

**AMD Alliance
International:
Campaign
Report 2003**

**Country Reports
on Early
Detection
and
Low Vision
Rehabilitation**



Netherlands



Acknowledgments

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AMD Alliance International: Campaign Report 2003

Country Reports on Early Detection and Low Vision Rehabilitation



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Summary of Main Findings and Call for Action

Age-related Macular Degeneration (AMD) is the main cause for blindness and severe visual impairment in the developed world affecting approximately 25-30 million people globally [1]. Given its potentially devastating effect [2] on an individual's independence and ability to live a fulfilling life two elements are essential in tackling the disease:

1. Early detection is vital, particularly in the case of the most aggressive form of AMD (wet AMD) where treatment can slow down or even halt the progress of the disease. By contrast, if undetected for as little as three months, wet AMD can result in irreversible severe vision loss and blindness.
2. The provision of low vision rehabilitation to enable patients to make the most of their remaining vision and to adjust gradually to further vision loss.

This country report is part of the result of research into eye examinations and low vision rehabilitation in 12 countries world-wide. It explores the situation with respect to early detection and low vision rehabilitation in the Netherlands set against the background of equivalent data on Australia, Canada, France, Germany, Ireland, Italy, Japan, Spain, Switzerland, the UK and the US. It is based on the results of a survey on eye examinations carried out by Gallup Europe in June 2003 [3], a comprehensive survey on public attitudes towards AMD in Canada carried out the same year [4] as well as interviews with experts in these areas and research on the Internet. The report is designed to provide a tool for our Dutch member organizations to use in their local campaigns to secure the attention of decision-makers.

For the area of eye examinations the facts contained in this report demonstrate the urgency of further increasing awareness of AMD and the importance of prophylactic eye health examinations at regular intervals (at least every 2 years). An average of 35% of Dutch people (or 5.6 million) [5] put their eye health at risk because they fail to recognise the importance of regular eye health checks that go beyond the assessment of visual acuity and are able to detect early signs of diseases such as AMD or Glaucoma. The number of people who have never had their eyes tested is higher than in any of the other countries (8%).



Even in the age group most affected by AMD (55+) the percentage of people who have not had an eye test in the past two years is as high as 25% (or 850,000 people) [6] and could be higher since the survey did not distinguish between different types of eye tests and therefore included tests for visual acuity that are not sufficient to detect the disease. AMD tends to develop in one eye initially without significantly affecting the person's vision until considerable damage has already been done. The survey suggests that a lack of symptoms of vision problems lulls people into a false sense of security: 89% of respondents who had not had their eyes tested in the past two years stated that they failed to do so because they "did not have anything wrong with their eyes". Given the low level of awareness of AMD (only 10% of respondents were familiar with the disease) this is perhaps not surprising but certainly a cause for serious concern. From an eye health perspective urgent action is required to encourage people to have their eyes tested more frequently (at least every two years). However, the Netherlands face a considerable challenge in this respect since waiting times for ophthalmology appointments are already too long (three to six months). Increased numbers of people seeking appointments would stretch the existing system even further thereby increasing the risk that treatable forms of AMD go undetected and lead to unnecessary sight loss.

Whilst systems for early detection of AMD and other eye diseases require urgent improvement, the provision of low vision rehabilitation in the Netherlands presents a much more positive picture. The services provided are comprehensive, multi-disciplinary, effective and tailored to each individual's needs. Still, waiting times are a problem in this area as well. It can take up to 4½ months before low vision devices are fitted and can be used by the individual. This causes frustration and avoidable dependence and requires a streamlining of procedures applied by both insurers and rehabilitation service providers.

Act now!

The AMD Alliance calls upon stakeholders in the Netherlands to take this report seriously and to act on its findings. There is an urgent need to raise awareness of AMD and the importance of early detection; an urgent need to encourage people to have regular eye examinations and an urgent need to reduce waiting times for ophthalmology appointments. Action should also be taken to speed up the provision of low vision rehabilitation to avoid unnecessary loss of independence.

