

Is Diabetic Eye Screening Beneficial? – A Patient's Perspective

Introduction

Diabetes Mellitus (commonly known as Diabetes) is a lifelong condition which affects all age groups, defined as a group of metabolic diseases caused by an excess of blood glucose (blood sugar). This is because of the insufficient production of the pancreatic hormone insulin (Type 1 Diabetes), or because the body's cells do not respond properly to insulin (Type 2 diabetes) (See Appendix 1), or both (National Institute of Diabetes and Digestive and Kidney Diseases 2016; Diabetes UK 2018a).

At present, there are almost 3.8 million people in the UK diagnosed with diabetes and predictions state that around 600,000 people have yet to be diagnosed. This equates to 1 in every 20 people having undiagnosed or diagnosed diabetes (Diabetes UK 2018b). Diabetes is very costly to the National Health Service (NHS). Currently, £10 billion each year or 10% of the NHS budget is spent on diabetes (Diabetes Digital Media Ltd 2018; Diabetes UK 2018b). The high costs of diabetes are mainly from the chronic/acute complications that arise with the condition (Diabetes UK 2018c) (See Appendix 2).

These high costs are set to get worse as current trends suggest that the prevalence of Type 2 diabetes (90% of the population diagnosed) could increase to 5 million by 2035 (Roberts 2018). The best ways to reduce these high costs are prevention of Type 2 diabetes such as healthier lifestyle changes as recommended by NICE (National Institute for Health and Care Excellence 2017) and for those diagnosed with diabetes, 15 essential annual health checks (See Appendix 3) as illustrated by Diabetes UK.

The author knows the checks required in order to maintain a healthy lifestyle and longevity in preventing complications with having Type 1 diabetes. One of these checks includes having your eyes screened for signs of diabetic retinopathy. Diabetic retinopathy is a complication of diabetes which arise as a result of high blood glucose levels which can damage the tiny blood vessels that supply the retina, if damaged, then this can lead to vision loss or blindness (NHS [no date]) (See Appendix 4).

In 2003, the four nations of the United Kingdom were the first countries in the world to introduce a systematic national diabetic eye screening programme, which was announced in the 2003 Delivery Strategy for the National Service Framework for Diabetes. By 2008, local eye screening programmes covered the whole country and was offered to all people diagnosed with diabetes aged 12 and over, as part of an essential healthcare requirement (Harris 2012; Scanlon 2017).

The aim of the National Diabetic Eye Screening Programme (NDESP) is to reduce the risk of preventable sight-loss from diabetic retinopathy (Scanlon 2008). There was a logical reason behind the implementation of the programme as diabetic retinopathy was the most common cause of sight-loss in the UK amongst people of working age (Fight for Sight 2015). Data was captured which illustrated that the incidence of sight-loss and certification of blindness due to diabetic eye disease was 1.99 per 100,000 population in 1991. By 2000, this had increased to 3.84 per 100,000 population (Bunce and Wormald 2006). With the incidence almost doubling in size, this gave a plausible reason for implementing the national diabetic eye screening programme because UK data had suggested almost a doubling in incidence of childhood onset Type 1 diabetes between 1966 and 2000 (Harvey 2003), and the prevalence of Type 2 diabetes was increasing as obesity or being overweight being singled out as the most predictive factor (De Lusignan et al. 2005).

In this study, the author's primary aim was to get a patient's perspective in to diabetic eye screening to see if they thought it was beneficial to them. The study also asked about a patient's diabetes management, if any changes had been implemented since starting to attend eye screening and whether they had been referred to a hospital eye service (HES) from eye screening. The answers provided would hopefully highlight any problems, bring suggestions or compliment the service.

Method

In order to obtain a patient's perspective to see if diabetic eye screening is beneficial, a population-based cohort study was conducted using diabetic patient's aged 12 and over. The study consisted of a series of questions in a survey (See Appendix 5) which was distributed between 7 diabetic eye screening programmes (See Table 1) and the author's local ophthalmology department. The author previously worked in diabetic eye screening and these programmes were chosen in order to benefit from the close professional links developed by the author during this time, thereby providing additional support and ensuring success of the study.

| |
|---|
| Sunderland and South Tyneside DESP |
| East Sussex DESP |
| West Sussex DESP |
| Birmingham, Solihull and Black Country DESP |
| North and East Devon DESP |

| |
|----------------------------------|
| North West Manchester DESP |
| East Yorkshire (The Humber) DESP |

Table 1 – The 7 diabetic eye screening programmes used in the study

According to the National Audit Office (2001), a reasonable sample size of 50 - 100 should provide adequate results. In the author's opinion, this didn't warrant sufficient, comparable to the amount of people with diabetes as larger samples would allow detecting smaller differences (Fryrear 2016). Each of the diabetic eye screening programmes received 100 surveys which were distributed by retinal screeners during their clinics. The exception was East Yorkshire (The Humber) where the surveys were undertaken by a nurse practitioner who specialises in diabetes, and only sees a small number of patients once a week, so was given 50 surveys. The surveys were distributed and collected over a 3 month period from June to September 2018.

The survey consisted of 6 questions with no patient identifiable information asked for. This was to anonymise the patient in accordance with the Data Protection Act (1998). The questions were designed so the respondent would avoid giving leading answers, but allow for a quantifiable and coherent set of results using a *Yes* or *No* response based around the study. Of the 6 questions, questions 1 to 5 were used in the study analysis whereas question 6 was not. The reason being that it was an open question which would not give numerical figures compared to a *Yes* or *No* answer from questions 1 to 5. .

Upon completion, the surveys were separated into 15 year age groups, in order to make analysis easier to interpret, apart from the first group which was 13 years, for example; 12 – 25, 26 – 40 etc. This was because eye screening starts at age 12. The results were collated into a series of tables and graphs through Microsoft Excel software.

Results

There were a total of 750 surveys distributed between the 7 eye screening programmes and the author's local ophthalmology department. A total of 648 surveys were returned and of those, 70 were made void due to either being incomplete or incorrectly filled in. This left a total of 578 surveys for analysis.

Question 1

From the 578 patients, this question was used to identify the age of the patient, their gender and the year they were diagnosed with diabetes. The age of the patients were separated in to different

age groups, along with the total number from each age range as illustrated in Table 2. The youngest participant was aged 16 and the oldest participant was aged 94 with the *mean* age shown in brackets for each age group.

| Age Range (Mean) | Total number of patients |
|------------------|--------------------------|
| Age 12 – 25 (20) | 18 |
| Age 26 – 40 (33) | 43 |
| Age 41 – 55 (48) | 132 |
| Age 56 – 70 (63) | 221 |
| Age 71 – 85 (78) | 147 |
| Age 86+ (90) | 17 |
| TOTAL | 578 |

Table 2 - Age range (Mean) and total number of patients in each group

There was a total of 322 males (55.71%) and 256 females (44.29%) in the gender ratio as illustrated in Figure 1. The year of diagnosis ranged from as far back as 1968 up until 2017.

