREDS formula. Of course, primary care doctors should be informed in case there is interaction with other medications.

The main supplements discussed in the context of prevention are lutein and zeaxanthin. Lutein and zeaxanthin are two antioxidants that are concentrated in the macula and constitute the macular pigment [27]. It has been suggested that they may play a significant role in preventing oxidative damage to the macula thereby preventing the development of AMD. What is particularly significant is the fact that some studies have shown lutein to improve some measures of visual function [28,29]. However, samples studied were small and further studies are required to come to a firm conclusion on the benefits of both antioxidants and decide whether this food supplementation is to be generally recommended as a preventative measure.

Obesity, high blood pressure, fat intake and cholesterol levels

Age-related macular degeneration has also been linked with obesity [30,31] and high blood pressure (hypertension) particularly in people taking antihypertensive drugs [32]. In addition, a high intake of dietary fats (especially saturated and mono-unsaturated) was linked to a higher risk of developing AMD [33] and of progressing from the early and intermediate stages to the late stages of the condition [34], whereas omega-3 fatty acids and fish tended to reduce risk [33, 34]. In addition, AMD has been linked with high cholesterol levels but again the evidence is not conclusive [35,36].

Light exposure

Ultraviolet light probably does not harm the macula since it does not reach it. However, there is some evidence that blue or visible light (400-700nm wavelength) may be associated with a higher risk of developing AMD [37]. The Beaver Dam Eye study [38] showed an increased incidence of AMD in people who spent long periods in the summer sun but no significant link with exposure to environmental light in general. On the other hand McCarty et al [39] did not find any link between light exposure and AMD.

2.3. Recommendations for preventative actions

Many of the preventative actions that people can take to decrease the risk of developing AMD are part of an overall focus on a healthy life style. These include:

- Eating a diet low in fat but rich in vegetables (especially green leafy vegetables), nuts and fish.
- Controlling body weight, blood pressure and cholesterol levels.
- Wearing sunglasses at midday to protect your eyes as part of a general eye health routine.

People should also check their family history in relation to eye disease. Those who have first-degree relatives with AMD should see their eye care professional, and have a fundus examination. If they are found to have intermediate AMD, or advanced AMD in one eye, then they should take the AREDS type supplement and should adhere to the healthy habits outlined above. These are recommended for everybody but they are particularly important for those with a family history or first signs of the disease.

However, the strongest and most important message regarding prevention of AMD is:

Do not smoke, and if you do, stop!

Since smoking is the one proven modifiable risk factor of developing AMD people need to be encouraged to give up. This is often easier said than done and it is therefore important to encourage people to seek help from qualified professionals. In most countries Governments and voluntary organisations run programmes to help people quit. (For addresses in the UK please see annex 2 below).



