PRIORITY BRIEFING

The purpose of this briefing paper is to aid Stakeholders in prioritising topics to be taken further by PenCLAHRC as the basis for a specific evaluation or implementation project.

QUESTION DETAILS

Question ID: 11
Question type: Implementation
Question: What are the factors associated with the non attendance of 13% of patients with diabetes at the diabetes retinal screening clinic, and how can we improve the attendance rate?

Population: Adult patients with diabetes who do not attend annual diabetic retinal screening clinic appointments.

Intervention: Identify factors associated with non attendance and implement new ways of working to improve the attendance rate (for example ringing the patient just before their appointment if 'forgetting' is one of the reasons for non attendance).

Control: Those who do attend the retinal screening clinic as required.

Outcome: Factors associated with non attendance will be identified. The number of non attendees will decrease. Changes in some methods of working will be established to reduce non attendance. Provide important information to help improve the current implementation strategy for retinal screening.

Note on retinal screening:
Adults with diabetes are more likely to incur (diabetes-related) blindness, the screening programme is designed to monitor diabetic retinopathy (potential eye disease) that may cause blindness. If the screening process identifies more severe retinopathy the patient is referred to a specialist for treatment.

Part 1: Research Background

Guidelines: The update of NICE guidelines on Type II Diabetes recommends:

- Arrange or perform eye screening at, or around, the time of diagnosis.
- Arrange repeat of structured eye surveillance annually.
- Explain the reasons for and success of eye surveillance systems to the individual and ensure attendance is not reduced by ignorance of need, or fear of outcome.

Research Summary:

One very relevant systematic review was identified which investigated the effectiveness of interventions to promote screening for diabetic retinopathy.[1] This review identified 48 studies that used a variety of methods and covered 162,157 patients in a range of interventions. The general conclusions reported that: increasing patient awareness of diabetic retinopathy, improving provider and practice performance, and improving healthcare system infrastructure and processes, can significantly increase screening for diabetic retinopathy. The study recommended that further research should explore strategies for increasing the rate of retinal screening among diverse or disadvantaged populations.

Seven relevant trials were identified as having been conducted since the date of the above systematic review. A number of studies based in the US found that even small interventions such as making a phone call or sending a note through the post to remind the patient of their appointment increased the numbers of people attending screening sessions.[2, 8] Sub-populations that tended to have lower attendance were: patients belonging to ethnic minorities, those wholly managed in primary care,[3] those who had longer diabetes duration, those with poor blood pressure control, smokers, and those who live in deprived areas.[5,6,8] The impact of age on attendance was uncertain.

Several studies across the UK tried to identify reasons for non attendance. These included: lack of knowledge regarding the need for ocular examination, a fear of the unknown and lack of encouragement from their GP.[4] In a study looking at health screening attendance in general in Denmark it was noted that non-attendees tended to have a rational knowledge of the limitations of health screening and their own responsibility to keep themselves healthy.[7] Some studies suggest using mobile screening units[5] and screening strategies targeted at specific patients groups[3] to help improve screening attendance.

Ongoing Research:

One piece of ongoing research has been identified, investigating the use of a link-worker to improve attendance for diabetic retinal screening in the Asian population of Coventry and Warwickshire In this study all patients who do not attend their first screening visit have a second visit arranged. In the 48 hours

prior to this, the link worker contacts the patient to ensure they are aware of the appointment and remind them to attend. This study was due to run from July 2007 to July 2008 but no results have been found.

One protocol for a systematic review which was put forward in 2005 (on the Cochrane Database of Systematic Reviews) was also found. It is unclear if this review has been completed or is currently underway. The review aims to look at Interventions to promote screening for diabetic retinopathy.

Part 2: Prioritisation Information

1. The health problem

Epidemiology:
Diabetic retinopathy is a chronic progressive sight-threatening disease of the retinal microvasculature associated with the prolonged hyperglycaemia and other conditions linked to diabetes mellitus (e.g. hypertension). Diabetic retinopathy is a potentially blinding disease in which the threat to sight comes through two main routes: growth of new vessels leading to intraocular haemorrhage and possible retinal detachment with profound global sight loss: and localised damage to the macula / fovea of the eye with loss of central visual acuity.

In the UK white population, rates of known diabetes range from 2 - 4%. Type 2 diabetes is commoner in ethnic minority peoples and those who are socio-economically deprived. In people with diabetes, cataracts and retinopathy are the most significant cause of visual impairment and blindness, and people with diabetes are 25 times more likely than the general population to become blind. In developed countries, diabetic eye disease represents the leading cause of blindness in adults under 65 years. Generally, the prevalence of retinopathy at diagnosis of type 1 diabetes is reportedly low, between 0% and 3%, while a higher proportion of those with newly diagnosed type 2 diabetes have evidence of diabetic retinopathy (6.7–30.2%).