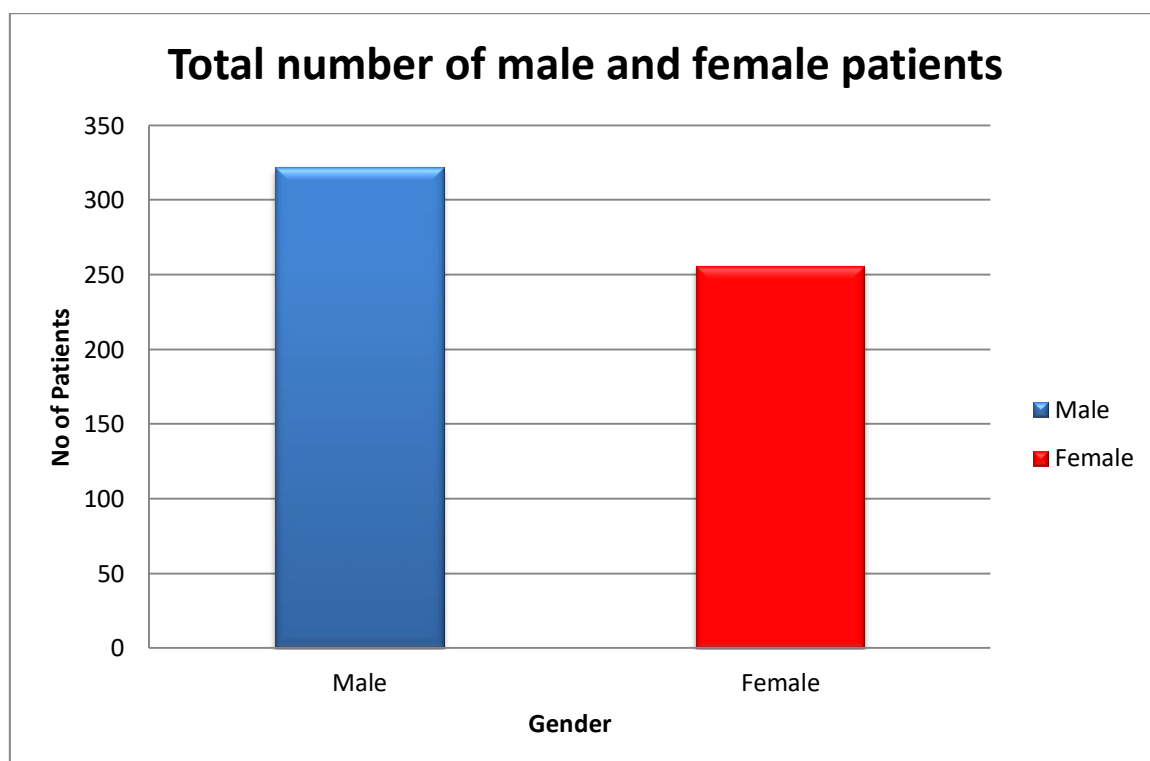


Figure 1 – Total number of male and female patients

Question 2

564 (97.6%) patients thought diabetic eye screening was beneficial and 14 (2.4%) patients did not (See Table 3). Figure 2 shows the patients responses to question 2.

| Age Range | Yes | No | Total |
|--------------|------------|-----------|------------|
| Age 12 - 25 | 16 | 2 | 18 |
| Age 26 – 40 | 42 | 1 | 43 |
| Age 41 – 55 | 130 | 2 | 132 |
| Age 56 – 70 | 218 | 3 | 221 |
| Age 71 – 85 | 143 | 4 | 147 |
| Age 86+ | 15 | 2 | 17 |
| TOTAL | 564 | 14 | 578 |

Table 3 – Do you think diabetic eye screening is beneficial?

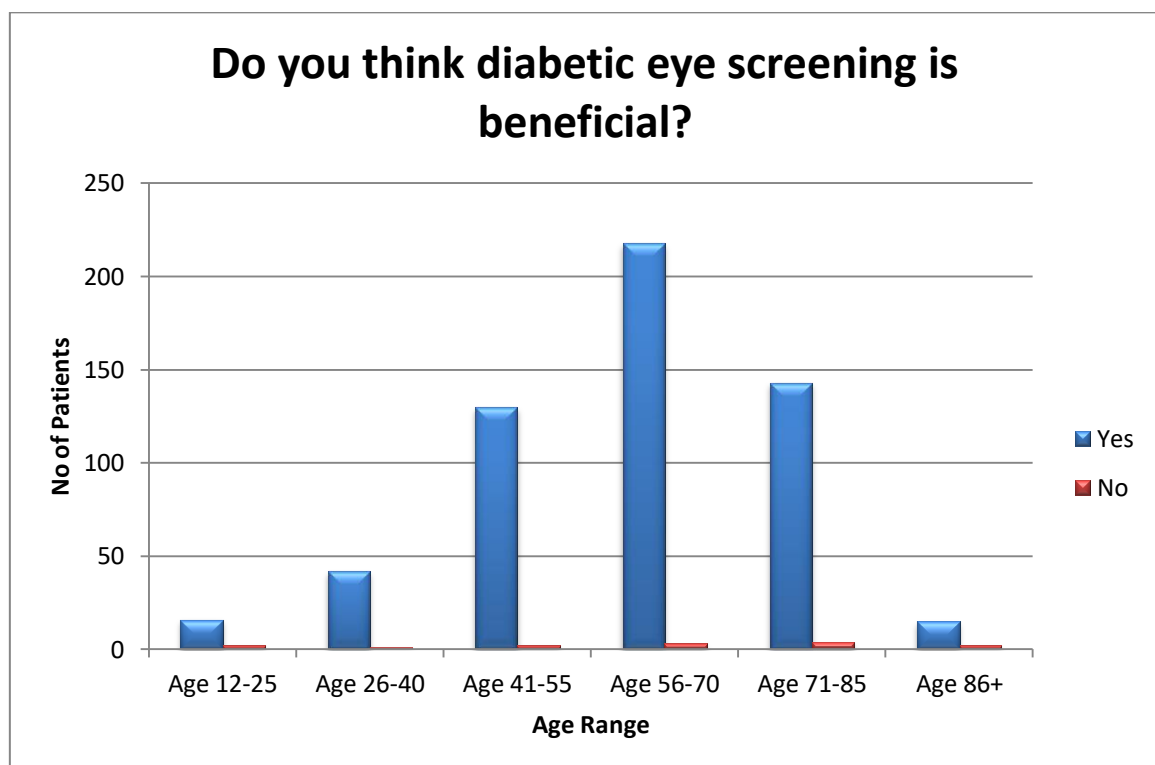


Figure 2 – Patient's responses to question 2

Question 3

510 (88.2%) patients thought diabetic eye screening gave them confidence in the way they manage their diabetes and 68 (11.8%) did not (See Table 4). Figure 3 shows the patients responses to question 3.

| Age Range | Yes | No | Total |
|--------------|------------|-----------|------------|
| Age 12 - 25 | 14 | 4 | 18 |
| Age 26 – 40 | 35 | 8 | 43 |
| Age 41 – 55 | 117 | 15 | 132 |
| Age 56 – 70 | 199 | 22 | 221 |
| Age 71 – 85 | 131 | 16 | 147 |
| Age 86+ | 14 | 3 | 17 |
| TOTAL | 510 | 68 | 578 |

Table 4 – Does eye screening give you confidence in the way you manage your diabetes?