On behalf of AMD Alliance International

Stephen Winyard
Vice-Chairman
AMD Alliance International

Dr. Marijn Gelten
Chairman
Macula Degeneratie Vereniging



Section 1

Early Detection of AMD

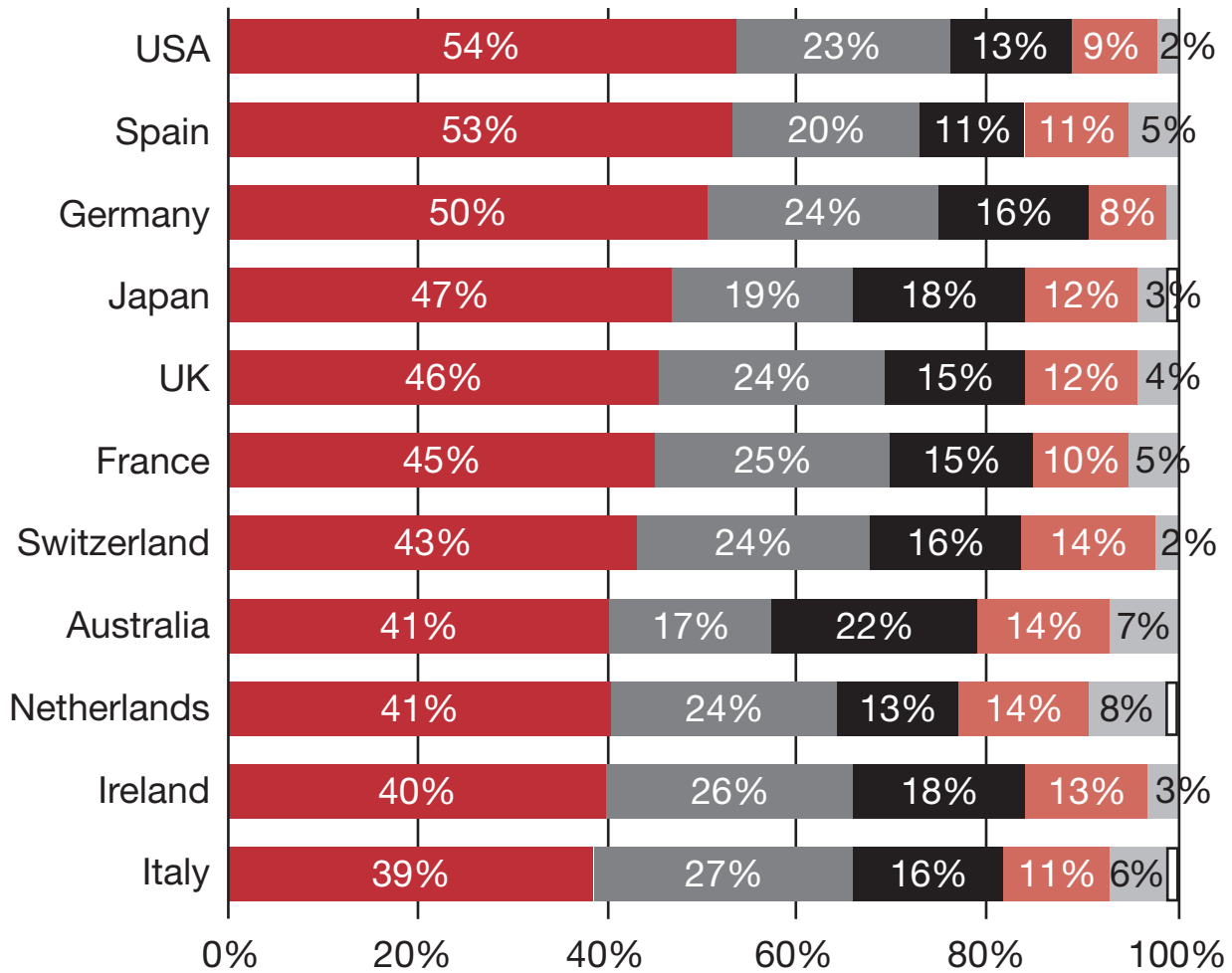
The Current Situation

Frequency of Eye Tests

Early detection of AMD requires regular eye examinations that go beyond the assessment of visual acuity and include eye health checks such as an inspection of the retina with an ophthalmoscope, inspection of the lens and glaucoma tests. This is particularly important for wet AMD which can cause a rapid deterioration of visual capacity leading to legal blindness within as little as three months. Changes to the macula can be detected at an early stage when surgical procedures are most successful in halting the progress of the disease.

The Gallup survey carried out on behalf of AMD Alliance International in the Netherlands in June 2003 revealed that 41% of respondents had their eyes tested in the previous year, 24% had their eyes tested within in the last 1-2 years, 13% within the last 2-5 years, 14% more than 5 years ago and 8% have never had their eyes tested. In terms of frequency of eye tests the Netherlands rank 8th out of the 11 countries surveyed and most significantly, the country has the highest percentage of people who have never had their eyes tested. It is therefore high time to act: based on these survey results it is clear that 35% of the population put their eye health at risk by failing to have their eyes checked at least once every two years. This figure could be even higher since the survey did not distinguish between different types of eye examinations. People who merely had their visual acuity tested before buying new glasses were included in the category of those who had had an eye test. Whilst opticians may suspect certain eye diseases and recommend a visit to an ophthalmologist a simple visual acuity test is not sufficient to detect the first signs of diseases such as AMD.