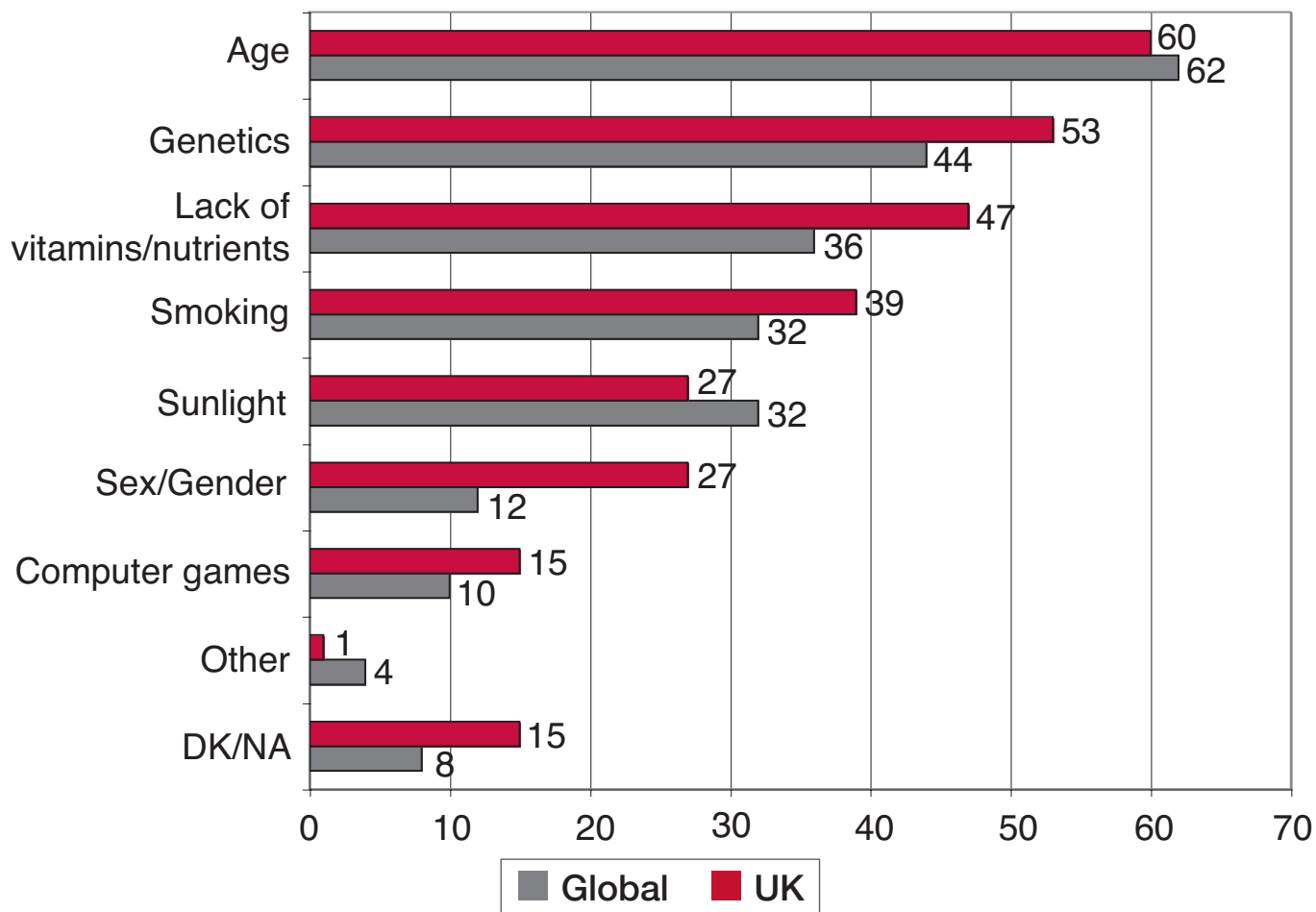
2.4. Measuring awareness of risk factors

In line with this report's topic our survey included two questions on awareness of risk factors. First, respondents were asked to identify risk factors for developing AMD from the following list: a) smoking, b) lack of vitamins/nutrients, c) age, d) unprotected exposure to sunlight, e) genetics, f) sex/gender, g) computer games, h) others, and k) don't know/no answer. In our analysis we will focus on the answers of those who had stated that they were familiar with AMD. Similar trends apply to those who correctly identified the eyes as the body part affected by AMD.

The results show that age was correctly identified as a risk factor by the highest percentage of respondents (62 per cent) followed by genetics/family history with 44 per cent. On a significantly smaller and therefore less reliable sample (163 respondents) the UK results were 60 per cent for age as a risk factor and 53 per cent for genetics/family history. As we have seen above these are the main non-modifiable factors that increase the risk of developing AMD. Since we cannot change them they do not play any role in prevention of AMD (at least as long as there is no gene therapy to suppress the effects of the changes to the CFH gene described above). Nonetheless, awareness of these risk factors is important since people in these categories should take early detection particularly seriously. We feel that these results reflect an adequate level of understanding of AMD as a condition that mainly affects older people. However, given the up to seven fold increased risk of developing AMD for people with a family history, more needs to be done to raise awareness of the genetic element in AMD.

By contrast, the results demonstrate a worrying lack of awareness of the main modifiable risk factor that has been proven to cause AMD: smoking. Out of the small sample of 167 people who were aware of AMD in the UK 39 per cent named this risk factor (32 per cent overall). Unprotected exposure to sunlight was named by 27 per cent of respondents (32 per cent overall) whereas 47 per cent named lack of vitamins and nutrients (36 per cent overall). Both of these risk factors remain subject to scientific debate with growing evidence of the importance of nutrition but increasing doubt about the impact of light exposure.

Figure 3. Awareness of Risk Factors – Global v. UK



To reflect the importance of smoking as the only established modifiable risk factor the last question asked in all surveys was whether people thought that smoking can harm their sight.

The results (see figure 4 on page 18) show that the percentage of people recognising the harmful effect of smoking on their sight is significantly higher than the percentage of people aware of AMD. Nonetheless, in the majority of countries more than half of the population (51 per cent in the UK) are not aware of the link between smoking and sight loss.