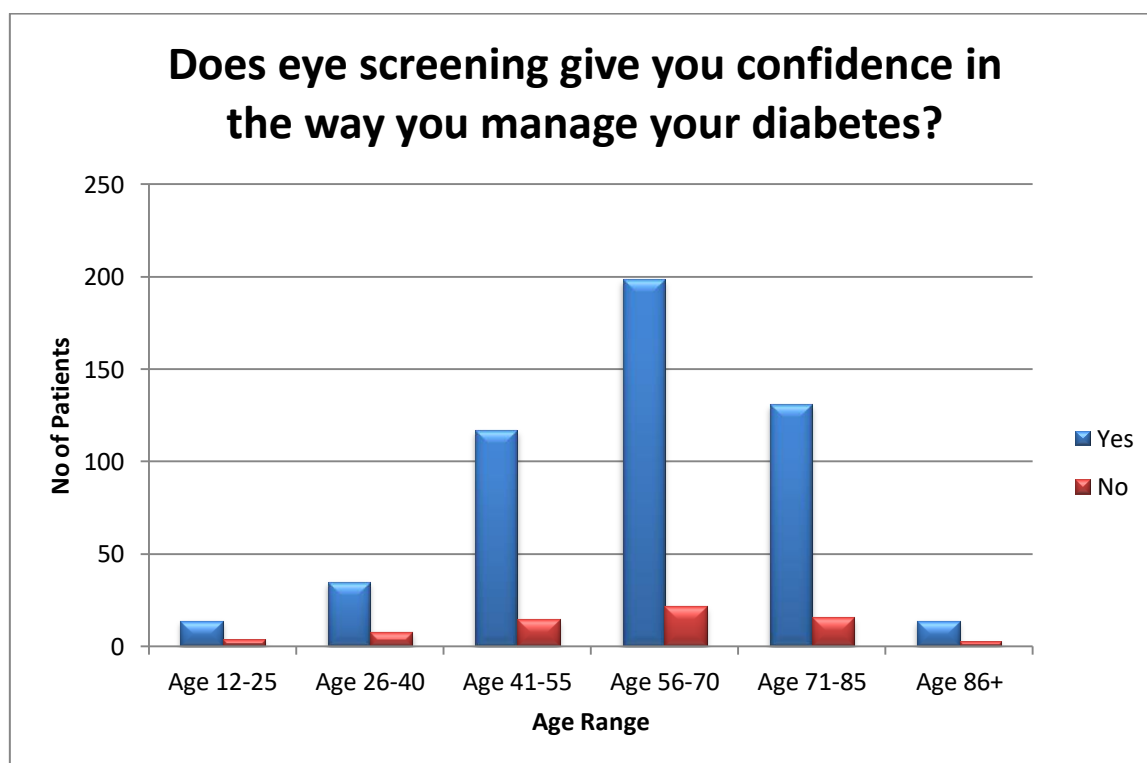


Figure 3 – Patient's responses to question 3

Only 147 (25.4%) patients had noticed any changes to the eye screening service since they first started attending whilst 431 (74.6%) had not (See Table 5). Figure 4 shows the patients responses to question 4.

| Age Range | Yes | No | Total |
|--------------|------------|------------|------------|
| Age 12 - 25 | 2 | 16 | 18 |
| Age 26 – 40 | 14 | 29 | 43 |
| Age 41 – 55 | 37 | 95 | 132 |
| Age 56 – 70 | 60 | 161 | 221 |
| Age 71 – 85 | 34 | 113 | 147 |
| Age 86+ | 0 | 17 | 17 |
| TOTAL | 147 | 431 | 578 |

Table 5 – Have you noticed any changes to the eye screening service since you first started attending?

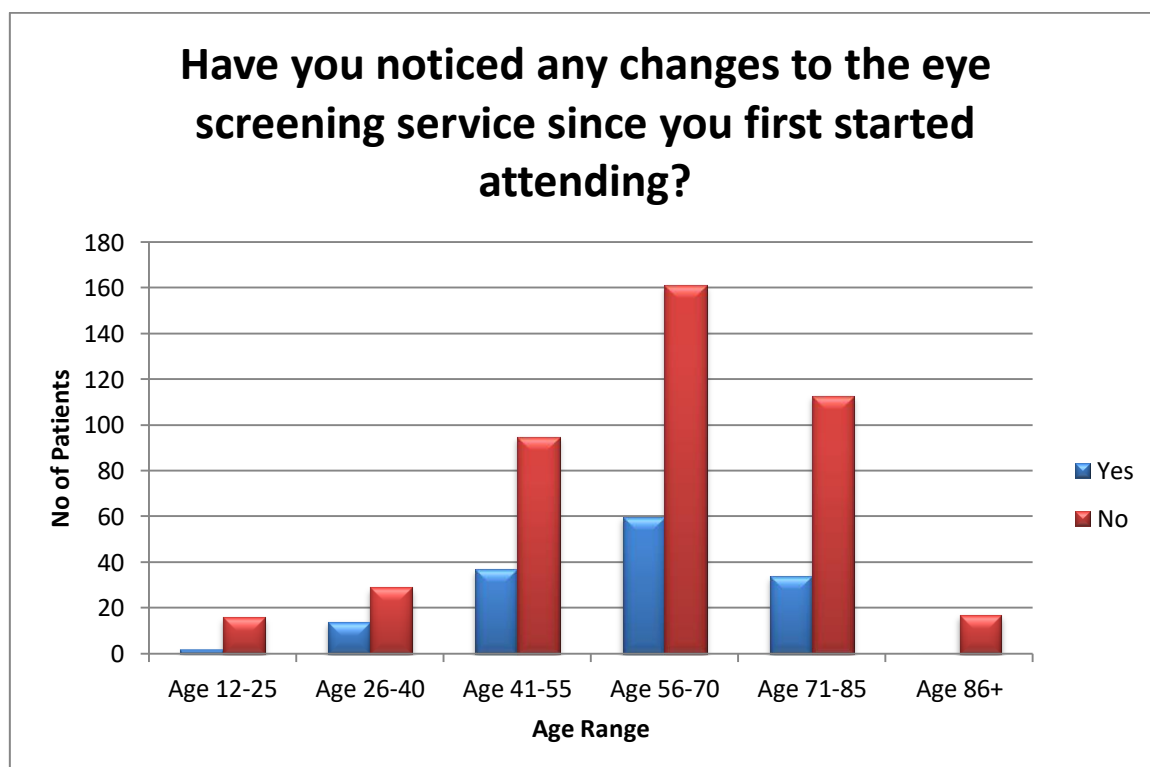


Figure 4 – Patient's responses to question 4

Question 5

A total of 152 (26.3%) patients had been referred to the hospital eye service from eye screening and 426 (73.7%) had not (See Table 6). Figure 5 shows patients responses to question 5.

| Age Range | Yes | No | Total |
|--------------|------------|------------|------------|
| Age 12 - 25 | 1 | 17 | 18 |
| Age 26 – 40 | 23 | 20 | 43 |
| Age 41 – 55 | 48 | 84 | 132 |
| Age 56 – 70 | 46 | 175 | 221 |
| Age 71 – 85 | 33 | 114 | 147 |
| Age 86+ | 1 | 16 | 17 |
| TOTAL | 152 | 426 | 578 |

Table 6 – Have you ever been referred to the hospital eye service from eye screening?