Figure 1. Frequency of Eye Tests – International Comparison



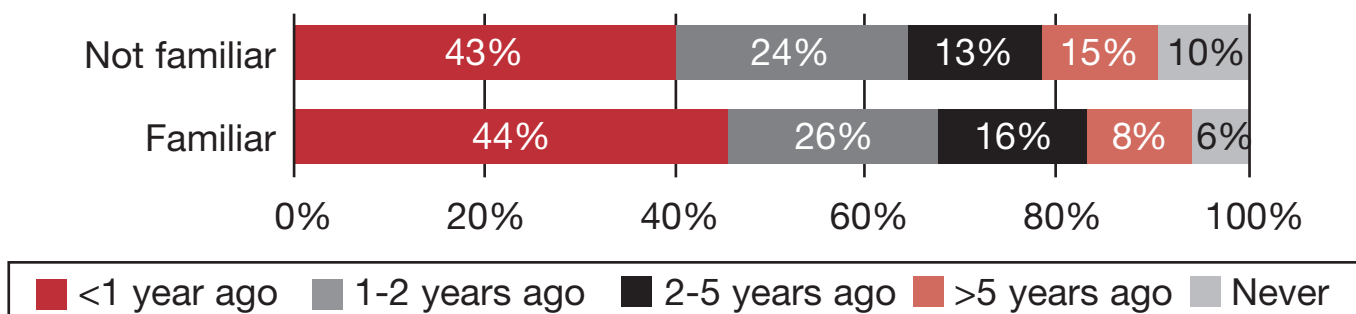
■ <1 year ago ■ 1-2 years ago ■ 2-5 years ago ■ >5 years ago ■ Never (DK/NA)

The frequency of eye tests seems to depend on the age of the respondent with people aged 55+ most likely to have had their eyes tested in the previous year (47%). Nonetheless, even in this age group the percentage of people who have not had their eyes tested in the last two years is 25%. People in the age group 18-24 are least likely to have had their eyes tested in the previous year (30%).

Significantly, awareness of AMD seems to have a positive impact on the likelihood of having had an eye test in the previous year, a result which confirms the importance of awareness raising measures to encourage people to have their eyes tested (See also section on "lack of awareness" page 10).



Figure 2. Frequency of Eye Tests – Awareness of AMD



Access to Regular Eye Examinations

In the Netherlands eye examinations are carried out by ophthalmologists, optometrists and opticians. However, opticians can only do refractive measurements, not eye health examinations such as optical pressure measurements.

Whilst optometrists were recognised as an independent profession by the Government in 2001 their recognition resulted in disputes between ophthalmologists and optometrists regarding the type of eye examinations optometrists are allowed to carry out. Although these have been resolved recently, the main problem is that services provided by independent optometrists are still not covered by health insurers. Thus, they are not an alternative for most people seeking ophthalmology appointments and are therefore unable to help tackle the problems of waiting times described below (p.12).

Costs of eye tests and specialist treatment

Eye tests carried out by an ophthalmologist or by an optometrist working for an ophthalmologist are free. Also, refractive measurements carried out by opticians and optometrists are free since they are usually linked to the purchase of glasses.

The costs of the eye tests are paid for by private or statutory health insurance. As a general rule higher income earners are insured privately whereas people on lower income are members of statutory health insurance schemes and pay a certain percentage of their salaries into the health insurance.

By contrast, eye tests are not covered by an individual's insurance where an optometrist does not work with an ophthalmologist or an optician.



The Challenges - Barriers to early detection of AMD

With 35% of the general population and 25% of those in the 55+ age group not having had their eyes tested in the previous two years early detection of AMD remains a major challenge. The first step towards identifying ways to address this problem is an analysis of the reasons why people fail to have their eyes checked on a regular basis.