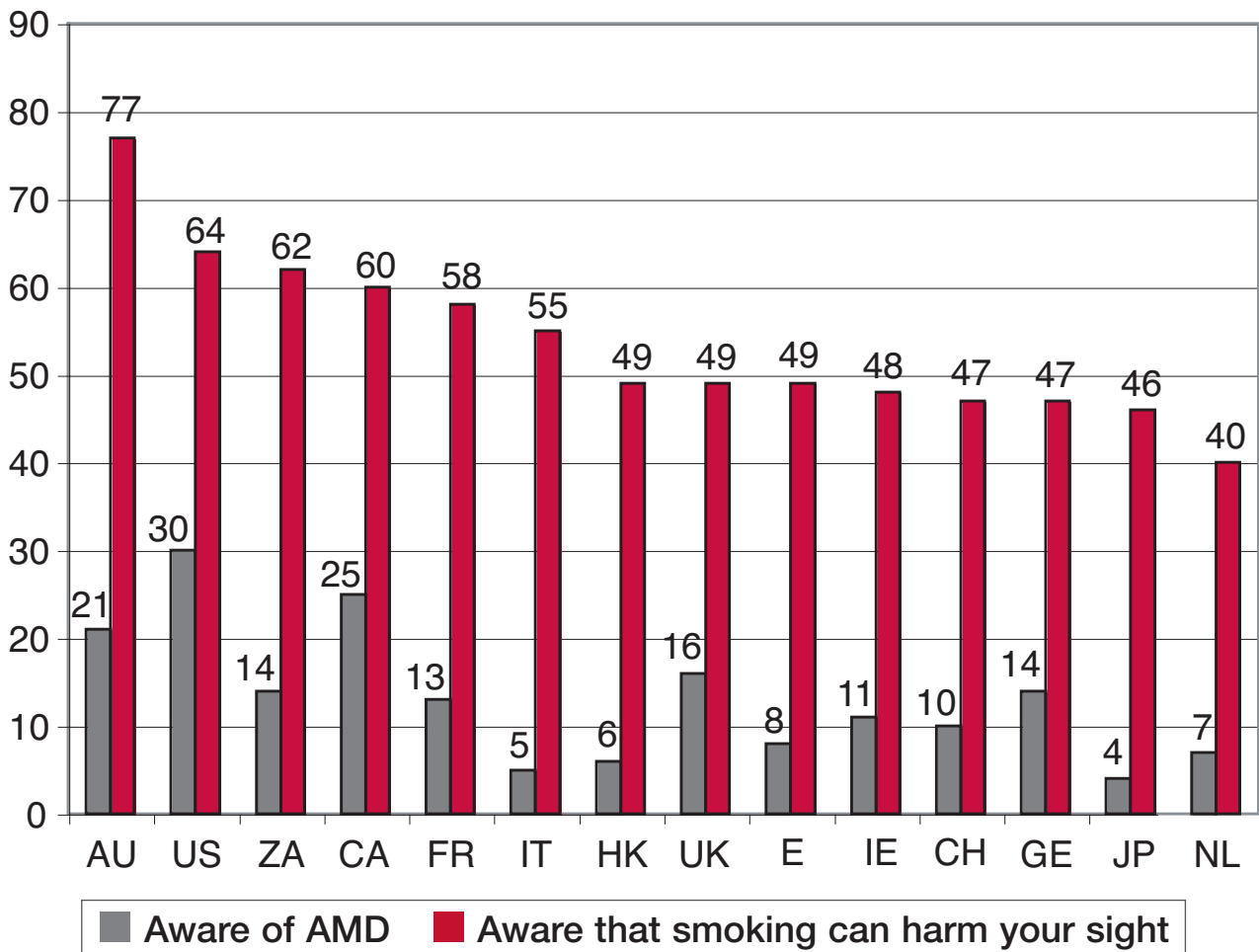
A major exception is Australia where 77 per cent of respondents are aware that smoking can harm their sight. This is not surprising since Australia is one of the few countries in the world to have introduced warnings about the link between smoking and blindness on tobacco products. In addition they have mounted a major advertising campaign with hard hitting pictures to illustrate the harmful effect of smoking on eye health. The campaign has shown that the fear of



blindness is a powerful incentive to give up smoking. This is in line with research that has shown blindness to be the disability feared most by people [40]. Hence it is not surprising that calls to Quitlines increased in Australia [41] and similar results were seen in New Zealand [42].

However, given the big gap between the number of people who are aware of the link between smoking and visual impairment (77 per cent) and those who are aware of AMD (21 per cent) we feel that more effort should be put into using the “anti-smoking” campaign to increase awareness rates of AMD as the condition causing the impairment. Stopping smoking is an important preventative step but equally important is the message about regular eye tests and early detection given the unavoidable risk factors of AMD.