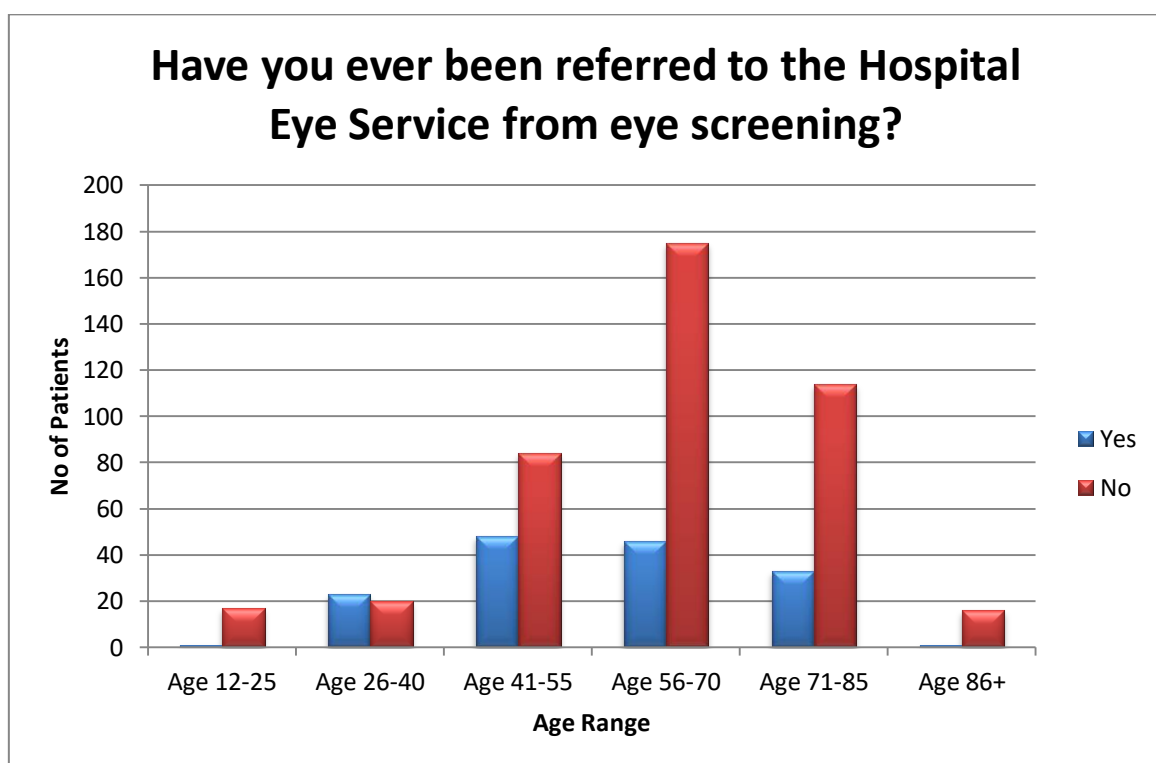


Figure 5 – Patient's responses to question 5

Discussion

With the NDESPs primary aim of reducing preventable sight-loss or blindness from diabetic retinopathy, it is important that a national programme which has been running for 15 years proves

successful. The recognition for the programme's success was officially announced by Public Health England (2014) which stated in a press release that "Diabetes no longer leading cause of blindness thanks to screening".

Looking at the results from the survey, question 2 of the study identified that 564 (97.6%) of patients found diabetic eye screening beneficial, which suggests that patients want to preserve their eye sight and supports the evidence from the success of the national programme. A recent retrospective audit, which was from one area of an English diabetic eye screening programme revealed that, there was a reduction in certifications of people with Serious Sight Impairment (SSI) or blindness with the principal cause of diabetic retinopathy. Between August 2005 and July 2008, 16 people were registered with SSI or blindness (annual rate 25.4 per 100,000 with diabetes) with a further 26 registered with Sight Impairment (SI) or partially sighted (annual rate 41.3 per 100,000 with diabetes). Between April 2014 and March 2017, there were 2 notifications of SSI or blindness (annual rate 2.0 per 100,000 with diabetes) and 10 notifications of SI or partially sighted (annual rate 10 per 100,000 with diabetes) (Aldington et al. 2018).

The evidence from the comments made in the survey identified that the benefit of eye screening was to preserve and prevent deterioration of their eyes. Any changes could be treated early minimising the risks of diabetic retinopathy progressing (See Appendix 4). Any changes that do occur go un-noticed by a patient as the author can confirm. One comment made by a patient stated "I would not have known there were problems with my eyes without having diabetic eye screening" (Survey 1 2018).

Furthermore, one patient commented by stating "Why would it be done if it is of no benefit!" (Survey 2 2018). In the author's opinion this clarifies the importance of being able to see as losing your vision could bring varying degrees of suffering, not only in terms of not been able to see everyday objects, but could mean a complete change in lifestyle which may impede a degree of psychological suffering such as depression. Of the five senses possessed by humans, sight has always been considered the most important (De Leo et al. 1999).

In spite of this, 14 (2.4%) of patients did not find diabetic eye screening beneficial. From these 14 patients, only 9 (64.29%) made comments explaining their answers. Some stated that they attend an optician who takes retinal images so do not understand why they have to attend both, 3 patients attend their local hospital eye service for other reasons with one stating that "...waste of time and money going to 3 places (optician, eye screening and hospital eye service)" (Survey 3

2018). Another patient stated that they have had the same results for the past few years and does not know why they have to keep attending. This leads the author to question how much information patients receive regarding the importance of diabetic eye screening.

Many patients acknowledge the awareness that diabetes can lead to eye disease but these statements suggest that there may be a gap between this knowledge and an understanding in the purpose of diabetic eye screening (Hartnett 2005). Furthermore, this could also suggest that patients who are not experiencing any visual problems assume that they have no diabetic eye disease present (Hipwell et al. 2014). In addition to this, a new study by Diabetes UK asking patients with diabetes about their top four health concerns resulted in only 60% with Type 1 diabetes and 45% with Type 2 diabetes see their condition as a serious/top health concern, suggesting that patients do not understand the seriousness of their condition (Aldridge 2018).

Education and the understanding of a health condition enable people to look after themselves in order to fulfil and manage their life. In the survey, question 3 asked whether diabetic eye screening gives confidence in the way they manage their diabetes. 510 (88.2%) of patients agreed that their eye screening helped them manage their diabetes. The top comments stated that it gave people confidence because they were in control of their diabetes. The results from their annual screening provided markers if there were any changes to the blood vessels. It allowed patients to change their lifestyle for better control as it is a reminder of the consequences of poor diabetes control with one patient stating; "I missed eye screening appointments for years and not caring in my twenties...now I attend regular as it picked up bleeds which made me change my lifestyle" (Survey 4 2018).