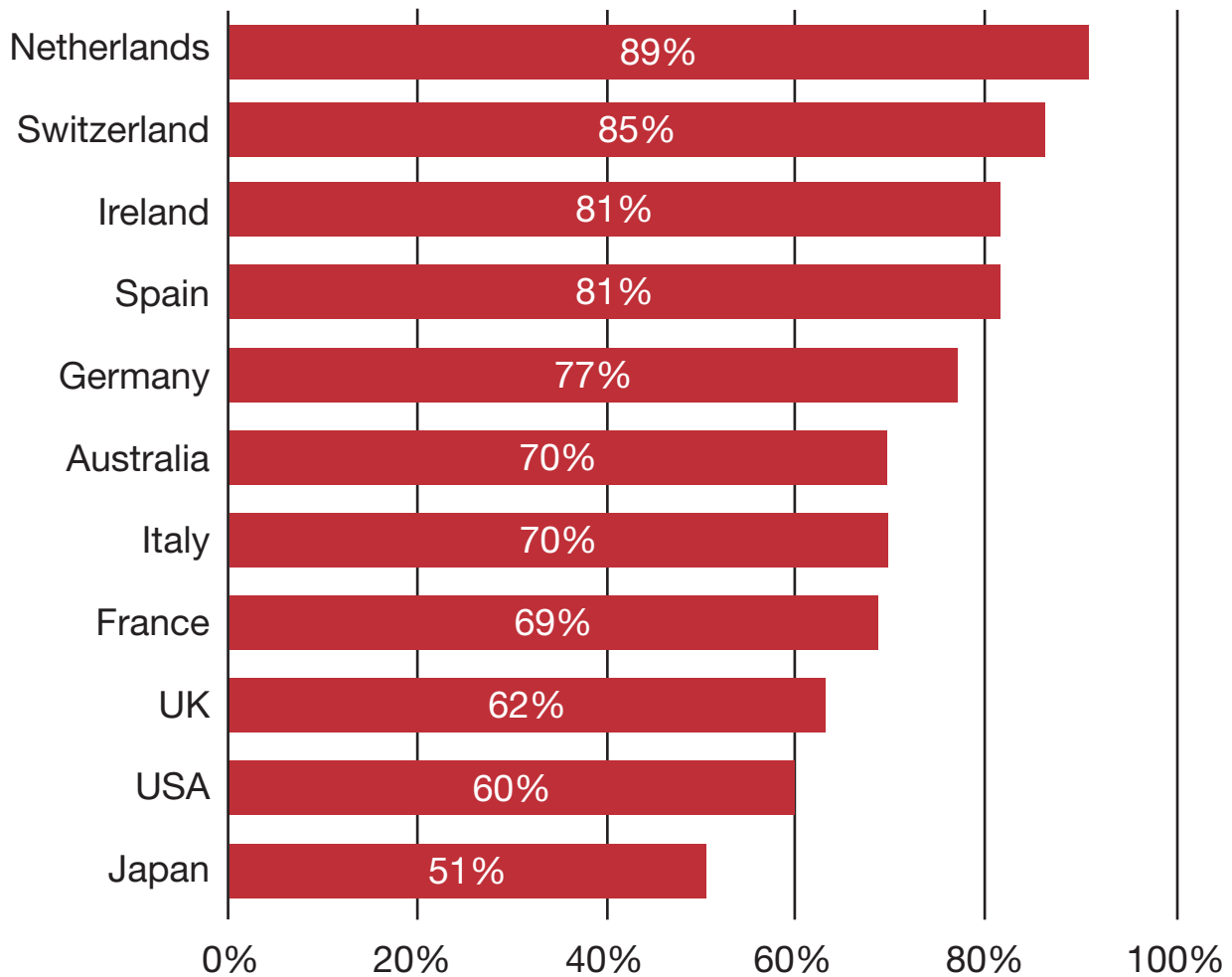
The main reasons discussed in the survey are:

1. Lack of awareness
2. Waiting times and
3. Costs.

Lack of Awareness

According to the Gallup survey the vast majority of respondents (89%) who did not have an eye test in the last two years indicate that their reason for not having one is that they "didn't have a problem with their eyes". However, respondents who cited this reason have either no solid basis for this defence as they have never had their eyes tested (24%) or, base their reasoning on an eye examination that they had more than two years ago (75%). In the Netherlands the link between subjective eye health and the frequency of eye tests seems to be particularly strong since the Netherlands has the highest percentage of people who have never had an eye test (8%) as well as the highest number of people who assume that there is nothing wrong with their eyes.

Figure 3. Reason for not having recent eye test: "didn't have a problem with eyes"