Figure 4. Awareness of AMD v. Knowledge that smoking can harm sight



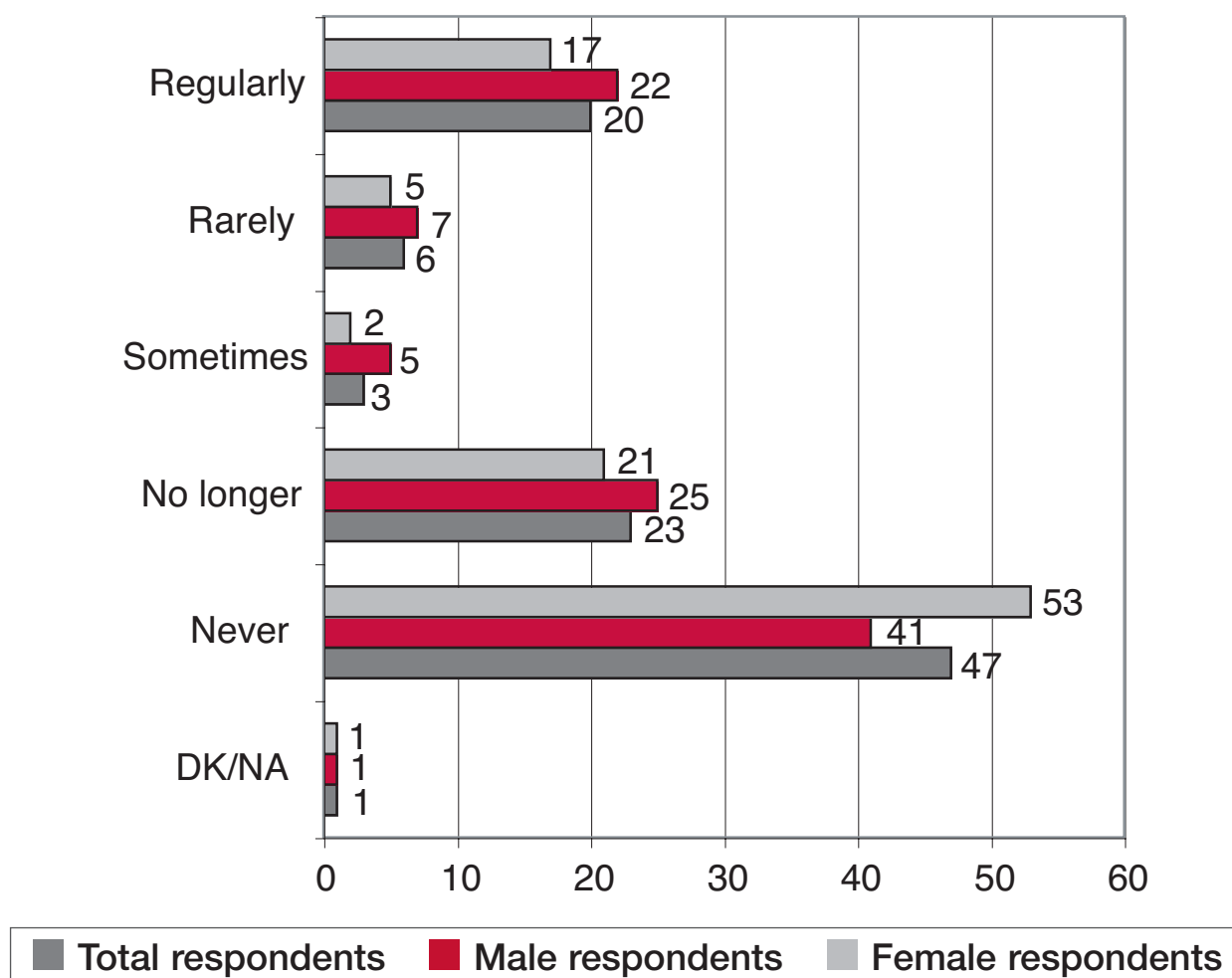
Section 3

Smoking habits in the UK

In the UK the members of the AMD Alliance International decided to add a couple of questions to the survey. One of them aimed to establish current smoking habits.