However, 68 (11.8%) of patients did not believe that eye screening gave them confidence in their diabetic control. 44 (64.71%) of the 68 patients made comments with various reasons stating being too old to worry, makes no difference as do not feel anything, other factors to consider and not sure how screening has a bearing on managing diabetes, I depend upon the doctors/nurses for confidence to one patient quoting; "...just shows if eyes are affected" (Survey 5 2018). Diabetes does not just affect the eyes, it affects the whole body, and it is a blood vessel disease that is symptom-free, until late. It is not an eye disease in isolation (Wilkinson 2016).

The author questions the comments made by the number of patients who said 'no' to questions 2 and 3, which could suggest that there is lack of understanding of the disease, the complications that can arise from poor control and the seriousness of the condition, be it Type 1 or Type 2. The

author knows that there are diabetes education courses available (See Table 7) as they help you take control, understand the condition and make living easier with diabetes to reduce the risk of complications.

| | |
|---|---|
| DAFNE (Dose Adjustment For Normal Eating) | For people with Type 1 diabetes which teaches how to estimate the carbohydrates in each meal and inject the right dose of insulin, so you can fit diabetes into your own lifestyle. |
| DESMOND (Diabetes Education & Self-Management for Ongoing & Newly Diagnosed) | For people with Type 2 diabetes which helps you understand your diabetes, make food choices and take control. |
| BERTIE | This is an interactive online course for people with Type 1 diabetes which helps you to understand and manage your diabetes in a way that is right for you. |
| X-PERT | For people with Type 2 diabetes which explores how diabetes affects your body and how lifestyle changes can help manage diabetes. |

Table 7: Diabetes education courses available

(Source: Diabetes UK. 2018. *Diabetes education: knowing more about your condition*. Available at: <https://www.diabetes.org.uk/guide-to-diabetes/managing-your-diabetes/education> [Accessed: 22 October 2018].)

The author suggests that people should be strongly encouraged to attend these courses with more help from clinical healthcare professionals, which could significantly reduce the already heavy burden of costs to the NHS. From the £10 billion of the NHS budget already been spent on diabetes, 80% of that finance is spent on treating complications which equates to £25,000 every minute (Diabetes Digital Media Ltd 2018; Diabetes UK 2018b). These figures could indicate that the longer you live with diabetes, the worse the condition will be or could more be done. As people's life-expectancy increases then this could bring burdens such as more diabetes complications arising, but also brings solutions (Stuart-Hamilton 2013) with enhanced medical interventions such as continuous glucose monitors and insulin pumps (Diabetes UK 2018d) which could define these high costs.

In an ever-changing world where technological advances move very quickly, question 4 asked whether patients had noticed any changes to the eye screening service since they started

attending. From the results, 147 (25.4%) had noticed changes whilst 431 (74.6%) had not. The top answer was equipment change. In conversation with local diabetic eye screening programme manager (Name with-held 2018) who stated:

“Moving from Polaroid (See Appendix 6) and film technology to digital made the service more streamlined. Digital is quick and instant whereas with Polaroid, you had to wait for the image to develop before sending the patient away. At the time, we could only take one 45° image of the macular (See Figure 6) but now we take two images which includes a nasal view (See Figure 7). It was very expensive as Polaroid was around £8 for a pack of 10 which only equates to 5 patients. And if anyone blinked then you were using more materials. With 35mm film you had a two week wait for it to get developed and you just used the photographs to grade the retinopathy”.

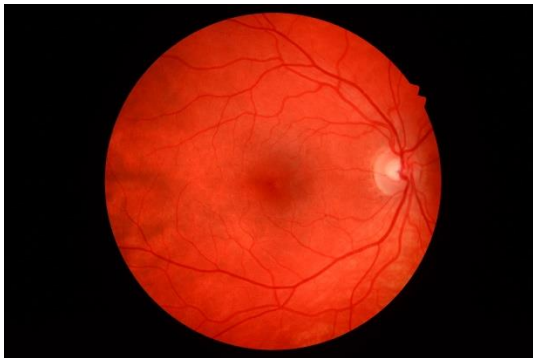


Figure 6: 45° macular view



Figure 7: 45° nasal view

The author questions the limitations of film by just taking one image as there could be other signs of diabetic retinopathy in areas not shown on a single image. This could potentially lead to sight problems in the peripheral regions of the eye. In a recent study looking at taking extra images during screening estimated that 10% of patients would not have been referred to the hospital eye service for proliferative retinopathy (Mann et al 2018). The author suggests that although 2 images are taken during screening, it should be down to the knowledge and experience of the screener to be able to take extra images if he/she notices sight-threatening pathology. This would allow the patient to be seen and treated more efficiently and quickly to reduce the risks of progression from diabetic retinopathy. The author knows that the cameras do have facilities to be able to create a 9 field mosaic style image (See Figure 8) which would allow more of the eye to be viewed.

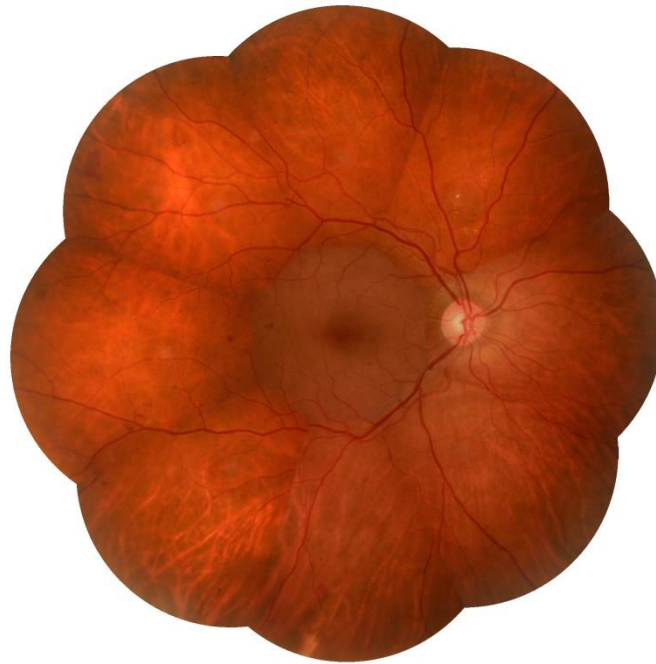


Figure 8: 9 field mosaic style image

Some of the other changes that had been noted was the service appeared more efficient which included more convenient appointment times including weekends and the screening procedure is more in depth, as some programmes incorporate a podiatrist and dietician check which suggests that the service are tailored towards the patients and gives confidence.