Population based studies from the UK generally show lower rates of retinopathy. Among 10,709 diabetes patients identified through health district audit and data linkage, 16.5% had retinopathy. In addition, more recent UK prevalence studies suggest that improvements in treatment of diabetes have led to lower rates of retinopathy, particularly of the sight threatening type. In the United Kingdom Prospective Diabetes Study (UKPDS), 22% of those with no sign of diabetic retinopathy at baseline developed diabetic retinopathy at 6 years, and in 29% of patients with baseline diabetic retinopathy it progressed 2 or more steps on the Early Treatment Diabetic Retinopathy Study scale after 6 years' disease duration.

Within Devon, rates of diabetes-related hospital admission vary by area. Allowing for differences in the age and sex profile of each area, the highest admission rates for diabetes are in the former Exeter Primary Care Trust area, which has an annual rate of 87 per 100,000 people; the lowest rates are in the former South Hams & West Devon and Mid Devon Primary Care Trust areas, which both have annual rates of 52 per 100,000 people. The annual overall diabetes admission rate in Devon is 68 per 100,000 people. In Exeter from April 2008 – March 2009 21,512 patients were invited for retinal screening, 2,800 (13%) patients did not attend.

2. Identification of the topic as a priority:

The Department of Health National Service Framework for Diabetes (2003) states that by 2006, a minimum of 80% of people with diabetes should be offered screening for the early detection (and treatment if needed) of diabetic retinopathy as part of a systematic programme that meets national standards, rising to 100% coverage of those at risk of retinopathy by end 2007.

The Royal College of Ophthalmologists Diabetic retinopathy guidelines (2005) also aim to maximise the number of invited persons accepting the screening test to 90% (at the initial screening stage) and 95% (at the repeat screening stage).

SW SHA Priorities framework 2008-11
- Fully implement the standards set out in National Service Framework for Diabetes.

3. Local perspective

Tractability:
- May be challenging contacting the people who do not attend.
- May be useful for sharing good practice.

An overview of the local context
There is a well developed retinal screening database and local expertise in different aspects of diabetes in Exeter.

References

(1) Zhang, X., S. L. Norris, et al. (2007). "Effectiveness of interventions to promote screening for diabetic retinopathy (Brief record)." SO: American Journal of Preventive Medicine(4): 318-335.
OBJECTIVE: To assess the effectiveness of interventions aimed to increase retinal screening among people with diabetes. METHODS: A systematic literature search was conducted of multiple electronic bibliographic databases up to May 2005. Studies were included if interventions were used to promote screening for diabetic retinopathy in any language and with any study design. RESULTS: Forty-eight studies (12 randomized controlled trials [RCTs], four nonrandomized studies, and 32 pre-post studies) with a total of 162,157 participants, examined a wide range of interventions, which focused on one or more of the following: (1) patients or populations, (2) providers or practices, and (3) healthcare system infrastructure and processes. Four of five RCTs focusing on patients demonstrated that interventions increased screening significantly, with relative risk ranging from 1.05 (95% confidence interval [CI]=1.01-1.08) to 2.01 (95% CI=1.48-2.73). Five RCTs with a focus on the system all demonstrated significant increases in screening with relative risk ranging from 1.12 (95% CI=1.03-1.22) to 5.56 (95% CI=2.19-14.10). Thirty-six non-RCTs, which included interventions with single or multiple foci, also generally demonstrated positive effects. CONCLUSIONS: Increasing patient awareness of diabetic retinopathy, improving provider and practice performance, and improving healthcare system infrastructure and processes, can significantly increase screening for diabetic retinopathy. Further research should explore strategies for increasing the rate of retinal screening among diverse or disadvantaged populations and the economic efficiency of effective interventions in large community populations.

(2) Anderson, R. M., D. C. Musch, et al. (2003). "Personalized follow-up increases return rate at urban eye disease screening clinics for African Americans with diabetes: results of a randomized trial." SO: Ethnicity & disease(1): 40-6.
OBJECTIVE: To evaluate the effectiveness of using personalized follow-up, as compared to reminder letters, in increasing return rates at urban eye disease screening clinics for African Americans with diabetes, and to identify factors predictive of the patient's likelihood of returning for annual follow-up exams. RESEARCH DESIGN AND METHODS: All patients attending free community-based retinopathy screening clinics who were advised to return in one year for another diabetes eye evaluation (DEE) were randomized to standard or personalized follow-up interventions. Patients in the standard follow-up group received reminder letters a month before it was time to return for their next annual DEE. Patients in the intensive personalized intervention also received the letters, but those patients who did not call for an appointment within 10 days received a phone call from project staff, encouraging them to return for a DEE. RESULTS: One hundred thirty-two African Americans with diabetes were randomized to one of the 2 treatments. The return rate for the intensive,

personalized follow-up group was 66%, significantly (P=.001) higher than the 35% return rate for the standard follow-up group. CONCLUSION: This study demonstrated the efficacy of personal contact by telephone in improving return rates for annual DEEs in this population of patients. This finding is consistent with one of the key design principles of the project, which was to establish credible personal relationships with community leaders and patients as a means to maximize the utilization of the eye screening clinics.