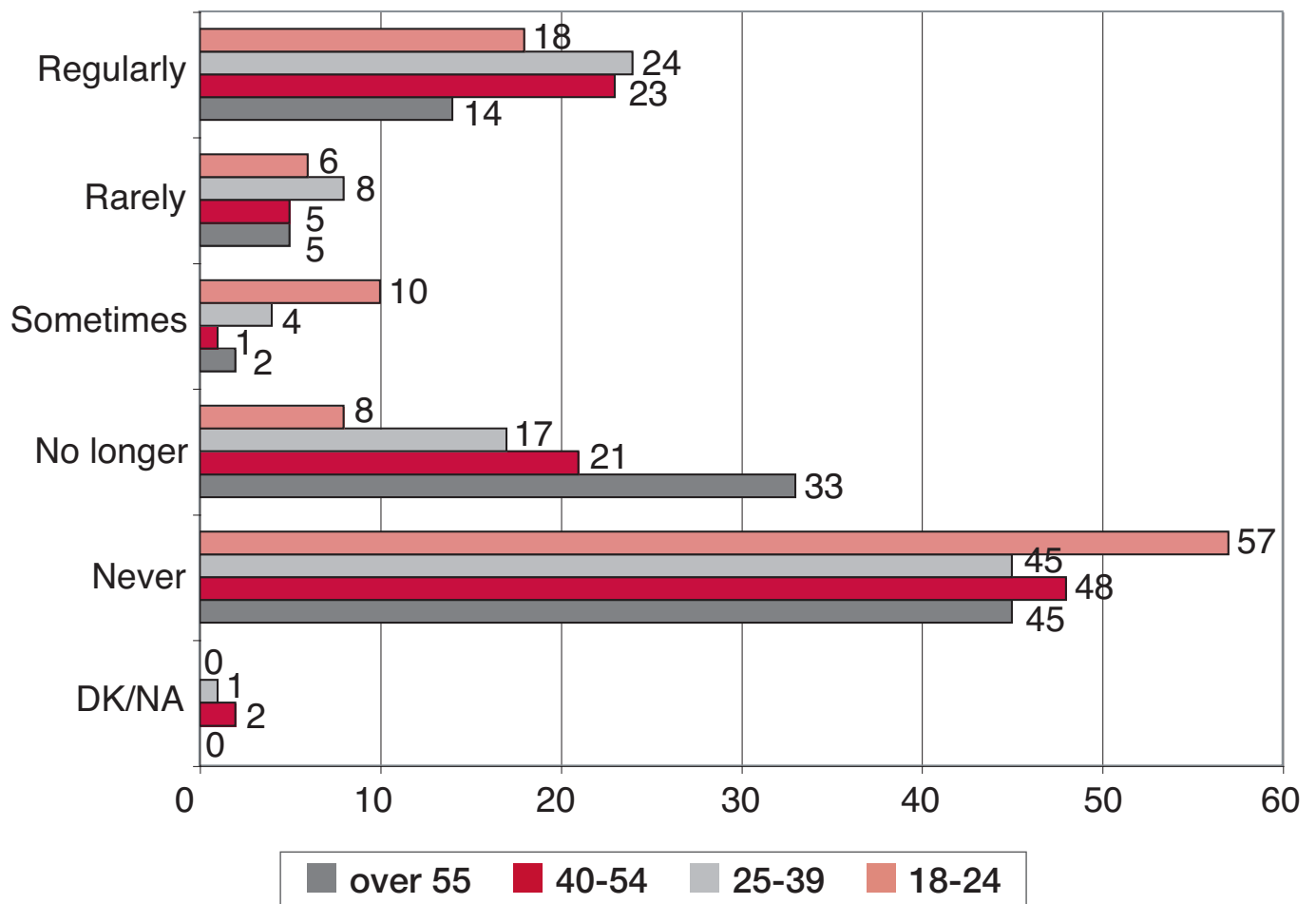
The results show that out of all respondents 20 per cent admitted to smoking regularly, six per cent to smoking sometimes and three per cent to smoking rarely, a total of 29 per cent. Despite growing concerns about the number of women taking up smoking the percentage of women who have never smoked is significantly higher than the percentage of men who have never smoked (53 per cent against 41).

Figure 5. Smoking habits per gender/sex



In terms of prevention it is important to note that the age group with the highest percentage (57 per cent) of people who have never smoked is that of 18-24 year olds. Only 18 per cent of this age group smoke regularly, six per cent smoke sometimes and 10 per cent smoke rarely whereas eight per cent used to smoke but have stopped. Although even fewer people smoke in the group of people aged over 55 (14 per cent regularly, five per cent sometimes and two per cent rarely) a large percentage of this age group (33 per cent) used to smoke but have now stopped. Although there are indications that the risk of developing AMD starts to decrease after ten years of not smoking it is obviously best to avoid this specific risk altogether by not smoking at all.