With diabetic retinopathy being the main reason for referrals to the hospital eye service (HES), there are occasions where other eye conditions may be picked up. In question 5 which asked if patients had been referred to the HES from eye screening, 152 (26.3%) patients had and 426 (73.7%) patients had not. 147 (96.7%) patients had been referred for diabetic retinopathy whilst 5 (3.3%) of the 152 patients had been referred for other eye conditions which included glaucoma, age-related macular degeneration, cataracts and arterial emboli. A further example includes the author's local DESP whose figures stated that from April 2017 to March 2018, 1,146 (1.8%) of patients from a cohort of 63,250 were referred to the HES with 48 (4.2%) patients referred for other eye conditions (DESP Manager, Name with-held 2018). With these low figures from a large cohort for referrals for diabetic retinopathy (1098 – 1.7%) from one DESP, only enhances the importance of eye screening. In the author's opinion, this suggests that the NDESP is not only protecting and preserving patient's eyes from diabetes but helping towards maintaining their sight from the various eye conditions that people may develop as they get older.

With the success of reducing the leading cause of blindness from diabetes, the author questions what the future holds for diabetic eye screening. This was question 6 of the survey although was not used in the analysis of the study. The results from this question were poor and not many responded (108 patients – 18.8%) with answers. From those that did, the top answers were about keeping the screening programme going and if more finance would be available, with 2 patients suggesting if computer automation would be applied.

Artificial Intelligence (AI) plays a huge part in today's modern automated world where computer based machines perform tasks normally performed by humans; for example, self-driving cars and aircraft with automatic landing (Duncan 2016; SAS Institute 2018). In diabetic eye screening, automated retinal image analysis has been established and is already in use in Scotland (Black 2016) to detect diabetic retinopathy. Results from a study concluded that automated grading gave acceptable sensitivity and specificity (terms used for grading quality) for referable retinopathy (Duncan 2016). The author suggests that automated grading may be beneficial for the patient as it may improve the manner to which diabetic eye care is provided by allowing a more streamlined efficient service so results are sent out quickly and treatment times could be reduced.

However, the author queries if the images are of poor quality from a severe cataract, would the automated device still provide an accurate result or would human intervention be required. This could delay the process of the results getting to the patient which could bring on anxiety.

The UK National Screening Committee has been looking in to extending the current annual screening to two yearly for diabetics at low risk of sight-loss (Public Health England 2016). In the author's opinion, this could bring the benefit for diabetics by providing a target to improve their lifestyle and get a clear retinopathy result which would significantly enhance the patient's wellbeing and health.

Limitations

The size and sample of this pilot study has to be representative of the target study population but with 3.8 million diabetics, the study would take months or possibly a year or two to complete, and has to be large enough to provide sufficient information about the aspects that are been assessed. The results from this study were extremely positive but further research could show more variation about the benefits of diabetic eye screening by using the whole of the UK.

Conclusion

To conclude, one patient quoted “Without diabetic eye screening, I would have gone blind” (Survey 6 2018). This study has provided insights of diabetic eye screening by illustrating how the benefits have saved deterioration of eye problems, has shown that education needs to be addressed to patients in order to fully understand the seriousness of the condition and reduce the costs of treatment, and with improved technology, may provide a more cost effective streamlined service.

(3542 words)

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Images

Verbal consent was obtained for Figures 6 and 7 as it was the author's work colleague who allowed the images to be used. No consent was required for Figure 8 as it was the author's eye.

Appendices

Appendix 1: Different types of diabetes and what they are

| Types of Diabetes | What is it? |
|---|--|
| Type 1 | Your body attacks the cells in your pancreas that make insulin, so you can't produce any insulin at all. |
| Type 2 | The insulin your pancreas makes can't work properly, or your pancreas can't make enough insulin. |
| Gestational | Gestational diabetes is a type of diabetes that affects pregnant women, usually during the second or third trimester. Women with gestational diabetes don't have diabetes before their pregnancy, and after giving birth it usually goes away. |
| Maturity onset diabetes of the young (MODY) | MODY is a rare form of diabetes which is different from both Type 1 and Type 2 diabetes, and runs strongly in families. MODY is caused by a mutation (or change) in a single gene. If a parent has this gene mutation, any child they have, has a 50 per cent chance of inheriting it from them. If a child does inherit the mutation they will generally go on to develop MODY before they're 25, whatever their weight, lifestyle, ethnic group etc. |
| Neonatal | Neonatal diabetes is a form of diabetes that is diagnosed under the age of six months. It's a different type of diabetes than the more common Type 1 diabetes as it's not an autoimmune condition (where the body has destroyed its insulin producing cells). |
| Wolfram Syndrome | Wolfram Syndrome is a rare genetic disorder which is also known as DIDMOAD syndrome after its four most common features (Diabetes Insipidus, Diabetes Mellitus, Optic Atrophy and Deafness). |
| Alström Syndrome | Alström Syndrome is a rare genetically inherited syndrome which has a number |

| | |
|--|---------------------|
| | of common features. |
|--|---------------------|

Reference

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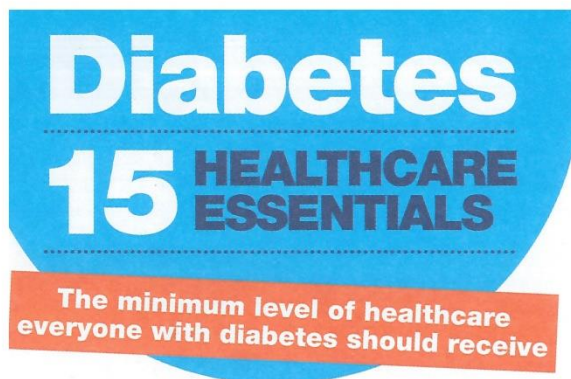
Appendix 2: The Chronic and Acute Complications associated with diabetes

| Chronic Complications | Acute Complications |
|----------------------------------|---|
| Eye Problems (Retinopathy) | Hypoglycaemia (Low blood sugar) |
| Kidney Problems (Nephropathy) | Hyperglycaemia (High blood sugar) |
| Heart Attack and Stroke | Hyperosmolar Hyperglycaemic State (HHS) – A life-threatening emergency that only happens in people with Type 2 diabetes. It's brought on by severe dehydration and very high blood sugars |
| Foot Problems (Amputations) | Diabetic Ketoacidosis (DKA) – A life-threatening emergency where the lack of insulin and high blood sugars leads to a build-up of ketones |
| Nerve Problems (Neuropathy) | |
| Related conditions like Cancer | |
| Sexual Problems in Men and Women | |

Reference

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Appendix 3: Diabetes 15 Healthcare Essentials



Having the right care is essential for the wellbeing of all people with diabetes. There is a minimum level of healthcare that every person with diabetes deserves and should expect. Here are the **15 essential checks and services you should receive.**

If you aren't getting all the care you need, take this checklist to your diabetes healthcare team and discuss it with them.