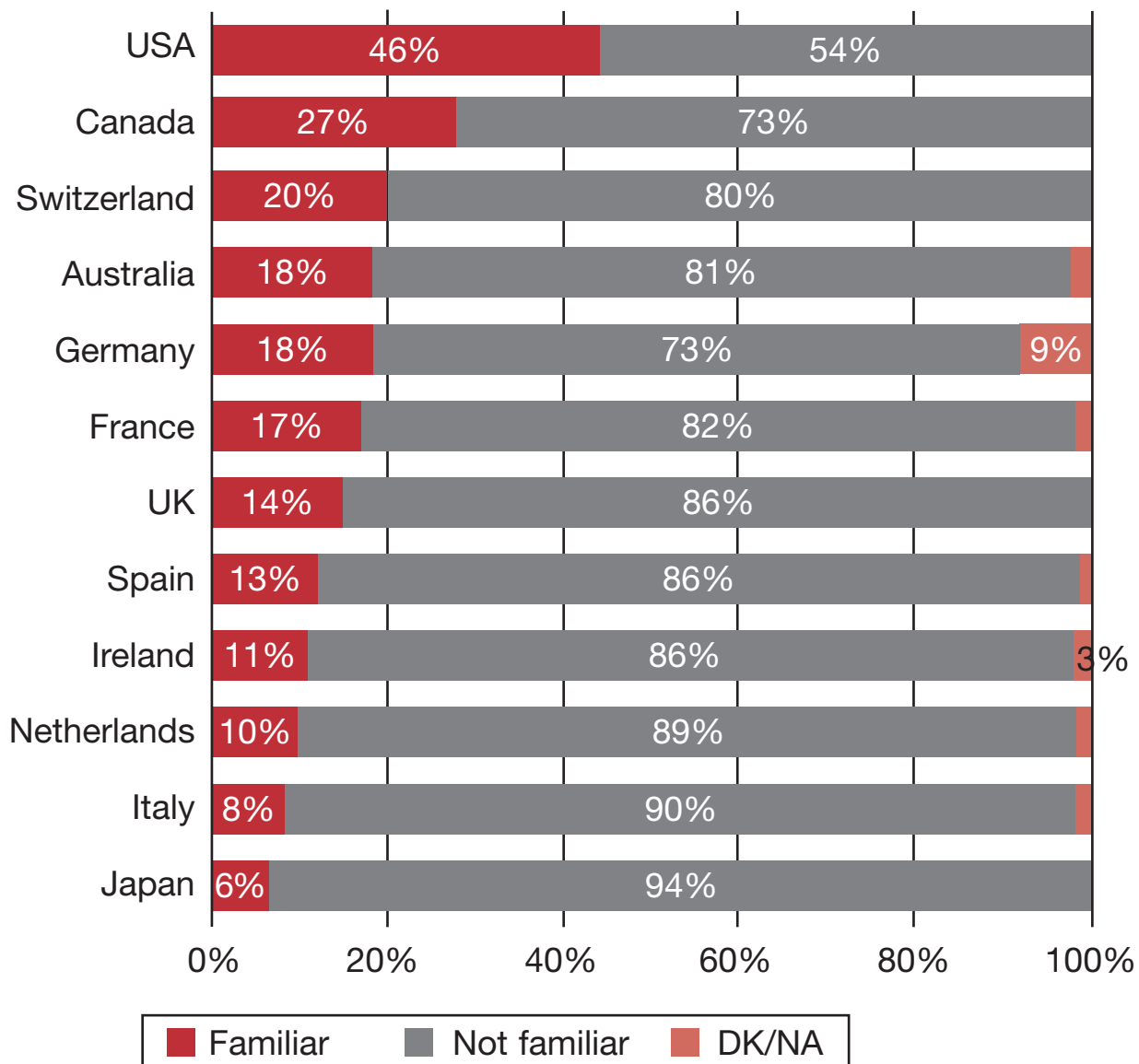


As in other countries, younger respondents ("18-24" and "25-39") and the more highly educated are particularly likely to give this reason for not having a recent eye test

Another interesting tendency is that those who are "not familiar" with AMD are more likely to indicate that they have not had a recent eye examination as they didn't have a problem with their eyes, compared to those who are "familiar" with AMD.

Lack of awareness therefore is a major problem. Those people who do not have their eyes tested regularly because they do not think that there is anything wrong with their eyes do not appreciate the importance of detecting the first signs of AMD before the onset of symptoms. According to the Gallup survey only 10% of Dutch respondents were familiar with AMD, 89% were not familiar and 1% did not know.