(3) Buch, H. N., D. M. Barton, et al. (2005). "An assessment of the coverage of a district-wide diabetic retinopathy screening service." Diabetic Medicine 22(7): 840-1.
AIMS: To assess the coverage of the diabetes retinopathy screening service (DRSS) in North Staffordshire, to identify patient characteristies associated with non-attendance and to assess the proportion of patients with diabetic retinopathy who achieved glycaemic and blood pressure (BP) control targets. METHODS: Data for all patients who underwent annual retinal screening between 1 May 2000 and 30 April 2001 were obtained from the North Staffordshire Diabetes Register. Age, gender, ethnicity, socio-economic status, type and duration of diabetes were compared between patients who underwent eye screening and those who did not. Frequencies of patients who achieved glycaemic and BP targets in these groups of patients were compared to the remaining patients. RESULTS: 5646 of the 11682 (48%) patients on the diabetes register underwent retinal screening during the year. Patients with Type 2 diabetes, older patients, patients belonging to ethnic minorities and those wholly managed in primary care were less likely to attend for eye screening ($P < 0.05$ for all groups) with ethnic minority or primary care management demonstrating independent influence ($P < 0.001$). The percentage of patients with retinopathy achieving HbA1c and systolic BP targets was significantly lower than in their unaffected counterparts ($chi2 = 63$, $P < 0.001$ and $chi2 = 71$, $P < 0.001$ respectively). CONCLUSIONS: The efficacy of the DRSS in North Staffordshire is low and might be improved by targeting specific patient groups. Glycaemic control and systolic BP control needs to be improved in patients with diabetic retinopathy.

(4) Dervan, E., D. Lillis, et al. (2008). "Factors that influence the patient uptake of diabetic retinopathy screening." Irish Journal of Medical Science 177(4): 303-8.
AIM: To assess whether patients were receiving regular diabetic retinopathy screening and to examine factors influencing screening uptake. METHODS: A questionnaire covering demographics, diabetic medical history and the knowledge of and attitudes to diabetic retinopathy was administered to all adults who were due to attend diabetes clinics in two centres in Dublin, Ireland over two months in 2001/2002. RESULTS: Of the 209 people who completed the questionaire, 169 (81%) had a dilated fundal examination within the last year. The most significant predictor for receiving screening was a previous physician recommendation about the necessity of a regular eye examination. The main barriers to receiving adequate screening were lack of knowledge regarding the need for ocular examination and the effect of mydriasis in prohibiting driving.

CONCLUSIONS: It is essential that patients are fully aware of the need for a regular eye examination. Once a physician recommends this the screening rate improves.

(5) Leese, G. P., P. Boyle, et al. (2008). "Screening uptake in a well-established diabetic retinopathy screening program: the role of geographical access and deprivation." Diabetes Care 31(11): 2131-5.
OBJECTIVE: To identify criteria that affect uptake of diabetes retinal screening in a community screening program using mobile retinal digital photography units. RESEARCH DESIGN AND METHODS: Data from the regional diabetes population-based retinal screening program and regional ophthalmology laser database were linked to patient postal code (zip code) data. We used distance from retinal screening event, social deprivation scores, and demographic information to identify risk factors for nonattendance at a diabetes retinal screening event. Patients were subdivided into urban (>125,000 population), other urban (3,000-125,000 population), or rural (<3,000 population) depending on where they lived. Data were collected from 2004 to 2006 inclusive and included 15,150 patients and 32,621 eye screening records. RESULTS: The mean +/- SD age of patients was 63 +/- 15 years, and 54% were male. Mean travel time to retinal screening event varied from 7.1 to 17.0 min. For 12% of missed appointments, patients were more likely to be younger, to have longer diabetes duration, to have poor A1C and blood pressure control, to be smokers, and to live in deprived areas. Poor attendance was not associated with sex or distance to retinal screening event. CONCLUSIONS: Social deprivation is strongly associated with poor attendance at retinal screening events. Time traveled to screening event was not associated with attendance in this study of a mobile retinal screening service, which visited general practitioner surgeries. This data can help inform population-based diabetes retinal screening programs about improving patient uptake.