- 1** **Get your blood glucose levels measured** at least once a year. An HbA1c blood test will measure your overall blood glucose control and help you and your diabetes healthcare team set your own target.
- 2** **Have your blood pressure measured** and recorded at least once a year, and set a personal target that is right for you.
- 3** **Have your blood fats (such as cholesterol) measured** every year. Like blood glucose levels and blood pressure, you should have your own target that is realistic and achievable.
- 4** **Have your eyes screened** for signs of retinopathy every year. A special digital camera is used to take a photograph of your retina (at the back of your eye) and a specialist will look for any changes. This free test is part of the annual diabetic screening service and is different to the checks carried out by an optician. If you notice any changes between appointments it is important to contact your optometrist or GP.
- 5** **Have your feet checked.** The skin, circulation and nerve supply of your feet should be examined annually. You should be told if you have any risk of foot problems, how serious they are and if you will be referred to a specialist podiatrist or specialist foot clinic.
- 6** **Have your kidney function monitored** annually. You should have two tests for your kidneys: urine test for protein (a sign of possible kidney problems) and a blood test to measure kidney function.
- 7** **Have your weight checked** and your waist measured to see if you need to lose weight.
- 8** **Get support if you are a smoker** including advice and support on how to quit. Having diabetes already puts people at increased risk of heart disease and stroke, and smoking further increases this risk.

- 9 Receive care planning to meet your individual needs.** You live with diabetes every day so you should have a say in every aspect of your care. Your yearly care plan should be agreed as a result of a discussion between you and your diabetes healthcare team, where you talk about your individual needs and set targets.*
- 10 Attend an education course** to help you understand and manage your diabetes. You should be offered and have the opportunity to attend courses in your local area.
- 11 Receive care from a specialist paediatric team if you are a child or young person.** The Type 1 essentials for children and young people set out what good diabetes care should look like. To find out more go to www.diabetes.org.uk/Type-1-essentials.
- 12 Receive high quality care if admitted to hospital.** If you have to stay in hospital, you should still continue to receive high-quality diabetes care from specialist diabetes healthcare professionals, regardless of whether you have been admitted due to your diabetes or not.
- 13 Get information and specialist care if you are planning to have a baby** as your diabetes control has to be a lot tighter and monitored very closely. You should expect care and support from specialist healthcare professionals at every stage from preconception to post-natal care.
- 14 See specialist diabetes healthcare professionals** to help you manage your diabetes. Diabetes affects different parts of the body and you should have the opportunity to see specialist professionals such as an ophthalmologist, podiatrist or dietitian.
- 15 Get emotional and psychological support.** Being diagnosed with diabetes and living with a long term condition can be difficult. You should be able to talk about your issues and concerns with specialist healthcare professionals.

To become a member of Diabetes UK go to www.diabetes.org.uk/membership or call 0345 123 2399. Get involved with our work and help improve services – www.diabetes.org.uk/get-involved. For advice and support call our Careline on 0345 123 2399.

To order the 15 healthcare essentials in another language, call **0345 123 2399**.

DiABETES UK
CARE. CONNECT. CAMPAIGN.



/diabetesuk



@DiabetesUK

All calls may be recorded for quality and training purposes.

*If you live in Northern Ireland, care planning is different. Talk to your diabetes healthcare team.

© Diabetes UK 2014 0005F 9863/07/14

Reference

Diabetes UK. 2018. *Your 15 diabetes healthcare essentials*. Available at:

<https://www.diabetes.org.uk/guide-to-diabetes/managing-your-diabetes/15-healthcare-essentials/what-are-the-15-healthcare-essentials> [Accessed: 23 September 2018].

Appendix 4: Guide to diabetic eye screening and retinopathy

NHS Diabetic Eye Screening Programme

Information for health professionals

All people with diabetes aged 12 and over should receive regular eye screening as one of their essential free NHS checks and services.

The NHS Diabetic Eye Screening Programme aims to reduce the risk of sight loss by the early detection and treatment, if needed, of diabetic retinopathy and maculopathy.

The screening process

Screening is offered every year to people with diabetes (type 1 and type 2) aged 12 and over

Each person should receive at least one invitation and one reminder to attend



Visual acuity test



Mydriatic agent applied to dilate the pupils



Digital photographs taken of both retinas



Images graded for signs of diabetic retinopathy and diabetic maculopathy using the RxMx grading system



Screening results sent to the patient and their GP within six weeks

Structure and delivery

The NHS Diabetic Eye Screening Programme is coordinated and led nationally as part of Public Health England. Screening is delivered locally by NHS and private providers in line with national quality standards and protocols.

All patients on the GP diabetic register aged 12 and over should be enrolled in their local eye screening programme. The local service organises the call and recall process, screening and surveillance clinics, results letters and hospital referrals. Result letters are sent to the patients and their GPs.

Prevalence

- around 4,200 people are at risk of blindness caused by diabetic retinopathy in England every year
- around 1,280 new cases of blindness are caused by diabetic retinopathy in England every year

Risk factors

All people with type 1 or type 2 diabetes are at risk, whether their diabetes is controlled by diet, tablets or insulin. Risk is increased by:

- length of time the person has had diabetes
- poor control of blood sugar
- high blood pressure

'Diabetes in remission' and 'Diabetes resolved' codes

- patients should be screened annually for life if there has ever been a definite diagnosis of diabetes, excluding gestational diabetes
- patients in remission – for example due to an intervention such as bariatric surgery – should be classified 'Diabetes in remission', not 'Diabetes resolved'. This ensures they will still be invited for screening
- patients will not be invited for screening if they have a read code of 'Diabetes resolved'. This code should not be used for patients whose diabetes is in remission due to an intervention
- GPs should review all patients with a 'Diabetes resolved' read code and amend to 'Diabetes in remission' as appropriate

Screening during pregnancy

Pregnant women with type 1 or type 2 diabetes are offered additional tests for diabetic retinopathy at, or soon after, their first antenatal clinic visit and also after 28 weeks of pregnancy. This is because there are risks to both mother and baby associated with diabetic retinopathy.

Pregnant women who develop gestational diabetes are not offered screening.

The RxMx grading system

| | |
|------------|------------------------------------|
| R0 | = No retinopathy |
| R1 | = Background retinopathy |
| R2 | = Pre-proliferative retinopathy |
| R3A | = Active proliferative retinopathy |
| R3S | = Stable proliferative retinopathy |
| M0 | = No maculopathy |
| M1 | = Maculopathy |

Photographs of the patients' retinas taken at screening are graded according to national protocol using the RxMx grading system definitions (left).

A lead clinician in each local screening service determines the final grade and outcome for the patient. The patient is then either returned to annual screening, referred to a digital surveillance clinic for more frequent monitoring or referred to hospital eye services for more tests and possible treatment.

Screening outcome

Role of primary care

No retinopathy or maculopathy

Possible result:

R0M0

Risk of progression:

Less than 1 in 50 chance of referable eye disease within 3 years

Follow-up:

Reinvited for routine annual screening in 12 months' time

Background retinopathy in one eye

Possible result:

R1M0

in one eye

Risk of progression:

Just over 1 in 20 chance of referable eye disease within 3 years

Follow-up:

Reinvited for routine annual screening in 12 months' time

Background retinopathy in both eyes

Possible result:

R1M0

in both eyes

Risk of progression:

More than 1 in 4 chance of referable eye disease within 3 years

Follow-up:

Reinvited for routine annual screening in 12 months' time

Continue to advise patient on good management of diabetes, including blood glucose, blood pressure and lipid levels.