Figure 6. Smoking habits by age group



Section 4

Prevention in the UK

Any discussion about steps to reduce the number of people who risk developing AMD should take into account what kind of action people are most willing to take.

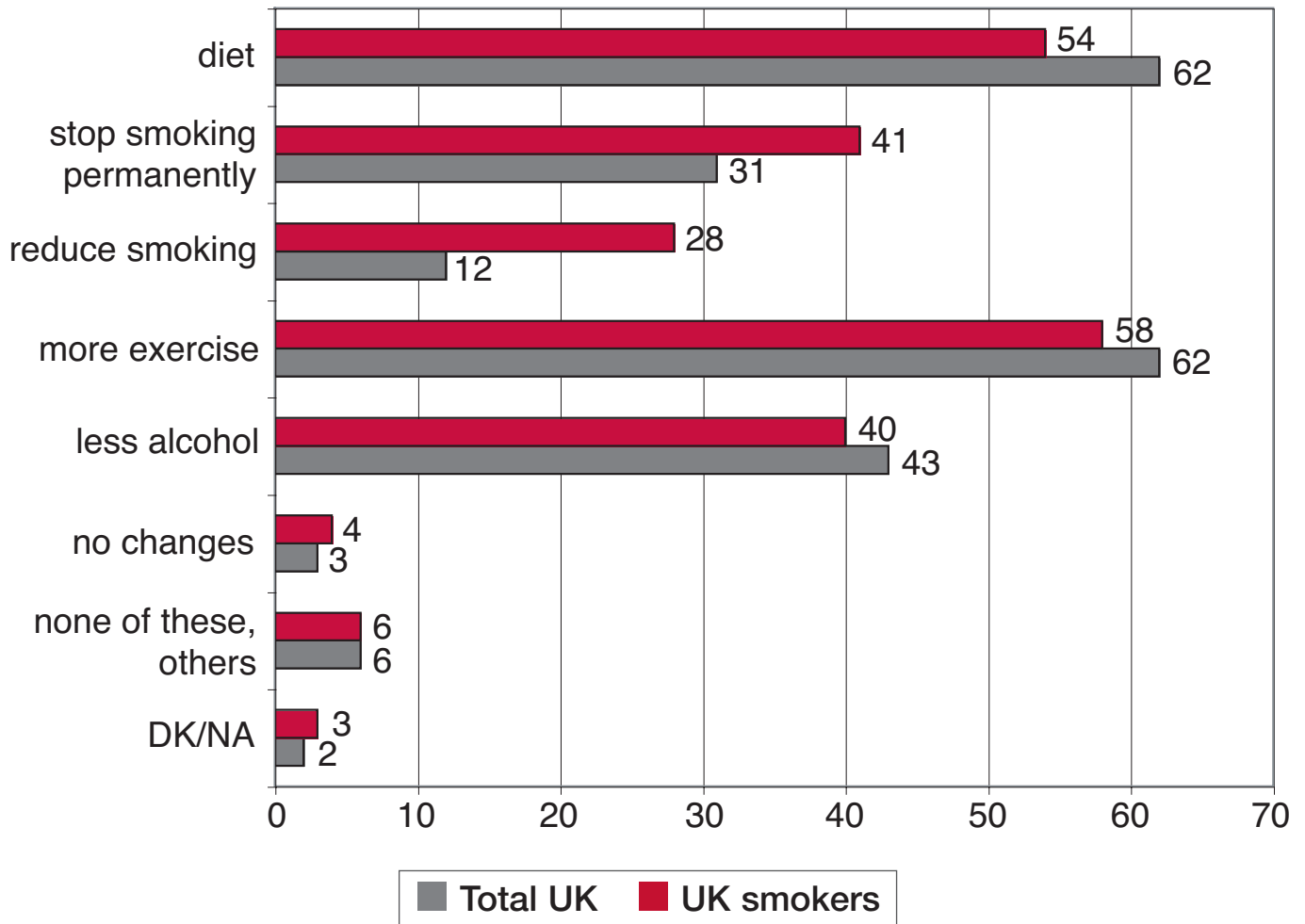
Our last question in the UK asked respondents what changes they would consider in order to avoid blindness in later life.

The results show that the fear of blindness acts as a powerful incentive for people to take preventative action. Out of all correspondents only three per cent would not consider making changes to their life style. 62 per cent would make permanent changes to their diet and / or exercise more whereas 43% would reduce their consumption of alcohol.

Most significantly, out of the total of 309 respondents who had stated that they were current smokers 69 per cent would either stop smoking permanently (41 per cent) or reduce their consumption of cigarettes/tobacco (28 per cent). Smokers were less inclined to opt for other types of action such as making permanent changes to their diet (54 per cent), taking more exercise (58 per cent) and/or reducing their consumption of alcohol (40 per cent).