(6) Millett, C., H. Dodhia, et al. (2006). "Diabetes retinopathy screening: audit of equity in participation and selected outcomes in South East London." Journal of Medical Screening 13(3): 152-5.
OBJECTIVES: To assess uptake of the diabetes retinopathy screening programme in South East London and examine variation in attendance and screening outcomes. METHODS: Cross-sectional study of patients on a centralized disease register invited for retinal screening during 2003. The influence of age, gender, deprivation, region of birth and type of diabetes on screening attendance and outcomes was assessed. RESULTS: An estimated 46% of residents with known diabetes (9750/21,104) were offered digital retinopathy screening during 2003. In all, 88.9% of patients who were invited for screening attended. Attendance rates were significantly lower in younger patients (< or = 40 years), in those with type 1 diabetes and in patients residing in areas with the highest levels of deprivation. A total of 28.9% of patients had background retinopathy or worse during 2003. Retinopathy was more common in older patients (>40 years) and in individuals with type 1 diabetes after adjusting

for other factors. Patients born outside the United Kingdom and the Republic of Ireland were significantly more likely to present with retinopathy.
CONCLUSIONS: This study identified considerable inequity in the delivery of a local diabetic retinopathy screening programme. Equity audits should form an integral component of ongoing quality assurance monitoring of retinopathy screening programmes.

(7) Nielsen, K. D., L. Dyhr, et al. (2004). "You can't prevent everything anyway: a qualitative study of beliefs and attitudes about refusing health screening in general practice." SO: Family Practice(1): 28-32.
OBJECTIVE: The aim of this study was to explore beliefs and attitudes about refusing health screening in general practice. METHODS: In 1991, in Ebeltoft, Denmark people aged between 30 and 50 years were invited to participate in a 5-year randomized, controlled, population-based project testing the value of health screenings and health discussions in general practice. In 1994, non-participants who declined the offered health screening but expressed willingness to be contacted in the future were asked to participate in a qualitative interview. They were drawn by stratified purposeful sampling which reflected variation in perceived health, body mass index, age and sex. The sample comprised six men and 12 women RESULTS: Some had not participated because they were busy, felt healthy or had recently been examined. The non-participants emphasized the limitations of health screening and did not want possible risk factors to be revealed, or their feeling of good health to be disturbed. They stressed the individual's own responsibility for maintaining good health and believed that a positive attitude promoted health. They would contact their GP if they had symptoms. CONCLUSION: Non-participants have rational views on risk factor testing and on their own responsibility for maintaining health. Non-attendance was due to a conscious choice which included consulting their own GP.

(8) Walker, E. A., C. B. Schechter, et al. (2008). "Telephone intervention to promote diabetic retinopathy screening among the urban poor." SO: American Journal of Preventive Medicine(3): 185-91.
BACKGROUND: Participation in diabetic retinopathy screening is suboptimal. The Vision is Precious study (2001-2005) tested the hypothesis that a tailored telephone intervention in urban minority diabetes populations, offered in English or Spanish, would result in greater screening for retinopathy than a standard print intervention. DESIGN: Randomized controlled trial SETTING/PARTICIPANTS: Subjects (N=598) were adults with diabetes without a dilated fundus examination (DFE) in >1 year from three healthcare centers in Bronx NY. INTERVENTION: A tailored telephone intervention to promote retinopathy screening compared to a standard print intervention over a 6-month period. MAIN OUTCOME MEASURES: Documentation of a DFE within 6 months was the main outcome. Data on risk perceptions using the Risk Perception Survey for Diabetes were collected pre- and post-intervention. Electronic databases were used to obtain hemoglobin A1c information. RESULTS: Subjects were 40% men, mean age 57 years; 39% reported household incomes as <$15K; 45% reported their race as

black, and 42% reported ethnicity as Hispanic/Latino; 23% chose Spanish as their preferred language. Data were analyzed in 2006. There was a 74% increase in retinopathy screening in the telephone versus print group ($p<0.0005$), with no differences by intervention language or by gender. Predictors of undergoing a DFE included: telephone intervention, baseline risk-perception scores indicating less worry and more realism about diabetes complications, and the interaction of self-reported worry and being in the telephone intervention. Subjects who had poor diabetes control responded with greater success to telephone interventions. CONCLUSIONS: A limited telephone intervention can improve significantly participation in retinopathy screening in a minority, low-income population. This intervention influenced risk perceptions about diabetes complications. Further research is needed to develop effective risk communications to prevent the complications of diabetes.