Ensure patient attends routine diabetes checks at GP practice.

Referral to digital surveillance clinic

Possible results:

R2

M1

R3S

Follow-up:

Screened in surveillance clinic every 3, 6 or 12 months depending on progression of disease.

Provide additional advice on good management of diabetes, including blood glucose, blood pressure and lipid levels.

Referral to hospital eye services

Possible results:

R3A

R2

M1

Follow-up:

Referred by the local programme to hospital for diagnosis, possible follow-up tests and treatment. Patients are suspended from screening by the local programme while under the care of hospital eye services for diabetic eye disease. They are returned to routine screening or surveillance after discharge.

Ensure patient attends routine diabetes checks.

Invite for additional checks if diabetic control indicates.

Refer to diabetologist if indicated.

Information leaflets

- all people with diabetes aged 12 and over receive a copy of the leaflet, **Your guide to diabetic eye screening**, with their screening invitation
- patients with background retinopathy receive a copy of the leaflet, **Your guide to diabetic retinopathy**

- patients referred to digital surveillance or hospital eye services receive a copy of the leaflet, **Closer monitoring and treatment for diabetic retinopathy**

Information online

- www.nhs.uk/diabeticeye
- www.gov.uk/topic/population-screening-programmes/diabetic-eye

What is background retinopathy?

Background retinopathy is the earliest stage of changes to your retina caused by diabetes. Background retinopathy is common.

At this stage, diabetes has started to affect the small blood vessels in your retina. This means they may:

- bulge slightly (microaneurysms)
- leak blood (retinal haemorrhages)
- leak fluid (exudates)

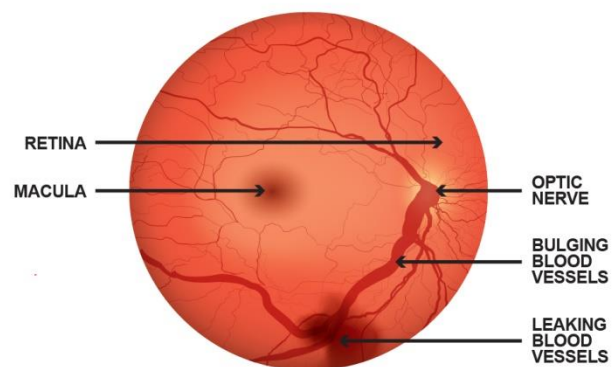
Background retinopathy does not affect your sight but means there is a greater risk that you will develop more serious changes that may damage your sight.

6

Proliferative retinopathy

Proliferative retinopathy is more serious and can cause loss of sight. It occurs if your retinopathy progresses further and large areas of your retina are starved of a proper blood supply.

Treatment for proliferative retinopathy reduces the risk of sight loss, particularly if given before your vision has been affected.



7

More advanced stages

Pre-proliferative retinopathy

Pre-proliferative retinopathy occurs when changes to the retina are more extensive than with background retinopathy. This means you may need to be monitored more closely because of the increased risk of developing changes that may damage your sight.

Maculopathy

The macula is the small central part of the retina that you use to see things clearly. It is the most used area of the retina and is the part you are using now to read this leaflet.

Maculopathy is when diabetic retinopathy occurs at or around your macula. If you have maculopathy, you may need to be monitored more closely or offered treatment to reduce the risk of sight loss.

Reference

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https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/704463/DES_03_web_version.pdf [Accessed: 8 October 2018].

Appendix 5: Survey



Is Diabetic Eye Screening beneficial? – A Patient's Perspective (Local hospital

logo removed)

Hello, my name is (Name with-held) and I am a medical photographer based at the (Name with-held). I am currently studying a Postgraduate Certificate in Clinical Photography at Cardiff University. As part of my studies; I have to produce a work based final project. For my project, I want a patient's perspective in to diabetic eye screening and how it has benefitted. If you could spare a few minutes to answer the following questions, I would really appreciate that. All answers are anonymous and thank you for your cooperation😊.

Question 1

| | | |
|-------------------|----------------------|--|
| What is your age? | What is your gender? | In what year were you diagnosed with diabetes? |
| | | |

Question 2

Do you think diabetic eye screening is been beneficial to you? **Yes or No** Please circle

Please explain your answer.

Question 3

Does eye screening give you confidence in the way you manage your diabetes? **Yes or No** Please circle

Please explain your answer.

Please continue overleaf...

Question 4

Have you noticed any changes to the eye screening service since you first started attending? **Yes or No**

Please circle

If yes, please explain your answer.

Question 5

Have you ever been referred to the Hospital Eye Service from eye screening? **Yes or No** Please circle

If yes, please explain your answer

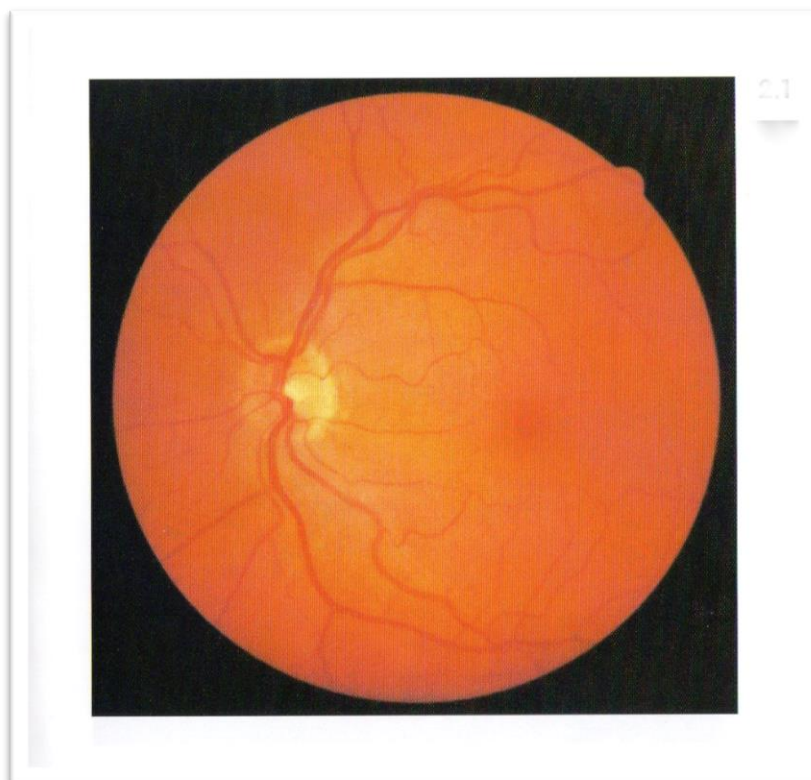
Question 6

What do you think the future holds for diabetic eye screening?

Please post this form in the box provided

(Local hospital logo removed)

Appendix 6: Example of a Polaroid image



Reference:

Taylor, R. et al. 1996. Normal retinal appearances. *A practical guide to polaroid retinal photography*. London: Times Mirror International Publishers Limited, p. 9.