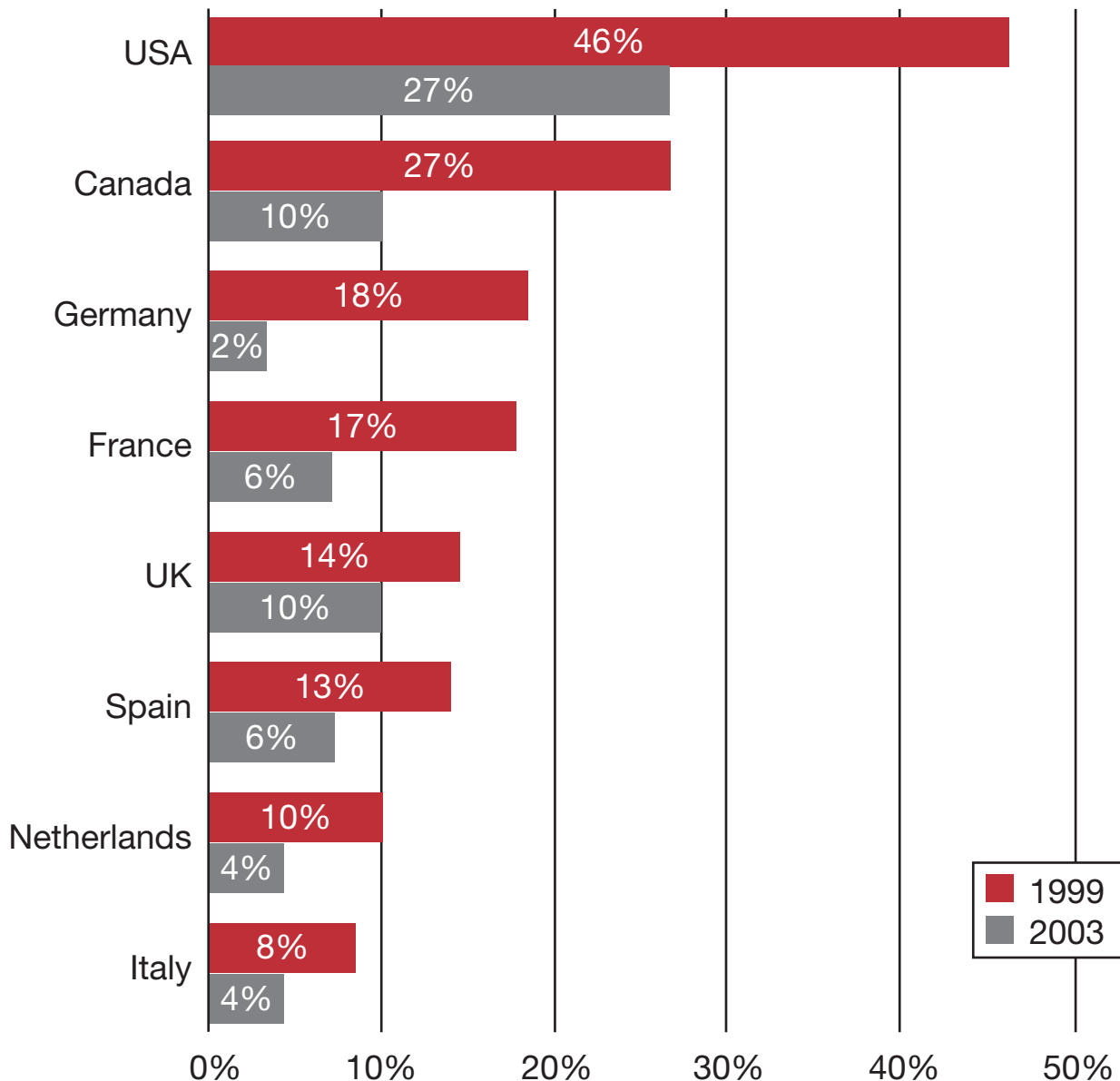
Figure 4. Familiarity with AMD



Whilst this amounts to an increase by 6% in comparison with an AMD Alliance survey carried out in 1999-2000 awareness of AMD remains at the lower end of the scale and needs to be addressed as a matter of urgency.



Figure 5. Increase in AMD Awareness



Waiting times

For emergency cases, it is possible to get a quick appointment with an ophthalmologist, directly or through referral from a general practitioner (Huisarts). However, as mentioned above patients currently wait three to six months for a routine ophthalmology appointment. This is the main reason why no efforts are made to encourage people aged 55+ to have their eyes tested on a regular basis. Increased awareness would lead to an increase in appointments with even longer waiting times thus defeating the purpose of ensuring a higher frequency of tests. Long waiting times may also explain the comparatively low number of people who have had their eyes tested in the past year (41%) and the high number of people (8%) who have never had their eyes tested.

It should be noted, however, that the Netherlands are not the only country facing problems with waiting times. For instance, waiting times of three months and more are not unusual in the Netherlands where an increasing number of ophthalmologists only accept private patients because of the low fees paid for routine eye examinations by statutory insurers. In France waiting times can be up to 10 months in rural areas whilst in Spain there are no waiting times for routine eye health checks but considerable waiting times for further investigative examinations.

Costs of Eye Tests and Specialist Treatment

Eye tests and specialist treatment are covered by the private and statutory health insurance. The Gallup survey confirms that in the Netherlands cost considerations are not a significant element that would deter people from having their eyes tested. Out of those people who had not had an eye test in the past two years only 1% said that the cost of glasses deterred them from having their eyes tested. This compares favorably with countries like the UK where 11% of respondents cited the cost of glasses as a deterrent and the US where the cost of glasses combined with the cost of eye tests is a deterring factor for 12% of respondents.