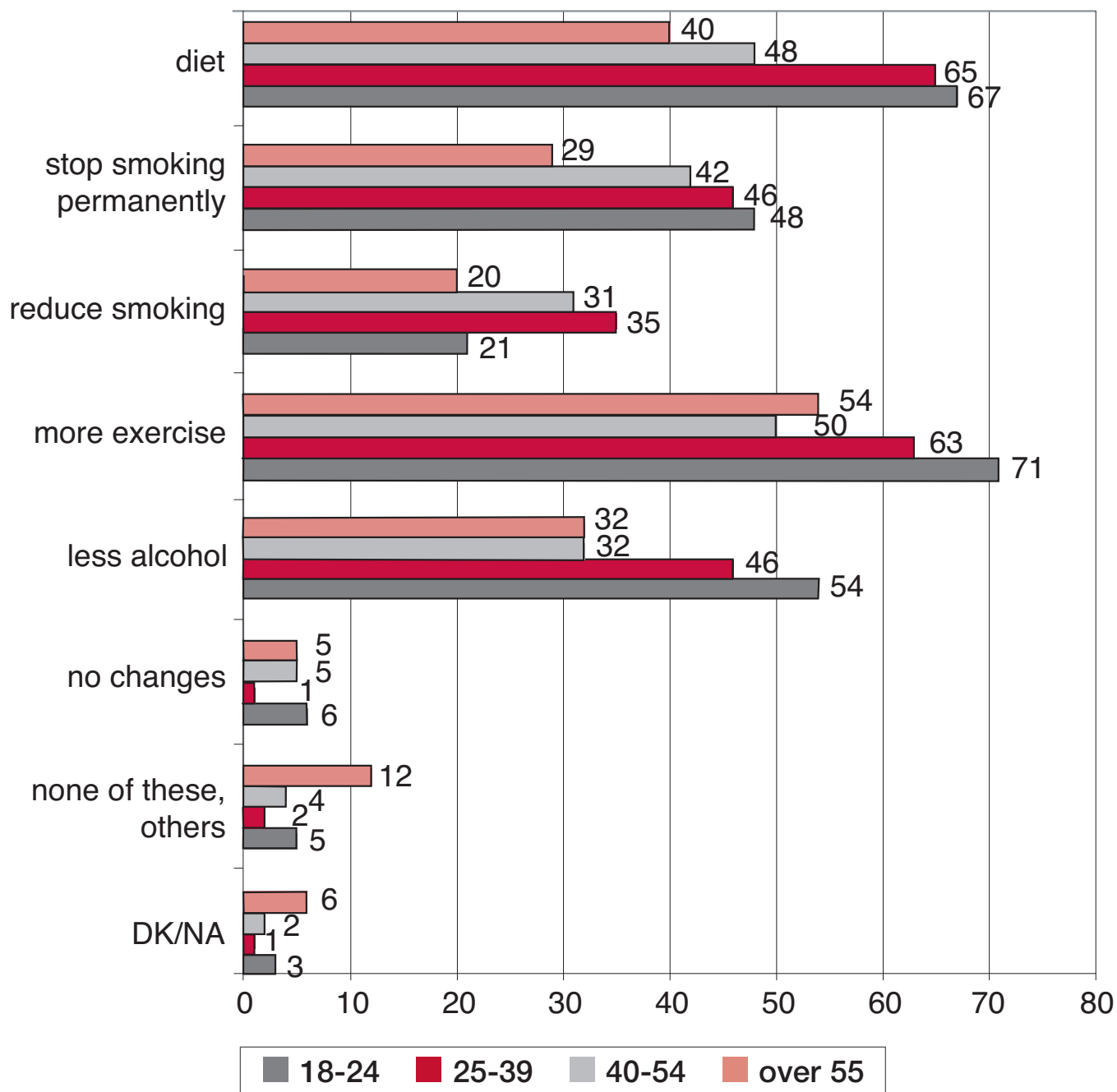
Among young smokers willingness to take action is particularly high. 69 per cent of smokers aged between 18 and 24 would stop smoking or smoke less, 71 per cent would take more exercise, 67 per cent would change their diet and 54 per cent would drink less alcohol. Amongst the group of smokers aged 29 to 35 81 per cent would either quit or smoke less, 65 per cent would change their diet, 63 per cent would take more exercise and 46 per cent would drink less alcohol. Older age groups are clearly more reluctant to make changes especially regarding smoking habits. 54 per cent of smokers aged over 55 would take more exercise, 49 per cent would either stop smoking or smoke less, 40 per cent would change their diet and 32 per cent would drink less alcohol.