Hence, the main reason why people fail to have their eyes tested at regular intervals appears to be false assumptions about eye health in the absence of symptoms as well as long waiting times as explained above.

Section 2

Low Vision Rehabilitation

The Current Situation

The system of Low Vision Rehabilitation

Since there is no treatment for dry AMD people with the disease are faced with the challenge of learning to adjust to their progressive vision loss. People with wet AMD who were not diagnosed early enough to prevent rapid vision loss through medical treatment may have to face this situation within as little as three months of noticing changes to their vision. Adapting to this situation is a complex process which has a psychological as well as a physical dimension that requires a holistic approach and the co-operation of several specialists. In this report we concentrate on the provision of low vision devices that allow patients to maximise the use of any residual vision.



At the beginning of the 1990s the structures for the provision of rehabilitation services for visually impaired adults changed in the Netherlands. Previously, Het Loo Erf, a national institute, offered intramural multi-disciplinary rehabilitation services, vocational rehabilitation training was offered by a different national institute, Sonneheerdt, and low vision aids were provided by optometrists working in the ophthalmic departments of hospitals. There was a gap between the mono-disciplinary delivery of low vision aids by the optometrists and the intensive rehabilitation services provided by Het Loo Erf. To address this gap ten regional centres were established which started to offer multi-disciplinary out-patient rehabilitation services for visually impaired people.

As a result the number of people involved in delivering care for visually impaired people in the Netherlands has grown in the past years. There are approximately 400 ophthalmologists who are responsible for referring their visually impaired patients to the different care systems. About 170 optometrists are involved in administering low vision aids and approximately 150 people are active in 15 regional and 2 national centers. They are staffed by social workers, occupational therapists, psychologists, low vision specialists, and others [7].

Rehabilitation services in the Netherlands are thus provided by

- a) Low vision clinics in hospitals that provide low vision devices;
- b) Regional specialised rehabilitation centres which provide both low vision devices as well as ADL (activities of daily living) training. There are 15 low vision clinics which cover the whole of the country. These combine the services of ophthalmologists, optometrists and psychologists to assess the rehabilitation needs of visually impaired people. In these clinics rehabilitation is viewed in the widest sense, comprising the provision of vision aids, mobility training, training in ADL tasks as well as psychological support; and
- c) Two national specialised centres where patients undergo 3-4 months of rehabilitation training to learn special skills. These can be linked to professional activities as well as leisure pursuits and are not limited to people of working age.

Most patients with AMD visit low vision clinics in hospitals whilst roughly 10-20% of them attend one of the regional centres.

In general, opticians are aware of the different rehabilitation options. Finally, there are private companies that work with ophthalmologists in



ophthalmology departments in hospitals. A large number of hospitals in the Netherlands use these low vision specialists to assess the need for low vision devices in visually impaired people. However, these companies do not provide mobility or ADL training or psychological support.

Professional Standards for Low Vision Specialists

Most people involved in low vision services have a degree as optometrists. The degree course lasts 4 years and includes 80 hours of low vision rehabilitation. This part of the training is compulsory. In addition, optometrists can attend a two-month training course in low vision clinics to become low vision specialists. The only college providing this training is the Hogeschool van Utrecht which trains 40-60 optometrists a year. 10% of these do the additional training to become low vision specialists. The training is paid for by the Government. In addition, training in low vision rehabilitation is provided by companies selling low vision devices. The length of the training depends on the company. In this case the training is paid for by the company.

Access to Low Vision Services – Referral Pathways, Information on Availability

Access to rehabilitation services requires the referral by an ophthalmologist. If the ophthalmologist has referred the patient rehabilitation services are covered by the patient's health insurance.

The Cost of Low Vision Devices

In principle, the health insurance pays for low vision devices whereas ADL aids and white canes are not covered. CCTVs, telescopic lenses, Daisy players, computer software such as screen readers, etc. are covered by the health insurance regardless of the age or professional status of the patient.

People requiring low vision devices have to fill in a form which is then signed by the ophthalmologist and sent to the insurance with a request for the provision of the necessary low vision device. Under the law the insurance company is required to provide the cheapest, yet also the most suitable low vision devices.

The Challenges

Delays in Referring People to Low Vision Rehabilitation

The Macular Disease Society in the Netherlands frequently receives complaints about the time it takes for a low vision device to be fitted. It usually takes 4-6 weeks to get an appointment for a first assessment of the individual's



rehabilitation needs. Once the initial assessment has been made it takes another 4-6 weeks until a second appointment to obtain advice on the specific equipment needed. This is followed by the insurance claim so that it can take another 4-6 weeks until the low vision device is made available. It can therefore take up to 4½ months to get the necessary low vision device, a long time for somebody who is struggling with his vision loss and had to accept that the experienced vision loss is irreversible and his vision may even deteriorate further.

Once the low vision device is adjusted there is a follow-up after 6 weeks to ensure that it is used properly. This is the only follow-up provided.

Other Factors Affecting the Provision of Low Vision Services and Devices

As mentioned above insurers are obliged to provide the cheapest and most suitable low vision device available. Since this is a question of interpretation there are frequent disputes about the standard of the vision aid provided. In the case of magnifying glasses insurers usually provide the requested model. However, CCTV is an example where problems occur because most insurers provide the equipment on a loan basis. This means that patients rely to some extent on what equipment is in store at any given time. As a result not all patients can be provided with the latest model (for instance, they are given a black and white CCTV rather than a colour one). A lot depends on the way the request is justified. This is not an entirely satisfactory situation. However, it is not seen as a serious problem since patient requests are never rejected outright: a CCTV is provided even if it is not the latest model.

Section 3

Conclusion – Call for Action

Action line 1 – Early detection

If detected early some types of macular degeneration can be treated successfully. However, if not detected early it is these types of AMD that cause the most severe and most rapid vision loss. Eye checks for visual acuity at an optician's are not sufficient. Regular eye health checks, at least every two years and more frequently with growing age, are required to ensure the best chances of success.

In the Netherlands a large proportion of the population does not have regular eye health checks assuming that they do not need them unless they experience problems with their vision. This attitude fails to recognize that the first signs of



disease can be detected long before the first symptoms occur. Action is required to improve early detection of eye disease by encouraging people to have their eyes tested more regularly. However, the lack of ophthalmologists creates a considerable barrier towards achieving this aim. The recognition of optometrists as an independent profession is an important step in the right direction. However, their competences need to be defined more clearly and prophylactic eye tests need to be covered by insurers whether they are carried out by ophthalmologists or by optometrists. This would increase the number of professionals available to carry out eye health checks thus decreasing waiting times and the risk of eye diseases such as Age-Related Macular Degeneration going undetected.

Action line 2 – Low vision rehabilitation

The high quality of low vision rehabilitation provided in the whole of the Netherlands is undeniable. Services are based on a holistic approach provided by multi-disciplinary teams that take account of the different needs of each patient. However, with respect to the provision of low vision devices there is an urgent need to speed up procedures to ensure that patients are fitted with appropriate devices as quickly as possible. Waiting times of up to 4½ months can cause irrevocable loss of independence. This should be avoided through measures to streamline approval procedures and co-operation between ophthalmologists, rehabilitation specialists and insurers.

References

- [1] Bulletin World Health Organization, 1995 (73:115-121)
- [2] For details on AMD see annex 2 as well as our web-site (www.amdalliance.org)
- [3] EOS Gallup Europe (2003): "Eye tests, awareness & age-related macular degeneration". Survey conducted on behalf of AMD Alliance International.
- [4] Environics Research Group (2003): "Public Attitudes Toward Age-Related Macular Degeneration (AMD)". Survey conducted on behalf of CNIB / Novartis Ophthalmics.
- [5] [6] Population figures see: www.geohive.com; percentages of elderly people see: <http://unstats.un.org/unsd/demographic/social/youth.htm>
- [7] Jorritsma, F.F. (2000): "Dutch Society for Professionals Working on Rehabilitation in Case of Visual Impairment" http://www.eurosight.org/abstract_jor.html.



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 About Age-Related Macular Degeneration

AMD is the leading cause of severe vision loss (also known as legal blindness) for people over the age of 50 in the Western world. Some form of AMD affects approximately 25-30 million people and this number is expected to triple over the next 25 years, yet awareness of this eye disease remains low. Age-Related Macular Degeneration (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 or driving. 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. There are 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 (approximately 10% 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.

Useful Addresses and Links

Macula Degeneratie Vereniging
PO Box 2034
3500 GA Utrecht
Tel: +31.30.298.0707
E-mail: mdvereniging@sb-belang.nl
Website: www.mdvereniging.nl
M.J.Gelten@tue.nl

Federatie Slechtzienden- en Blindenbelang
Postbus 2062
3500 GB UTRECHT
Tel: +31.30.299.2878
Fax: +31.30.293.2544
E-mail: info@sb-belang.nl
Website: www.sb-belang.nl

For more information on the AMD Alliance International please visit our website:
www.amdalliance.org or

Contact our European Co-ordinator:

Barbara McLaughlan
9 Ardshiel Drive
Redhill RH1 6QN
UK
Tel: +44.1737.766988
Fax: +44.1737.770739
e-mail: bmclaughlan@btinternet.com