Figure 7. Preventative action – Total UK v. Smokers



As we have seen in the risk factor section many of the potential risk factors of AMD point to the importance of a healthy life-style. Since the vast majority of people would be ready to make changes to their life style to avoid blindness in later life this could be a powerful incentive for people to lead healthier lives. Whilst more research is necessary to confirm the role of these potential risk factors there is sufficient scientific evidence to take action in relation to smoking now.

Figure 8. Preventative action per age group



Section 5

Call for Action

Our report shows that in the UK (and all other countries surveyed) awareness of age-related macular degeneration as the leading cause of visual impairment is alarmingly low. Along with other interested partners the AMD Alliance UK will continue its efforts to raise awareness of AMD amongst the general population and specific target groups (elderly people, eye health professionals, pharmacists, decision-makers, etc.). However, more extensive efforts are needed to achieve substantial increases in awareness.

We therefore call on the UK Government to partner with voluntary organisations and other stakeholders to undertake essential large scale public awareness campaigns on AMD, focusing on prevention and early detection.

Information on AMD and the importance of a healthy life style to maintain eye health should be incorporated in overall government health policies. Since smoking is the only established avoidable risk factor for AMD the link between smoking and blindness should be incorporated into anti-smoking campaigns with large scale advertising and warnings on tobacco products. The challenge here will be to ensure that knowledge of the link between smoking and blindness includes awareness of the condition causing the vision loss.

Campaigns with a focus on prevention are an important step in the right direction. However, since AMD is not entirely preventable, these steps need to be complemented by action to raise awareness of the importance of early detection. Early detection is crucial to access treatment options as appropriate. Early detection also helps people to adjust gradually to their vision loss and make the most of their residual vision with the help of low vision devices. If they access low vision rehabilitation early and particularly if they receive counselling they are much more likely to learn to cope with their vision loss and remain autonomous for longer.

There are moral as well as economic arguments for our call for action. It is a moral imperative to prevent blindness and the associated isolation, depression and loss of autonomy. But even without this moral imperative governments need to take account of the very real costs of blindness in terms of direct costs (research, treatment, medication, hospital and nursing home care, etc.) and

indirect costs (loss of earnings, vision aids, benefit payments, etc.). For the UK these costs have been estimated at £4.9 billion per annum [43]. Given that AMD is the leading cause of vision loss in developed countries, a considerable part of these costs is attributable to AMD. It is therefore in all of our interest to ensure that AMD is no longer the most common “unknown” cause and cost of blindness.



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Annex 1 About the AMD Alliance International

AMD Alliance International is dedicated to raising awareness of Age-Related Macular Degeneration (AMD), as well as improving prevention, early detection and access to treatment, rehabilitation and low vision services. The Alliance currently represents organisations in over 20 countries across the globe. The mission of the AMD Alliance International is to bring knowledge, help and hope to individuals around the world affected by AMD.

Annex 2 Quit smoking helplines

If you are a smoker and want to reduce your risk of developing AMD and losing your sight in later life you may want to contact one of the following numbers for advice on strategies to kick the habit or visit www.nwash.co.uk.

Quitline: 0800 002200

Helpline: 0800 1690 169

Urdu: 0800 1690 881
Punjabi: 0800 1690 882
Hindi: 0800 1690 883
Gujarati: 0800 1690 884
Bengali: 0800 1690 885

Textphone: 0800 1690 171

NHS Direct: 0845 4647

Useful Addresses and Links

For more information, please contact:

Royal National Institute of the Blind
105 Judd Street
London, England, WC1H 9NE
Tel: 44-207-391-2082
Fax: 44-207-388-2706
Website: www.rnib.org.uk

Macular Disease Society
Darwin House
13a Bridge Street
Andover
Hampshire, England, SP10 1BE
0845 - 241 - 2041 (UK)
44 - 1264 - 350836 (outside UK)

Fight for Sight
Institute of Ophthalmology
Bath Street
London, England, EC1V 9EL
Tel: 020-7608-4000
Fax: 020-7608-4001

Age Concern England
1268 London Road
London, England, SW16 4ER,
Tel: 0208 765 7701
Fax: 0208 679 6997

Wales National Council for the Blind
Shand House 3rd Floor
20 Newport Road
Cardiff, CF24 0DB Wales
Tel: 02920-473-954
Fax: 02920-433-920
Website: www.wcb-ccd.org.uk

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